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Strengthening the commitment

The report of the UK Modernising Learning Disabilities Nursing Review

Contents

Foreword 2

Foreword by the Modernising Learning Disabilities Nursing Review Co-production Steering Group 3

Executive summary 4
The issue 4
What we want to achieve 4
The way forward 5

Introduction 6
Health and social care challenges 6
Current position 7
The UK Modernising Learning Disabilities Nursing Review 9
Overview of the report 10

Chapter 1. Strengthening capacity 14
1.1 Location and employment 14
1.2 Strategic workforce planning and development 15
1.3 New ways of working and new roles 16
1.4 Career choices 19

Chapter 2. Strengthening capability 24
2.1 Maximising the contribution of learning disabilities nursing 24
2.2 Working with people of all ages 26
2.3 Addressing health needs 28
2.4 Providing specialist services 30

Chapter 3. Strengthening quality 36
3.1 Demonstrating quality outcomes 36
3.2 Quality improvement 39
3.3 Preparing and developing learning disabilities nurses 39
3.4 Maximising recruitment and retention 40
3.5 Developing workforce knowledge and skills for the future 41
3.6 Accessing supervision 43

Chapter 4. Strengthening the profession 46
4.1 Leadership and management 46
4.2 Promoting the profession 47
4.3 Research and evidence 49

Conclusion and next steps 54

Appendix 1. Key policy and professional drivers within the four countries 58

Appendix 2. Steering group memberships 64

References 70

Foreword

My professional commitment to learning disabilities nursing is long standing. It emerged from a personal insight early in my career into the vital role that learning disabilities nurses play in the lives of people with learning disabilities, their families and carers, the very complex and high-level competences they possess, and the advocacy, passion and dedication they show. I am therefore proud, and delighted, to be introducing this report of the UK Modernising Learning Disabilities Nursing Review on behalf of my fellow government chief nursing officers.

The role and profile of learning disabilities nursing has changed significantly over the last three decades. The wholesale shift from institutionalised care to a social model of provision based on independence, inclusion and empowerment has improved significantly the lives of people with learning disabilities, but has served to reduce demand for learning disabilities nursing as a specialism. As a result, the learning disabilities nursing workforce today is smaller and more widely distributed across the health and social care sector than ever before; and while some occupy specialist learning disabilities nursing roles, many others have more generic care or managerial roles.

This has resulted in a lack of focus and direction for learning disabilities nursing, fragmentation of the learning disabilities nursing community and, potentially, a loss of core nursing and specialist learning disabilities nursing skills to the system at a time when demand (which is already growing) is likely to increase. More and more children born with learning disabilities are now surviving into adolescence, adulthood and into older age, with the complex range of medical and health problems that brings: they require specialist learning disabilities nursing support across the lifespan.

In initiating the review, the UK chief nursing officers sought to bring this issue to the forefront for people with learning disabilities, their families and carers, policy-makers, commissioners, services, professional leaders and the learning disabilities workforce so that together we can prepare for the challenges and opportunities ahead. At the same time, we wanted to remind everyone of the very proud tradition that underpins learning disabilities nursing and of the importance of their contribution and commitment in a changing world.

The four countries are now invited to consider the report's recommendations and progress then as appropriate within their own contexts.



Ros Moore
Chief Nursing Officer, Scottish Government

Foreword by the Modernising Learning Disabilities Nursing Review Co-production Steering Group

We are the Co-production Steering Group for the UK Modernising Learning Disabilities Nursing Review and we are people with learning disabilities, people with autism and family carers. We all have experience of learning disabilities nursing and want to see it improve and develop. This should be consistent across the UK.

It has been enjoyable working on this and putting forward our ideas. We can see our ideas in the report but this is only the first step. The implementation stage will be even more important as this will lead to the goal of good outcomes for people. We want to see people with learning disabilities, people with autism and family carers meaningfully involved throughout all this work.

Our hopes are that the recommendations will develop a better future of nursing care for people with learning disabilities throughout their lifespan. People are complex and learning disabilities nurses need to find accessible ways to share information and work with people with learning disabilities to ensure good quality holistic health care. People are the experts on their life, health and care.

We want to see decision-makers buying into these recommendations and committing to budgeting to take them forward. As a group, we value the report and feel that it is important that the recommendations are carried out.

Executive summary

The issue

There are approximately 1.5 million people in Britain living with learning disabilities.[A] That number is likely to grow by 14 per cent between 2001 and 2021[B] as advances in science and care mean many more children with learning disabilities live longer, more fulfilled lives than has ever been the case before and the increasing adult population of people with learning disabilities grows into older age. While this is very welcome, the governments of the four countries of the UK must be sure their health and social care systems are ready for the changing health needs of people with learning disabilities.

Learning disabilities nursing has always had a major input into the health of people with learning disabilities, their families and carers, and demand is likely to grow. However, as a result of changes in societal attitudes to people with learning disabilities and to their care, learning disabilities nurses have become geographically dispersed within a range of public and independent sector providers and are employed in a variety of roles. The overall number of learning disabilities nurses has consequently decreased over time, with many now nearing retirement.

What we want to achieve

The UK Modernising Learning Disabilities Nursing Review wants to ensure that people with learning disabilities of all ages, today and tomorrow, will have access to the expert learning disabilities nursing they need, want and deserve. That requires a renewed focus on learning disabilities nursing and may require service and strategic investment in building and developing the workforce. The review aims to set the direction of travel for learning disabilities nursing to ensure we can meet current and future demand and that the workforce is ready and able to maximise its role throughout the entire health and social care system. We also want to ensure the best staff experiences and career opportunities for learning disabilities nurses and, most importantly, the best experience of support and care for people with learning disabilities, their families and carers.

The review makes a number of detailed recommendations (seen throughout this report and summarised in Table 2) that are about "strengthening the commitment" to learning disabilities nursing across the public sector. Underlying them are four clear organising principles for supporting reform.

Strengthening capacity

Accurate information on where learning disabilities nurses are working both within and outside the NHS is important for workforce planning and to ensure education programmes remain relevant. Further work is required across the four countries to scope the workforce, including those working in the independent/voluntary sector and in social care, so that strategic workforce development plans are developed and enacted. There should be a clear statement about what we want from learning disabilities nurses going forward and

[A] Source: Mencap (www.mencap.org.uk/all-about-learning-disability/information-professionals/more-about-learning-disability).

[B] **Emerson E, Hatton C (2008)** *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England.* Centre for Disability Research: Lancaster.

they should be enabled to plan their career development to meet the needs of people with learning disabilities now and in the future.

Strengthening capability

The values base for learning disabilities nursing remains strong and we should ensure that systems retain and reinforce attitudes and abilities to deliver person-centred and strengths-based approaches. At the same time, skills, knowledge and competencies are changing and must be extended to reflect the changing needs of people with learning disabilities.

Evidence clearly shows that people with learning disabilities have poorer health than the general population. In addition, many have difficulties accessing and using general health services. Learning disabilities nurses have an important role to play in supporting timely access to services, as well as contributing to preventative and anticipatory care.

Strengthening quality

All four countries are currently engaged in significant programmes of system transformation, efficiency and quality improvement. Learning disabilities nurses must embrace that movement and consider how they can demonstrate impact through measurable outcomes and evidence-based interventions that improve safety, productivity and effectiveness alongside traditional person-centred approaches.

A well-prepared, developed and supported workforce at all levels (including nonregistered staff) is essential to the delivery of quality health care for people with learning disabilities and education and training throughout the career pathway is key to achieving this.

Strengthening the profession

Strong leadership will be crucial to ensuring the recommendations from this report are taken forward and that existing networks for learning disabilities nurses across the UK continue to provide a powerful platform from which to celebrate, promote and develop their unique contribution. These have tended to be developed mainly for NHS staff, so a key step is for the learning disabilities nursing profession to embrace members from all sectors to create a critical mass of leaders working together to effect change and advocate for the profession and those they serve.

The way forward

We do not underestimate the challenge this will present. All this will take place in a time of recession, uncertainty and increasing diversity across the four UK health care systems. However, the demographic factors set out above cannot be ignored, and that's why high levels of commitment and engagement from key players are needed. UK government health departments, employers, educators, people with learning disabilities, their families and carers, learning disabilities nurses and wider health and social care staff are all crucial to its success.

Introduction

Health and social care systems across the UK continue to face significant strategic, structural and economic change, with an increased focus on localism and integration, changes in commissioning structures and a strong emphasis on outcomes and transparency. Learning disabilities nursing must adapt to meet the demands of this change.

The UK Modernising Learning Disabilities Nursing Review aims to ensure the best possible services are provided to people with learning disabilities, their families and carers now and in the future and that we have a valued and thriving learning disabilities nursing profession.

Health and social care challenges

Population

The population of people with learning disabilities is increasing across the UK and internationally. Demographic projections suggest that the numbers of people with learning disabilities will increase by 14% between 2001 and 2021 (1), with rises at both ends of the age spectrum linked to better survival rates in premature babies and improvements in health care and general standards of living (2,3).

Health inequalities

The number of individuals with complex needs, including co-morbid health problems and behaviours perceived as challenging, is increasing across the UK (4). A third of people with severe and profound learning disabilities also have an associated autism spectrum disorder (5). People with learning disabilities often experience health and social problems associated with ageing earlier than the general population and there is a higher than average incidence of dementia within some groups (6).

There is evidence showing that many physical, sensory and mental health needs of people with learning disabilities go unrecognised and unmet by services, with consequent negative impacts on their quality of life, life chances, life expectancy and experience of services.

Evidence also demonstrates the increased susceptibility of people with learning disabilities to discrimination and to potential violation of human rights within care settings (7,8).

These compounding issues can lead to people with learning disabilities being at higher risk of poor physical and mental health and to early mortality. If these issues aren't addressed, all services, be they specialist or general, can expect to experience greater demands from people with learning disabilities, their families and carers in the future (9).

Policy shift

Service modernisation initiatives across the four countries are similar in direction of travel, although they may differ in detail. They all aim to:

- promote independence, social inclusion and citizenship;
- develop a service ideology influenced by the social model of disability and values-based, rights-based, person-centred approaches;
- progress the integrated services agenda;
- promote community-based services; and
- ensure equitable access to health care for people with learning disabilities, their families and carers.

Examples of specific policies across the four countries are cited in Appendix 1.

Current position

Learning disabilities nurses remain important in the eyes of stakeholders

In the past, there was some debate about the relevance of learning disabilities nursing in the context of the shift to a social model of provision. Other countries have moved to a workforce with generically prepared registered nurses, or to training more closely aligned to social work or social education. The UK, however, has retained specific preparation towards registration as a Registered Nurse Learning Disabilities for over a century. Some countries are now reconsidering the benefits of having specifically prepared nurses for people with learning disabilities. More recently, there has been recognition that learning disabilities nursing continues to play a crucial role in moving the care of people with learning disabilities from an institutional setting to communities, in championing health improvement and working to tackle the health inequalities experienced by those they work for.

Learning disabilities nursing has a strong values base

Learning disabilities nurses respond to individuals with learning disabilities, their families and carers in a creative, flexible and effective manner, ensuring that interventions are informed by the most recent evidence- and values-based practice. They have a commitment to lifelong learning and promote the empowerment of people with learning disabilities, their families and carers in all aspects of care.

The values base for learning disabilities nursing (see Box 1) is strong and remains the key element underpinning practice. We have built on this base to develop a modernised vision of learning disabilities nursing across the four countries of the UK.

[C] "Carer" refers to: *"... someone who looks after a partner, husband or wife, son or daughter, relative or friend with a disability or illness. Many carers live with the person they care for, but many look after someone who lives independently, in supported accommodation, in hospital, or in a care home ... Carers are family members or friends who look after someone without pay or financial reward. They are sometimes known as 'informal' carers or more frequently as unpaid carers."* Source: Scottish Government (2011) The Future of Unpaid Care in Scotland: headline report and recommendations [online]. Available at: www.scotland.gov.uk/Publications/2006/02/28094157/0

Box 1

The values base for learning disabilities nursing

Learning disabilities nursing is based on clear values that include placing individuals at the centre of care and ensuring they are fully involved in all aspects of planning and intervention. It also acknowledges the critical contribution of family and informal carers.[C] Central to this are the following underpinning principles that guide learning disabilities nursing practice.

Human rights
Placing the individual at the centre, valuing choice, inclusion, citizenship and social justice. Incorporates equality, individuality, person-centred and strength-based approaches, empowerment, self-determination, dignity and anti-oppression.

Personalisation
Supporting the individual's control and choice over their own life and services through empowering people with learning disabilities, their families and carers and relinquishing "control".

Equality and inclusion
Recognising diversity and challenging inequality and inequity by supporting people with learning disabilities to use the same services and have the same opportunities and entitlements as anyone else.

Person-centred
Meaningful engagement with people to identify goals significant to the person.

Strengths-based
Focusing on existing strengths, skills, talents and resources and increasing personal competence.

Respect
Valuing the whole person and the diversity of people who support and sustain him or her. Appreciating the contribution of families and carers and, where possible, enhancing the contribution of others.

Partnerships
Recognising that health and social outcomes are interdependent.

Health-focused
Focusing on the individual's health and well-being to enable inclusive lifestyles.

Current role of learning disabilities nurses

Learning disabilities nurses work with people, families and carers with a wide range of abilities and needs and within a diverse range of settings, providing both generalist and specialist nursing care. Consequently, they require a wide range of skills (including "traditional" skills such as care planning and "non-traditional" skills such as accessible communication[D]) alongside specific clinical, behavioural and psychological interventions.

[C] "Carer" refers to: *"... someone who looks after a partner, husband or wife, son or daughter, relative or friend with a disability or illness. Many carers live with the person they care for, but many look after someone who lives independently, in supported accommodation, in hospital, or in a care home … Carers are family members or friends who look after someone without pay or financial reward. They are sometimes known as 'informal' carers or more frequently as unpaid carers."* Source: Scottish Government (2011) The Future of Unpaid Care in Scotland: headline report and recommendations [online]. Available at: www.scotland.gov.uk/Publications/2006/02/28094157/0

[D] Accessible communication means designing information that is easier for everyone to use. This may mean producing material in a specific format such as large print, audio or Easy read. (Source: www.romathomas.co.uk/articles/index.php/accessible-communications)

Central roles of learning disabilities nurses can be summarised as:

- effectively identifying and meeting health needs;
- reducing health inequalities through the promotion and implementation of reasonable adjustments; and
- promoting improved health outcomes and increasing access to (and understanding of) general health services, consequently enabling social inclusion.

They also have an increasingly important role in helping to keep people safe and in supporting decision-making around capacity to consent and best interests.

These strengths provide a solid foundation for the development of learning disabilities nursing within the current demographic and policy context.

The UK Modernising Learning Disabilities Nursing Review

Learning disabilities nurses have been at the forefront in introducing and leading new ways of working to support reform, service modernisation and redesign initiatives, but an accountable and forward-thinking profession must future-proof itself.

The UK Modernising Learning Disabilities Nursing Review was commissioned and led by the Chief Nursing Officer for Scotland on behalf of the chief nursing officers across the UK. It reflects a four-country commitment to gathering and considering evidence on the current and future contribution of learning disabilities nursing. At the heart of the review is the commitment to supporting people with learning disabilities, their families and carers to achieve and maintain good health.[E]

The review does not stand alone: it is part of an ongoing consultative programme of work (see Box 2).

Box 2

Ongoing consultative programme of work

The programme aims to:

- set out the value that learning disabilities nurses bring;
- identify and share good practice in learning disabilities nursing;
- assess regional recruitment and retention issues;
- prioritise areas for development that reflect future models of care and population trends within specialist and generic services;
- consider what improvements can be made in areas such as education, careers, leadership, research, outcome indicators, public health and workforce; and
- identify the organisational, education and development strategies that will support and enable the learning disabilities nursing profession to realise its full potential.

[E] Within this report, "health" is viewed as encompassing physical, social and psychological conditions that enable individuals to achieve their potential (10). Recognising that each person's potential will differ, the role of learning disabilities nurses is in advising against, preventing and/or removing obstacles that limit the extent to which people with learning disabilities are able to achieve their individual potential.

Each country has involved people with learning disabilities, families and carers in a range of ways, either as members of steering groups or through focus groups and meetings with local organisations. In addition to hosting the UK Co-production Steering Group for people with learning disabilities, their families and carers, the Scottish Consortium for Learning Disability held focus groups for children and young people and people receiving support from forensic services.

The review was supported by a national programme manager reporting to the UK Programme Board, with four country-specific steering groups (Appendix 2).

Review processes included literature reviews, the collection of positive practice examples and visits to practice and education settings. Nurses were involved through workshops, conferences and information in the professional press, and focus groups were held for student nurses. In addition, a consultation was carried out with learning disabilities nursing students across the UK via two facilitated sessions using Facebook webchat, and two UK-wide events were held (one for learning disabilities nursing educationalists and one for professionals working in the independent/voluntary sector).

The review also worked closely with the Royal College of Nursing (RCN) to explore student aspirations and careers and to take forward work on image and recruitment.

Overview of the report

This report is relevant to all who design, develop, commission or deliver services for people with learning disabilities, their families and carers. This includes those working in the non-statutory sector, acknowledging their important role in improving outcomes and experiences.[F]

We recognise that people with learning disabilities, their families and carers already benefit from a raft of socially progressive legislation and policy throughout the UK, targeting their needs in areas such as health, social care, transport, housing and benefits. The recommendations consequently build on and support these national and local initiatives.

A fully accessible version of this report is being prepared for people with learning disabilities, their families and carers.

The report is structured around four chapters based on the four key themes set out in the executive summary with sections linking directly to the headings from *Modernising Nursing Careers* (11). Each chapter offers a brief narrative setting out key issues and recommendations for action. Positive practice examples collected through the review processes feature throughout, and the report ends with a conclusion and next steps.

The report's recommendations are also set out in Table 2, where the role of key players is proposed.

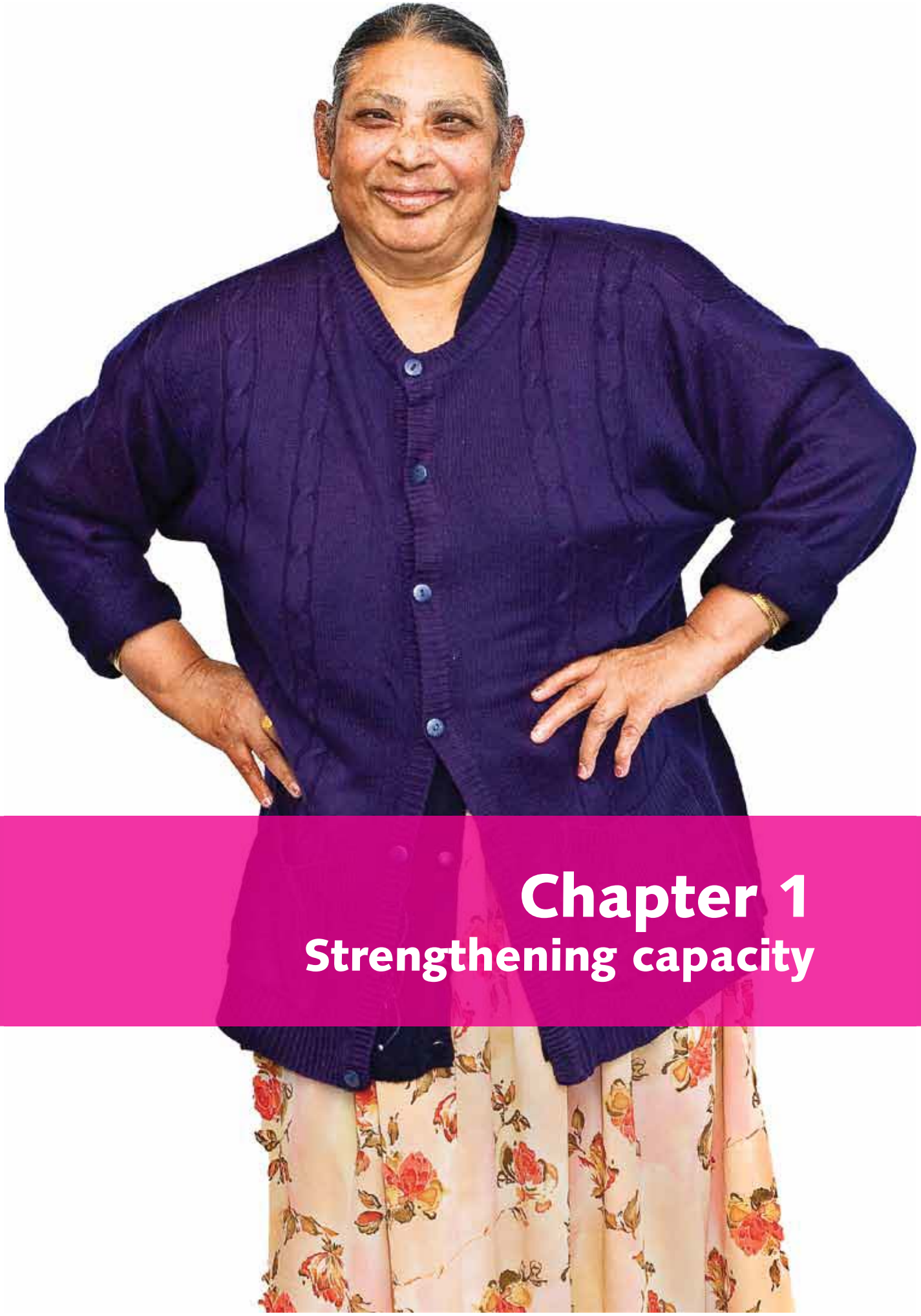
[F] NHS provision may include partly or fully integrated health and social care structures/services.

"I'm going into hospital soon and I'm not frightened anymore because [learning disabilities liaison nurse based in the hospital] will be there to make sure I'm all right."

Person with learning disabilities

"I believe learning disabilities nurses have helped support and move supporting people with profound and multiple learning disabilities onto people's agenda."

Senior community resource worker



Chapter 1
Strengthening capacity

Chapter 1. Strengthening capacity

This chapter addresses some of the key considerations underpinning efforts to strengthen capacity through developing the learning disabilities nursing workforce in relation to:

- **location and employment**
- **strategic workforce planning and development**
- **new ways of working and new roles**
- **career choices.**

1.1 Location and employment

Where we are now

Learning disabilities nurses work in a diverse range of settings, including assessment and treatment services, community teams, the independent/voluntary sector, the criminal justice system and the education sector, providing generalist and specialist nursing care.

Changing patterns of service provision mean that most nurses now do not work in institutions. Instead, they work within geographically dispersed, interdisciplinary and interagency community-based models. Some have strong links to, or are even located within, primary, secondary, mental health or acute services, though this is not common.

The independent/voluntary sector has increased its contribution to service delivery, becoming major employers of learning disabilities nurses in the process, although the precise extent of independent/voluntary sector involvement varies among the countries of the UK.

In some cases, learning disabilities nurses are employed in generic caring or managerial roles. This can lead to the loss of their specialist nursing skills to the service and disadvantage those nurses wishing to progress within appropriate career frameworks.

Where we want to be

Given the demographic and policy challenges highlighted in the introduction, there is a compelling case to assess the learning disabilities nursing workforce required to meet needs within general health services. This may include nurses working in health facilitator roles, in mental health or prison health services or in providing specialist input on a consultancy basis. Learning disabilities nursing skills and knowledge should also be valued in independent/voluntary settings.

In circumstances where nurses are employed in generic caring roles, consideration should be given to how the individual's range of nursing skills and expertise can be utilised to best effect to ensure good health outcomes for people with learning disabilities, their families and carers. In addition, nurses working outside the NHS and their employers should give serious consideration to the benefits of maintaining their professional registration.

Positive practice example

Positive behaviour support in community settings

The Richmond Fellowship Scotland is a social care provider supporting people throughout Scotland with a range of needs, including learning disabilities, autism, forensic needs and mental health difficulties.

The positive behaviour support team was set up in recognition of the fact that many individuals displayed behaviours perceived as challenging and that the organisation needed expertise and skills to support individuals effectively and train staff appropriately. The team comprises a manager and six behaviour support advisors from a range of backgrounds and includes staff with a learning disabilities nursing background. The team carries out functional assessments and, following this, behaviour support plans are developed for the local staff team to implement with support. This direct work with staff and people with learning disabilities is a key factor in successful implementation of the approach.

The model includes proactive and reactive strategies such as teaching new skills, developing communication, using reinforcement strategies and making adjustments to the environment as necessary. A periodic service review is implemented as an ongoing quality assurance tool; outcomes from this are graphed and fed back to staff teams to promote their commitment and involvement. Outcomes for people with learning disabilities are demonstrated by improvements in quality of life and reductions in behaviours perceived as challenging. Changes to staff attitudes and approaches are also evaluated.

For further information, contact Anne MacDonald at [redacted]

Recommendation 1

The four UK health departments and the independent/voluntary sector should establish a national collaborative to enable better understanding of, and planning for, a high-quality and sustainable registered learning disabilities nursing workforce across all sectors.

1.2 Strategic workforce planning and development

Where we are now

There are over 21 000 learning disabilities nursing registrants in the UK (see Table 1). Not all of these will be in current employment.

Table 1

Learning disabilities nurses on the NMC register, 2011

Country	Total number of registered nurses	Number of registered learning disabilities nurses
England	533 205	17 458
Scotland	66 750	1913
Wales	33 416	1030
Northern Ireland	22 564	722
Totals	**655 935**	**21 123**

Source: Nursing and Midwifery Council

New registrant numbers have slowly reduced over the last 10 years, and the numbers employed by the NHS have also fallen. Questions on the viability of some pre-registration education programmes across the UK have arisen as a consequence.

We have tried to establish where these registrants are working as part of the review, but this has proved difficult, even within NHS settings. A number of factors could account for this, including learning disabilities nurses moving to employment in the wider health and social care sectors. As a result, we are unable to effectively plan for the future.

It is also worth noting that the current learning disabilities nursing workforce is ageing, with the potential for a significant gap in the workforce as experienced nurses retire or leave the profession.

Where we want to be

Further work is required to collect accurate data in relation to the size, location and setting of the current workforce to effectively plan for the future and to monitor progress with the modernisation of learning disabilities nursing. Systems are needed within each country to enable robust and sophisticated assessments of workforce requirements and enable appropriate responses, such as appropriate levels of education provision with comparisons across the UK. This must be taken forward in a partnership involving the statutory and independent/voluntary sectors to ensure a clearer understanding of future workforce requirements across all sectors and promote collaboration and integration.

Effective planning and the development of flexible working patterns will help to ensure valuable experience is maintained within the workforce.

Recommendation 2

Systems to collect workforce data are required in each country, with links across the UK, for workforce planning for future provision of learning disabilities nursing. These should be able to capture information on service provision, educational and research requirements and should cover the independent/voluntary sector.

1.3 New ways of working and new roles

Where we are now

Learning disabilities nurses are highly valued by people with learning disabilities, their families and carers. Compassion, respect and human-rights based values and attitudes are the core skills people with learning disabilities, their families and carers look for in learning disabilities nurses and in all health professionals. They have told us throughout the review that we are doing well in the following areas:

- encouraging empowerment and participation;
- promoting communication skills, including accessible communication;
- carrying out health checks, supporting access to hospital or primary care, helping with behaviour and teaching people about health;
- helping people to keep healthy and live in the community;
- supporting access to general health care (liaison roles are highly valued); and
- raising awareness around learning disabilities through education and training for all health professionals.

However, they also told us that we need to do better in a number of areas. These are reflected in our recommendations and include the following.

- Some people with learning disabilities do not have good experiences in specialist assessment and treatment services. Learning disabilities nurses need to involve people more in their assessment and treatment in these settings and avoid restrictive practices (linked to Recommendation 8).
- Children with very complex needs who are being excluded from education – learning disabilities nurses could support services to manage this better (linked to Recommendation 6).
- Consistency is important: where possible, people prefer to have the same nurse/named nurse (linked to Recommendation 5).
- Nonregistered workers should have a more robust training in learning disabilities (linked to Recommendation 13).

Where we want to be

Going forward, people with learning disabilities, their families and carers have told us that we should keep on doing the things we do now, but reduce the variability they experience and start to extend the role in the following areas.

- Supporting transition from children's to adult services continues to be problematic and carers would value more involvement from learning disabilities nurses (linked to Recommendation 6).
- Learning disabilities nurses could develop their role around discharge planning (linked to Recommendation 7).
- Learning disabilities nurses need to take time to get to know people, build trust and recognise that the person is the expert (linked to Recommendation 5).
- People with learning disabilities, their families and carers would like to be more involved in the selection of learning disabilities nurses, including students and the nonregistered workforce (linked to recommendations 5 and 11).
- People with learning disabilities, their families and carers could be more involved in nurse education for all fields of nursing. Other nurses still need more knowledge and skills in working with people with learning disabilities (linked to Recommendation 11).
- Nurses could expand their role into other areas, such as mental health and prisons (linked to Recommendation 4).

The potential for learning disabilities nurses to undertake new, advanced and extended roles should be developed in line with advances in other fields of nursing. Evidence collected throughout the review would support particular attention being paid to the development of competence around non-medical prescribing, psychological therapies, telehealth, and new roles supporting children and families (see Chapter 2) and people with learning disabilities within the criminal justice system. Some of these are considered in more detail below.

Criminal justice system

A high proportion of people with learning disabilities (7%, compared to 2.5% in the mainstream population (12)) travel through the criminal justice system as victims or perpetrators of crime, in police custody or within courts and prisons. It is essential to ensure that sufficient numbers of learning disabilities nurses work in these services, utilising their specialist skills in assessment, planning, diversion (where appropriate) and liaising with different agencies within custodial settings and after release.

Non-medical prescribing

Non-medical prescribing offers opportunities to improve access to medicines and reduce waiting times and is positively viewed by people who have experienced it as part of their care (13). The potential for extending roles through non-medical prescribing for learning disabilities nurses should be explored, particularly in relation to epilepsy and mental health care.

Positive practice example

Non-medical prescribing

An epilepsy nurse specialist in Northern Ireland is demonstrating the benefits to people with learning disabilities of undertaking a non-medical prescribing course.

The epilepsy specialist nurse role is varied in that it involves clinical management, education and training, and practice development. The post-holder recognised opportunities to provide advice to people with learning disabilities, their families and carers on medication changes rather than them having to wait for the medical clinician, enabling a timely, effective treatment regime to be initiated and reducing risks by preventing seizures and/or adverse effects.

As a result, the nurse sought to further her knowledge and skills to support competency in prescribing and titrating antiepileptic drugs and her understanding of pharmacokinetic properties and interactions. She successfully completed the non-medical prescribing course and an epilepsy nurse prescribing pathway was agreed within service.

She is now in a position to advise people with learning disabilities, their families and carers on medication changes promptly, based on assessed need. As is the case with the medical consultant who reviews the client's epilepsy at outpatient clinics, she will recommend medication changes to the client's GP, enabling the person's electronic record to be updated and the necessary medication to be provided for the long term. She also provides expert knowledge around epilepsy in people with learning disabilities to support GPs.

For more information, contact Edna O'Neill at [redacted]

Psychological therapies

A growing evidence base around psychological therapies and their benefits for people with learning disabilities supports the development of relevant skills by learning disabilities nurses (14,15). Nurses are encouraged to maintain and practice psychological interventions, supported by effective supervision. The ethos behind this process is to enable nurses to deliver approaches in line with a stepped-care framework, ensuring assessment and treatment delivery at the earliest opportunity and linking with other parts of the care system to reduce hospital admissions.

Telehealth

The increasing use of telehealth and telemonitoring across the UK has the potential to advance the personalisation, strengths-based and assets-focused agenda for people with learning disabilities, their families and carers. Learning disabilities nurses need to explore this potential within the systems in which they work.

Recommendation 3

The development of new, specialist and advanced role opportunities should be considered in light of workforce planning, service development and education provision. In particular, this should focus on the roles of non-medical prescribing, psychological therapies and telehealth and in specific settings such as the criminal justice system, mental health services (particularly dementia) and autism services.

1.4 Career choices

Where we are now

The range of statutory and non-statutory employment opportunities, alongside the integration of health and social care services, means that career choices are not always clear and career options can be limited by a lack of transferability between sectors and employers.

Where we want to be

Career pathways and progression should be clear across all services and settings to allow learning disabilities nurses to plan their career development. *Modernising Nursing Careers* (11) introduced the notion of structured career planning for nurses to enable them to develop knowledge and skills within existing roles that would also allow progression to more senior roles. Many initiatives relating to different levels of the NHS career framework have subsequently been advanced throughout the UK.

Education and training elements at all levels of the NHS career framework should be further developed to outline the knowledge, skills, attitudes and values required by the learning disabilities nursing workforce, including those in specialist practice and consultant nurse roles. This would enable the planning of education to meet workforce development needs, better meet the needs of people with learning disabilities, their families and carers, and act as the foundation for informing future developments in post-registration learning disabilities nursing education, research and scholarly activity. These developments could be utilised across sectors (with appropriate adaptation) to give a coherent career framework.

Positive practice example

Supporting reasonable adjustments

Working as a consultant nurse and senior lecturer, Jim Blair has a remit to lead the delivery and development of clinically effective, safe, lawful and appropriate practice within acute services for people with learning disabilities. The following examples show how the consultant nurse has been able to drive reasonable adjustments in hospitals to enhance the care and treatment experienced by people with learning disabilities.

Katherine has severe learning disabilities and her passport* says she is allergic to eggs. After reading this, the ward sister telephoned Katherine's home to clarify whether she experienced anaphylactic reactions or a rash. This was a precautionary measure, rather than a response to anything that had happened.

Vivek's passport stated that he "bubbles up liquids and regurgitates food". A doctor noted this and knew that this could indicate dysphagia, which can result in a person choking. Dysphagia is more common in people with learning disabilities, so it is vital to look for indications, as there were in Vivek's case, and quickly identify how to ensure optimum nutrition.

Without hospital passports, serious issues may be missed or left unaddressed. Clinicians at St George's Hospital in London were able to act on the information in the passports and to alert colleagues about the issues, resulting in effective care and treatment for both individuals.

Core reasonable adjustments at St George's

The following are standard for people with learning disabilities, their families and carers in St George's Hospital to help reduce anxiety, permit experts (such as family) to provide emotional and advocacy support, and to enable professionals to treat people in an efficient and timely way.

- No fixed visiting times for family, carers and friends of people with learning disabilities is general policy, so they can be with them for as long as they want.
- Food and drink is offered to family and carers to ensure they can be with the person they support at any time.
- The first or last appointment of the day should always be offered, so people who find it traumatic to wait do not have to do so.
- Double appointments are helpful because they permit a fuller assessment of people's needs, which is likely to result in more effective treatment and outcomes.
- A bed and/or chair are provided for a family member or carer.

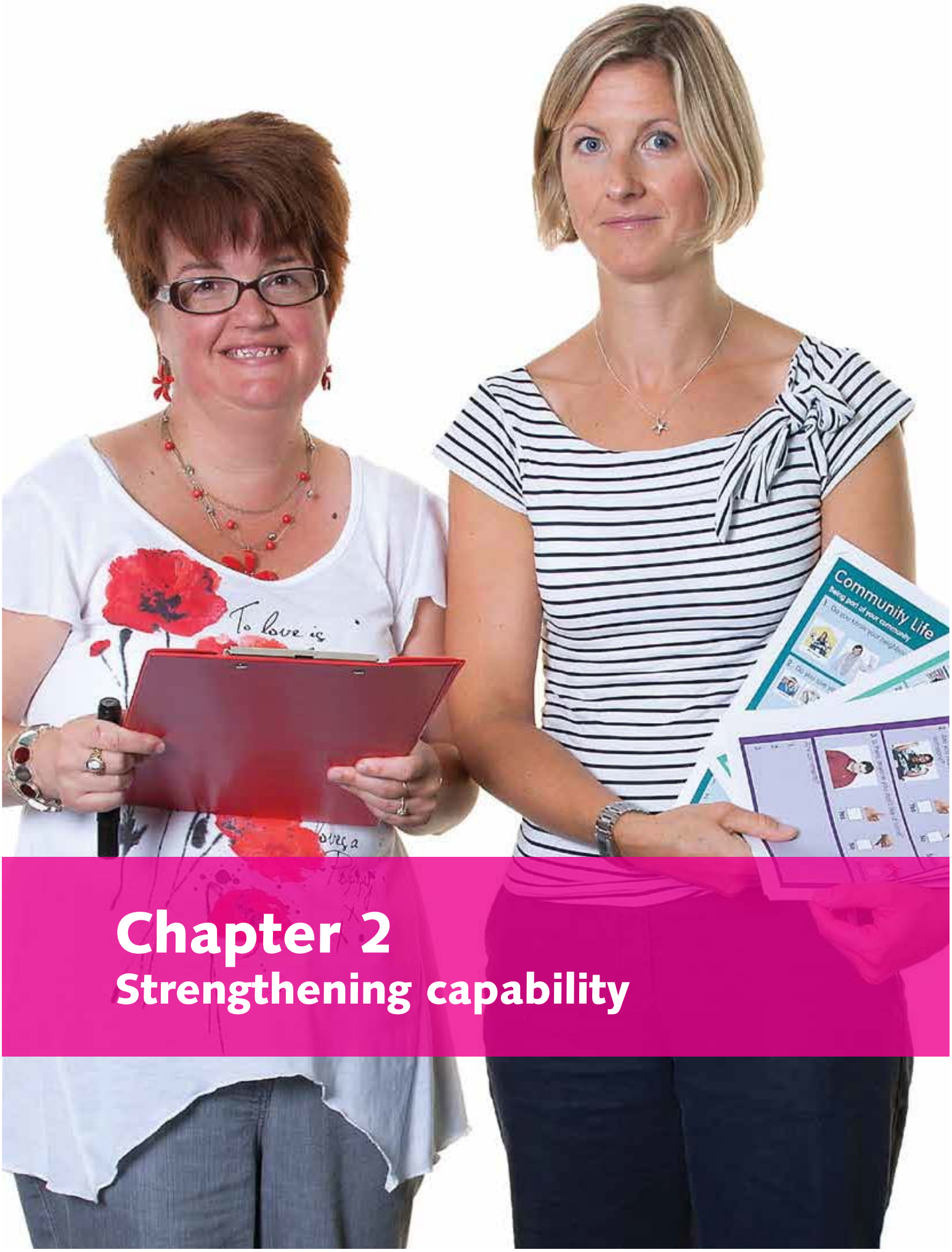
For care and treatment to be equitable, adjustments need to be made so that the health care experiences and outcomes of people with learning disabilities in hospital are improved. An example of reasonable adjustments at St George's involved Trevor, a man who had capacity to consent to have dialysis but who pulled out the tubes after 30 minutes because he was unable to judge how long the procedure had taken and wanted to leave. The reasonable adjustment in his case was to provide a health care assistant to be with him throughout the four-hour treatment to talk with him and encourage him to complete dialysis. Over time, he stopped needing to have someone with him and now has dialysis by himself.

For further information, contact Jim Blair at [redacted]

*A hospital passport is a guide to the individual's health and well-being that is completed in advance of the hospital visit so that hospital staff have an accurate record of key information relating to their health and medical history (source: **www.sabp.nhs.uk/services/ld**).

Recommendation 4

Each of the four countries should consider aligning their existing post-registration career frameworks for learning disabilities nursing to clearly articulate the knowledge and skills required by learning disabilities nurses at all levels and across all settings. These developments could be utilised across sectors (with appropriate adaptation) to give a coherent career framework.



Chapter 2
Strengthening capability

"Learning disabilities nursing is vital for ensuring people with learning disabilities and their carers get access to general health care in the same way as you or I do. They help people navigate the NHS system to ensure people with learning disabilities, their families and carers get the best health outcomes and support possible. They also support other health professionals to modify their delivery care models to best suit the client's circumstances and enable the delivery of true person-centred care."

Deputy director of nursing, general hospital



Chapter 2. Strengthening capability

This chapter outlines key considerations underpinning efforts to ensure a competent and flexible learning disabilities nursing workforce for the future by:

- **maximising the contribution of learning disabilities nursing**
- **working with people of all ages**
- **addressing health needs**
- **providing specialist services.**

2.1 Maximising the contribution of learning disabilities nursing

Where we are now

The Royal College of Nursing (16) defines nursing as:

> *"The use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems and to achieve the best possible quality of life whatever their disease or disability, until death."*

Learning disabilities nurses are the only professional group specifically prepared to work with people with learning disabilities. This level of preparation, currently provided at degree level, alongside the breadth of biopsychosocial skills, competence and knowledge they develop, makes them a unique and critical component of the delivery of comprehensive services.

Too often in this review examples were cited of how learning disabilities nursing is being under-utilised. Considering the small pool of registered learning disabilities nurses available across the UK and the workforce challenges ahead, it is essential that their expertise is used to best effect for the populations they serve.

Where we want to be

A central requirement for the transformation agenda across the four countries and across all organisations is the need to target the skills, knowledge and competencies of learning disabilities nurses to the right people, in the right places and at the right times.

Positive practice example

Prescriber nurse-led clinics – a community model for people with learning disabilities and epilepsy

A community learning disabilities nurse in Gloucestershire has developed a nurse-led service to enhance epilepsy care for people with learning disabilities, reducing the risk of sudden unexpected death in epilepsy (SUDEP).

Regular appointments, partnership working and training have led to improved recording and medication concordance. This has enabled effective evidence-based nurse prescribing to rationalise people's medication. Reasonable adjustments have also been made by strengthening links and providing relevant data to support access to generic services.

Health outcomes have included:

- 75% seizure reduction;
- 33 people on the epilepsy care pathway with history and medication timeline;
- 9 people accessed a bone density scan, with 7 bone disorders identified (2 results pending);
- 5 women on long-term valproate medication accessed ultrasound scans, with 4 ovarian conditions identified (1 outcome awaited); and
- 544 hours of epilepsy training delivered to carers, empowering people to manage their condition.

The following have been implemented to reduce the risk of SUDEP:

- 17 epilepsy night bed monitors
- risk management plans
- protocols for all people prescribed rescue medication.

Quality, innovation, productivity and prevention savings have also been realised, including:

- reduced unscheduled hospitalisation and emergency calls through improved seizure control, risk management plans and prevention of fractures;
- reduced fuel and travel costs to complement the organisation's Green policy;
- improvements in training, appointment attendance, monitoring and medication concordance, with rationalisation of therapy;
- auditable outcomes using the National Institute for Health and Clinical Excellence's (NICE's) epilepsy-adapted learning disability tool;
- reduction in "did not attends" (13 of 412 consultations); and
- the nurse achieving up to 83 quality monthly contacts (working 22.5 hours/week).

For further information, contact Penny Shewell at [redacted]

Recommendation 5

Commissioners and service planners should have a clear vision for how they ensure the knowledge and skills of learning disabilities nurses are provided to the right people, in the right places, and at the right time in a way that reflects the values- and rights-based focus of learning disabilities nurses' work.

2.2 Working with people of all ages

Where we are now

Learning disabilities nurses already make a key contribution to quality nursing service delivery across the lifespan. This includes contact and interventions with babies and children, during school years, at transition to and throughout adulthood and, increasingly, in the later years to end of life. The skills and competencies of learning disabilities nurses must be available at these key life stages.

Where we want to be

Early years

Learning disability nurses should give specific and conscious attention to ensuring the health needs of children and young people with learning disabilities are appropriately prioritised and addressed. Their skills, knowledge and expertise must be maximised to ensure high-quality services and interventions for children with learning disabilities and their families (17).

Not all children with learning disabilities will require support from learning disabilities nurses, and it is essential that the shift towards improving access to general health services for children continues. Learning disabilities nurses nevertheless possess specific knowledge and competencies that can bring added value, particularly to those with the most complex needs, and they must be a central component of services that deliver care to this population in areas such as skills development, mental health and emotional well-being, behavioural management, complex physical health needs and family-focused intervention and support.

Positive practice example

Supporting parents with learning disabilities – new ways of working

The special parenting service in Cornwell provides assessment of parenting skills for people with learning disabilities who are expecting a baby. Areas where support or teaching is required are identified following assessment of knowledge on all aspects of parenting. The service also provides support, advice and consultation to statutory agencies, midwives and health visitors.

Following birth, the nurses work with all agencies involved to ensure that parents can provide "good enough" parenting, ensure that safeguarding issues do not arise and provide follow-up support to parents at identified key developmental stages. The *Parent Assessment Manual* is used as an initial assessment tool: this is designed to assess parenting ability for those with mild learning disabilities. Following assessment, interventions can include solution-focused therapy, video interaction guidance therapy, family therapy and skills teaching. Outcomes include:

- enabling clients to gain the knowledge and skills required for successful parenting
- raising confidence and self-esteem levels
- ensuring good attachment
- reducing family members' concerns about the parents' ability to succeed
- empowering the parents to feel confident to access universal services
- reducing the number of referrals to children's social care over safeguarding issues.

Next steps for the service are to:

- work in collaboration with universal services, midwives and health visitors to promote early referral to special parenting;
- collate evidence from the early intervention project to identify the effectiveness of current interventions; and
- be aware of current evidence-based practice and best-practice guidance to ensure that standards are maintained at the highest level.

For further information, contact Jan Line at [redacted] and Paul Thomas at [redacted]

Older age

Learning disabilities nurses must be prepared for the continuing rise in the number of older people with learning disabilities. These individuals are at risk of a range of physical and mental health conditions and may be frequent users of health and care services and other related agencies. In addition, some people with learning disabilities may be at risk from conditions that are similar to those experienced by older people (such as dementia), but may be too young to access generic older people's care services.

Recommendation 6

Commissioners and providers of health and social care should ensure the skills, knowledge and expertise of learning disabilities nurses are available across the lifespan. This should be enabled through effective collaborative working across health and social care structures.

2.3 Addressing health needs

Where we are now

There is strong evidence that people with learning disabilities have poorer physical and mental health and greater health needs (including needs related to behavioural difficulties) than the general population. In addition, many have difficulties accessing and using general health services. Learning disabilities nurses have expertise in facilitating and supporting access to general health care services.

The Nursing and Midwifery Council (NMC) standards for pre-registration nursing education (18) reflect the health role and function of learning disabilities nurses, stating:

> *"Learning disabilities nurses must have an enhanced knowledge of the health and developmental needs of all people with learning disabilities, and the factors that might influence them. They must aim to improve and maintain their health and independence through skilled direct and indirect nursing care. They must also be able to provide direct care to meet the essential and complex physical and mental health needs of people with learning disabilities."*

The contribution of learning disabilities nursing in addressing health needs within the social model of disability has been the source of some confusion. It is important that learning disabilities nurses and services recognise that poor health (in its widest context) limits participation in society.

Where we want to be

As the Learning Disability Consultant Nurse Network (19) states:

> *"The primary focus of learning disabilities nursing interventions within the social model of disability is upon reducing or eliminating barriers to good health and thereby increasing social inclusion."*

Learning disabilities nurses and their employers should recognise their crucial responsibility in improving health and well-being and reducing inequalities and should engage actively in commissioning, designing, monitoring and delivering services to ensure their accessibility.

A partnership approach across the lifespan involving primary care, child health, mental health, secondary care and specialist learning disabilities health services is essential.

Learning disabilities nurses are ideally placed to contribute to the preventative, early-intervention, strengths-based and public health approaches that are increasingly being applied to the general population to address health needs. While health promotion activity has been at the forefront of learning disabilities nurses' practice for many years, other more proactive preventative and public health approaches to addressing health needs have been less visible in their day-to-day work.

This broader holistic approach to addressing health needs will:

- ensure preventative action and early intervention is a core component of assessment and care planning;
- encourage people with learning disabilities, their families and carers to take a more active role in controlling their own health; and
- support strengths- or assets-based approaches to care and interventions.

There is a clear need for public health interventions to meet the needs of people with learning disabilities, their families and carers and for learning disabilities nurses to engage with colleagues within public health, primary care and other relevant health and cross-sectoral agencies, such as criminal justice and homelessness services.

A proposed model for addressing health needs in the context of learning disabilities nursing is set out in Fig. 1.

Fig. 1

Proposed model for addressing health needs in the context of learning disabilities nursing

Context	Nursing roles/interventions	Outcomes
Working with children →	Family support. Early intervention. Skills teaching. →	Maximised potential of the child. Improved interagency working. Reduced incidence of long-term health issues.
Inequalities in health →	Health screening/facilitation. Health action planning/ interventions. Improving access. Education of others. Policy-influencing. Advocacy. →	Healthier lifestyles. Reduced morbidity and mortality. Reduced risk for patients in generic services. Social inclusion.
Working with parents and families →	Supporting parents and siblings of people with learning disabilities. Supporting parents with learning disability. Family therapy. Education/awareness. →	Family-orientated service delivery. Reduced safeguarding issues. Improved family health and lifestyle.
People facing additional risks →	Targeting relevant public health needs (e.g. mental health, drugs/alcohol and sexuality). Group interventions. Strengths-based approaches. →	Enhanced self-care, peer support and independence. Reduced risk and safeguarding issues. Reduced self-harm and distress.
Commissioning →	Caseload/population needs assessment. →	Improved and informed commissioning of services.

Positive practice example

Health facilitation

The health facilitator role focuses on ensuring people with learning disabilities live healthier lives and enjoy better health. A significant number of adults with learning disabilities are not receiving a service from community learning disabilities teams but are known to GP practice staff.

A database is presently being constructed in the Southern Trust region of Northern Ireland to provide accurate figures. All practices have been visited by the health care facilitator who will:

- meet with the practice manager to cross-reference names of adults with learning disabilities with practice population lists;
- deliver an education session to GPs, practice nurses and reception staff on health needs and barriers to meeting need;
- encourage practice staff to establish clinics and complete a thorough health check on each individual;
- explain the requirements of the direct enhanced services (DES); and
- agree dates for clinics with GPs and advise on how to ensure good uptake of appointments.

Figures from primary care show that 932 health assessments were carried out in 2009 and 904 in 2010. GPs and practice nursing staff appreciate clinical input and support to develop understanding about people with learning disabilities, especially around behaviour management, communication difficulties, consent issues and health needs. Analysis to date suggests that practices with the health facilitator on site are more likely to meet the requirements of the DES.

A large number of health issues have been identified, including obesity, diabetes, hypertension, lack of medication review and lack of electrocardiograms for people on anti-psychotic medication. Many of these health issues have previously been undetected and unaddressed. GPs and practice staff have developed a rapport with people with learning disabilities, their families and carers, and practice staff have a better understanding of their health issues.

For further information, contact Brea Crothers at [redacted] or Marie Loughran at [redacted]

Recommendation 7

Commissioners and providers of health and social care should ensure that learning disabilities nurses are able to collaborative effectively with general health services, including mental health services, to address the barriers that exist for people with learning disabilities to improving their health. This should include proactive health improvement, prevention, whole-family and public health approaches.

2.4 Providing specialist services

Where we are now

Existing specialist services, when appropriately deployed, provide early intervention, crisis resolution and outreach that can reduce unnecessary admissions to hospital through expert assessment, care planning, interventions and evaluations for individuals and their families.

The need for specialist nursing skills in these areas is already significant and is likely to grow in the future. Learning disabilities nurses working within specialist services should possess, or be working towards developing, the appropriate specialist skills and should be able to demonstrate higher levels of judgement, discretion and decision-making in clinical care (20) relevant to their role.

Where we want to be

Evidence collected by the review suggests that assessment and treatment services could further develop and use a range of therapeutic interventions that have positive outcomes for people with learning disabilities. This would require further support and investment in education and development. The specialist role of learning disabilities nursing within assessment and treatment services must therefore be supported through the development of appropriate models of care and provision of relevant education support.

Health care providers and commissioners should review the needs of their populations and make provision to ensure delivery of specialist learning disabilities nursing skills where needed. This may involve reviewing their current workforce configuration and increasing collaboration with education providers.

To ensure that people with learning disabilities and their families receive the best holistic care, skills traditionally associated with acute and community nursing will need to become a core part of learning disabilities nurses' "toolkit".

Positive practice example

Specialist services

A low-secure unit that provides assessment and treatment for men with learning disabilities and forensic issues in Northern Ireland has developed group work and 1:1 therapeutic work for individuals who exhibit behaviours (or who are at risk of committing behaviours) that are sexually harmful to others.

The assessment and treatment programme initially implemented for this group was the Home Office accredited "Adapted Sex Offender Treatment Programme". Prior to implementation, two nursing staff were required to undertake intensive accredited training in advanced group work delivery and complete a period of secondment with probation services, delivering programmes and compiling risk assessments and management plans for offenders. Further training was then completed to deliver treatment specifically to those with learning disabilities.

The programme was based on the cognitive behavioural therapy model, giving individuals the opportunity to take responsibility for their offending behaviour and work towards skills development that would help them identify their specific areas of dynamic risk and formulate relapse-prevention strategies to lower their risk of reoffending.

The work was acknowledged in 2008 when two nurses from the hospital were granted the RCN Nurse of the Year for Northern Ireland award in recognition of setting up and facilitating a programme of treatment that at the time was unparalleled in Northern Ireland.

Nursing staff are providing consultancy on facilitation techniques, programme content and delivery. It is envisaged that nurses who are already qualified to deliver advanced group work will also become involved in training other staff to deliver the new programme. This will lead to a core group of nurses within the hospital who are able to work as therapists, delivering treatment within group work and 1:1 settings and compiling risk assessments and management plans in partnership with people with learning disabilities to facilitate return to community living in the most appropriate and safest way.

For further information, contact Rhonda Scott at [redacted]

Recommendation 8

Commissioners and service providers should ensure that specialist learning disabilities services for complex and intensive needs (including assessment and treatment services across all sectors) employ sufficient numbers of appropriately prepared and supported registered learning disabilities nurses. This highlights the need to support and develop the availability of specialist and advanced clinical skills and knowledge of learning disabilities nurses in all settings.

"I had concerns about the [learning disabilities nurse] student being there… they were completely dispelled… His understanding and natural affinity for dealing with difficult situations mean if he is an example of the future we have no issues."

Family carer



Chapter 3
Strengthening quality

"Learning disabilities nurses listen to you and make sure I have a say about what happens to me."

Person with learning disabilities


ABERCROMBIE
18 92
W YORK
ABERCROMBIE AND FITCH

Chapter 3. Strengthening quality

This chapter addresses some of the key considerations underpinning quality. Clearly, the appropriate preparation and development of learning disabilities nursing will contribute to all chapters of this report, but in this case has been linked to quality in relation to the following issues:

- **demonstrating quality outcomes**
- **quality improvement**
- **preparing and developing learning disabilities nurses**
- **maximising recruitment and retention**
- **developing workforce knowledge and skills for the future**
- **accessing supervision.**

3.1 Demonstrating quality outcomes

Where we are now

Demonstrating the quality, effectiveness and impact of learning disabilities nursing through outcome measurement presents a range of challenges, not least of which is the fact that learning disabilities nurses' work is often placed within a wider interdisciplinary and interagency team context that makes it difficult to identify their particular contribution to achieving outcomes.

Where we want to be

Positive health outcomes not only improve people's health status and quality of life, but also contribute to the achievement of organisational and policy drivers such as person-centredness, safety, effectiveness and efficiency through improving access to general health services, preventing admissions to hospital and securing early discharge.

A measurement framework of outcomes and outcome indicators would allow learning disabilities nurses to demonstrate their effectiveness in assessments, care planning and nursing interventions at individual and service levels within a multidisciplinary context. The potential for such measurement frameworks to be adapted and used across sectors to support health and social care integration should be explored.

A measurement framework should focus on effective assessment, care planning, intervention and evaluation. All interventions by nurses, individually or as part of a wider team, should be based on a competent and structured nursing assessment of the abilities and needs of the person with learning disabilities. Person-centred objectives for nursing interventions with identified timescales for evaluation should then be clearly written within nursing care plans.

An agreed set of indicators developed in collaboration with nurses and people with learning disabilities, their families and carers would allow the contribution of learning disabilities nurses to be evidenced and measured. This is particularly important given the current emphasis on efficiency, effectiveness and added value.

A range of outcomes and outcome indicators can identify effective and high-quality nursing care related to specific roles and practice settings. Examples may include:

- improvements in health status
- increasing access to general health services
- promoting independence and social functioning
- improving nutrition
- enhancing psychological and emotional well-being
- reducing seizures.

A more targeted and specific approach to outcome measurement dependent on role, function and setting may also be necessary. Role-specific indicators (for learning disabilities nurses employed, for example, as health facilitators or those working in acute liaison roles or within forensic services), condition-specific indicators (such as for epilepsy nurses), patient experience and quality-of-life outcome measures (via service user questionnaires and surveys, complaints and compliments, for example) and inclusion of learning disabilities in measurement of generic key performance indicators at service or policy level or via established rating scales (such as the Health of the Nation Outcome Scales for People with Learning Disabilities (HONOS-LD) (21)) will be required.

It is important that people with learning disabilities, their families and carers are involved in determining the outcomes.

Positive practice example

Developing behavioural family therapy

A specialist learning disabilities nurse in Lothian has worked with other clinicians in adapting and delivering behavioural family therapy (BFT) for people with learning disabilities and has trained 18 nurses to use the approach. The service now has three BFT trainers who specialise in learning disabilities and has developed close links with general mental health clinicians and trainers.

The approach is being implemented within several community learning disabilities teams. Clinicians now routinely use a series of outcome measures to monitor its effectiveness, with the client completing the Clinical Outcomes in Routine Evaluation – Learning Disability (CORE-LD) assessment and family members completing the Caregiver Strain Questionnaire (CGSQ) and the Family Functioning Questionnaire (FFQ). Care agency staff also complete an adjusted FFQ.

A successful case study demonstrating a reduction in carer stress for a family member and an increase in functioning for support staff and the family member was presented at the British Association of Behavioural and Cognitive Psychotherapy conference in 2011. A case series of five families was presented at the Seattle Club conference on research in intellectual and developmental disabilities in 2011. The results demonstrated a decrease in family stress on the CGSQ over the five cases, with family functioning improving in all members. There was a decrease in levels of distress in three of the four people with learning disabilities who completed the CORE-LD. It is noteworthy that services had been involved over a prolonged period of time for all five cases, suggesting that their problems were longstanding and that other treatment approaches had not been effective.

Learning disabilities nurses have increased knowledge and confidence following BFT training. The training has also given clinicians a clear structure to deliver the approach. Regular supervision has helped to maintain delivery while maintaining clinician confidence. Plans to further develop this work include:

- continuing to develop the evidence base evaluating the efficacy of the approach;
- expanding the BFT training to all community learning disabilities teams in NHS Lothian and continuing to expand the supervision network;
- developing better pathways for referrals and level of intensity of BFT based on the complexity of mental health issues;
- extending the BFT training to social work, allowing better joint working between health and social care; and
- establishing links with NHS Education for Scotland with a view to developing the approach for nurses on a wider scale.

For further information, contact Keith Marshall at [redacted]

Recommendation 9

Learning disabilities nurses, their managers and leaders should develop and apply outcomes-focused measurement frameworks to evidence their contribution to improving person-centred health outcomes and demonstrating value for money. This may require a specific piece of work to scope current frameworks.

3.2 Quality improvement

Where we are now
Learning disabilities nurses embrace the wider drive for evidence-based practice and improvement, but their contribution could be enhanced. Transformational work is currently being undertaken across the UK under patient safety programmes and work to drive quality, innovation, productivity and prevention. Elements of learning disabilities nursing practice may benefit from the systematic application of productivity tools like the Productive Series/Releasing Time to Care and robust improvement science.

Where we want to be
Learning disabilities nurses should increase their involvement in the range of transformational work, productivity, improvement and practice development.

Recommendation 10

Learning disabilities nurses should strengthen their involvement and links to transformational work, productivity improvement and practice development.

3.3 Preparing and developing learning disabilities nurses

Where we are now
A well-prepared, developed and supported workforce at all levels is essential to the delivery of quality health care for people with learning disabilities, and education and training throughout the career pathway is key to achieving this.

People with learning disabilities, their families and carers should be involved in all aspects of curriculum design, development and delivery.

Person-centred care (22) should be the foundation of learning disabilities nurse education. It has been defined as:

> *"... the delivery of a healthcare experience that recognises and responds flexibly to each person as a unique individual, builds trust and empathy, and engages them in decisions that affect their healthcare and wellbeing. Person-centred care is an approach which recognises that the quality of communication and human engagement with the person receiving healthcare will underpin the effectiveness of the clinical encounter, and therefore impact on the person's healthcare experience and outcomes."*

This means working alongside people to identify meaningful goals that fit with their aspirations and the outcomes they want to achieve, rather than focusing on what health and social services think people need.

Where we want to be
Pre- and post-registration education programmes should be designed to reflect issues such as person-centred care and the personalisation agenda and the more complex care needs that are now presenting within the population.

This review focuses on learning disabilities nurses, but the importance of all nursing students at undergraduate level developing core knowledge and skills to work with people with learning disabilities, their families and carers cannot be ignored. This has been emphasised with the NMC standards for pre-registration nursing education (20) and the Michael Report into access to health care for people with learning disabilities (23).

Positive practice example

Supporting the development of skills and knowledge in other fields of nursing (percutaneous endoscopic gastrostomy (PEG))

People who are reliant on their nutrition, hydration and medication being administered via PEG can experience difficulties when their devices block or are removed. This can result in attendance at accident and emergency departments. Community learning disabilities nurses in Swansea work in collaboration with the accident and emergency liaison nurse, specialist nutrition nurse and hospital nurse practitioners to develop individual pathways for direct access to intervention. The outcomes of this work include:

- clear and safe pathways to access secondary care
- reduced risk of invasive interventions such as surgery or endoscopic procedures.

The nurses also identified that people with learning disabilities who had enteral feeding needs were sometimes having to access nursing home facilities for respite care, were relying on registered nurse home visits for domiciliary care, and were unable to access day services unless registered nurses were available. The community learning disabilities nurses worked in partnership with a wide range of organisations to develop a programme of training for independent sector care providers and social services to enable individualised person-centred care plans to be devised, meaning people no longer have to access nursing environments for respite and day services or be reliant on district or continuing care nursing services to deliver support. This process entailed seamless joint working and planning to minimise the identified risks to individuals and those involved in their care, while promoting person-centred services.

For further information, contact Helen Lewis at [redacted]
or Paula Phillips at [redacted]

Recommendation 11

Those who commission, develop or deliver education should ensure that all learning disabilities nursing education programmes reflect the key values, content and approaches recommended in this report. They should also ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services.

3.4 Maximising recruitment and retention

Where we are now

As we noted previously, the number of providers of pre-registration learning disabilities nursing education has reduced over the years. This will need to be addressed to reflect population and workforce planning needs.

Access to learning disabilities nurse preparation can be problematic for students in some parts of the UK, including remote and rural areas where no learning disabilities nursing education programmes are available locally. High attrition rates are a problem on some pre-registration programmes and the changing face of service provision for people with learning disabilities requires higher education institutions to develop a range of options for clinical placements that support the attainment of competences required by the NMC.

Throughout the review, students said that they feel more valued and better supported where there is strong mentorship in practice placements and close collaboration between practice and education settings. There are opportunities for learning disabilities nursing to trailblaze new models of delivery in education programmes that strengthen work-based support for students and enhance partnership working between education and practice settings.

Where we want to be

New approaches to identify and engage with potential recruitment pools, particularly existing nonregistered staff and students undertaking higher national certificate (HNC) programmes in further education colleges, are required. These opportunities are currently underexploited. The use of IT and social media may offer a route to accessing these groups.

The development of a wider range of accelerated routes and award models could further maximise potential to recruit from existing groups, including nurses on other parts of the register and people wishing to change their careers.

The wide range of educational technology now available provides more flexible options in relation to delivery of education programmes. Flexible and sustainable models of pre-registration curriculum development offer the most positive options for future progression in learning disabilities nursing, and the NMC standards promote these kinds of approaches. Models that support flexibility and sustainability, such as hub and spoke, blended learning approaches and disseminated models, should be considered to support effective delivery of pre-registration education across the UK. Innovative approaches to programme design and delivery that involve people with learning disabilities and families, promote rights-based and person-centred approaches and review options in interprofessional education must be more widely explored.

Recommendation 12

Updated strategic plans for pre- and post-registration learning disabilities nursing programmes are necessary for each country of the UK to support flexibility and ensure an efficient and sustainable model of delivery for the long term. This highlights the need for appropriate numbers of places on pre-registration learning disabilities nursing programmes to meet future workforce requirements.

3.5 Developing workforce knowledge and skills for the future

Where we are now

Post-registration education and continuing professional development (CPD) options are restricted by the relatively small learning disabilities nursing workforce. In addition, data on education needs and development opportunities, including those at post-registration level, are not easily available.

The skills profile of learning disabilities nursing is changing, with greater emphasis being placed on meeting complex health needs and employing specific interventions such as psychological therapies; some learning disabilities nurses are also assuming prescribing responsibilities. There are opportunities for higher education institutions and CPD providers to respond to these changes in the development and delivery of their programmes.

Nonregistered staff already play a vital role, which will change as the role of registered nurses develops. It is important that service providers build an educational infrastructure that meets the needs of this group.

Where we want to be

Creative opportunities for the development of education programmes include blended learning approaches, collaborative working across education providers and across sectors and further development of interprofessional education opportunities.

Positive practice example

Collaborative curriculum design and delivery

The learning disabilities team at Edinburgh Napier University has worked with people with learning disabilities, their families and carers, mentors and other stakeholders for a number of years to influence, design and deliver pre-registration nurse education for learning disabilities. People with learning disabilities, their families and carers and learning disabilities nurses are involved in the selection and interview of students and in developing learning materials, delivering sessions in the classroom, online and in the clinical skills labs, and assessing students in practice.

This partnership approach is central to education provision. In addition to a wide group of people who work as associate lecturers, a learning disabilities nursing development group and stakeholder group meet regularly to review and develop joint initiatives such as creating new modules, expanding the use of educational technology, supporting practice learning environments and promoting practice-based projects. The content of the learning materials has application to practice and the involvement of experts in delivery ensures students experience a strong focus on person-centred, family-centred health care that is relevant to practice.

With the move to increasing use of online technologies, a strategy is being developed to support people with learning disabilities, their families and carers and mentors to develop skills and competence in using technologies such as Elluminate Live and online discussion forums. This work has been commended by NHS Education for Scotland and the agency undertaking revalidation work for the NMC.

For further information, contact Janet Smith at [redacted]

Recommendation 13

Education providers and services must work in partnership to ensure that educational and developmental opportunities for nonregistered staff are developed and strengthened and their benefits are evidenced through appraisal systems, and that educational and development opportunities are available for registered learning disabilities nurses to support their ongoing development, reflecting the needs of people with learning disabilities.

3.6 Accessing supervision

Where we are now

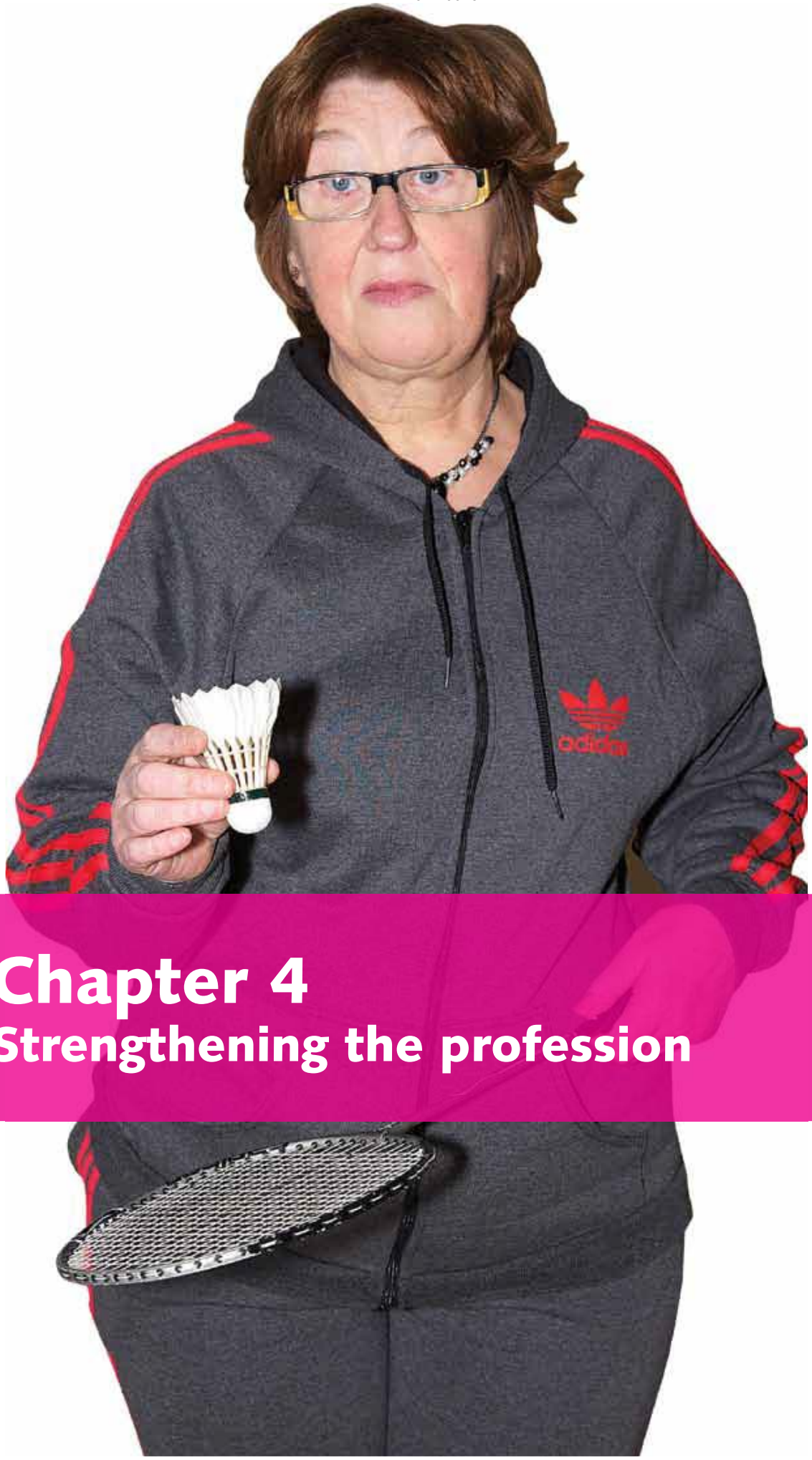
Clinical supervision is recognised as a supportive way to enable learning from experience with the aim of developing knowledge and improving care (24). It was evident through the review processes that learning disabilities nurses engage in supervision at a number of levels and with a variety of professionals during their careers. Engagement with clinical supervision nevertheless varies throughout the UK and possibly between sectors.

Where we want to be

Given the link between effective supervision, reflective learning and safe person-centred practice, supervision should be viewed as essential to contemporary learning disabilities nursing practice and must be supported by employers and nurses. They can demonstrate its value by creating and maintaining protected time and support for clinical supervision and by seeking to illustrate the outcomes of supervision in a way that demonstrates improvements in care.

Recommendation 14

Services should provide systems to ensure that learning disabilities nurses have access to regular and effective clinical supervision and that its impact is monitored and evaluated on a regular basis.



Chapter 4
Strengthening the profession

"Learning disabilities nurses listen to us and respect us as adults."

Person with learning disabilities

"My eyes have been opened to the world of adults with learning disabilities by the learning disabilities nurse. Delivering teaching sessions about young people and transition together has been an invaluable learning experience for us both."

Consultant paediatrician

Chapter 4. Strengthening the profession

This chapter addresses some of the key considerations underpinning modernising the learning disabilities nursing workforce in relation to:

- **leadership and management**
- **promoting the profession**
- **research and evidence.**

4.1 Leadership and management

Where we are now

Health and social care structures often bring together learning disabilities, mental health and/or community services, which means there may not be a senior learning disabilities nurse in a leadership role to ensure that learning disabilities nursing issues are identified and addressed. This local situation is reflected at national level: devolution in the UK has led to differences in policy and service provision across the four countries, which impacts on how leadership is defined nationally. There may not always be clear opportunities for learning disabilities nurses to demonstrate political leadership at this level.

There has been a lack of investment in some areas in leadership roles at senior level, including consultant nurse and advanced nurse practitioner roles, despite changing patterns of need giving rise to a requirement for strong leadership to drive the development of appropriate service provision.

Changing patterns of service provision and organisational structures have had an impact on the scope of management roles, affecting managerial responsibilities, accountability lines and supervision and appraisal mechanisms. Learning disabilities nurses working in multidisciplinary teams often manage, and/or are managed by, other professions.

The demographic profile of the profession indicates that many managers will be retiring from services over the next decade, resulting in a need for sophisticated workforce and succession planning.

Where we want to be

Strong leadership in learning disabilities nursing is essential, given the challenges set out in earlier chapters. Leadership is also important to drive forward the profession and to ensure a modernised workforce is in place to meet current and future needs. Learning disabilities nurses need to continue to acknowledge and develop their clinical leadership responsibilities and demonstrate and develop strong professionalism.

The leadership role should be supported through the development of clear career pathways, succession planning and leadership "champions" in all areas and through the creation of consultant nurse posts in key areas where there currently are none.

The need for a dynamic career and development framework to support learning disabilities nurses to become the leaders and managers of the future has been covered in Recommendation 4.

Positive practice example

Leading and influencing services (palliative care)

Community learning disabilities nurses in Bridgend, Wales demonstrated leadership in service development through making links with local palliative care services to increase their knowledge base and to "map out" services. Working collaboratively with these services, it became evident that individuals with learning disabilities within the locality rarely accessed palliative care services, which reflects the wider picture nationally.

The learning disabilities nurses identified resources to support people with learning disabilities, their families and carers and took measures to raise awareness of their needs for palliative and end-of-life care through an initiative called "Living Well, Dying Well." This and other measures were presented at a national palliative care conference in 2011.

The awareness-raising has led to requests to provide advice and support, creating opportunities to forge closer links with other services to meet the needs of people with learning disabilities, their families and carers. This work is continuing, with learning disabilities nurses:

- investigating systems to identify individuals with learning disabilities who have a life-limiting condition (this database will enable health professionals to strategically plan person-centred care for their future palliative and end-of-life care needs);
- continuing to work collaboratively with palliative care services to improve experiences of life and death; and
- continuing to contribute to the evaluation of the palliative care and end-of-life pathway with the aim of improving its efficiency.

For further information, contact Sharon Dixon at [redacted]
or Claire Jenkins at [redacted]

Recommendation 15

Leadership in learning disabilities nursing needs to be strengthened in practice, education and research settings with robust, visible leadership at all levels, including strategic and national levels. Services must ensure all learning disabilities nurses in clinical practice have access to a dedicated professional lead for learning disabilities nursing. In addition to existing leadership and development programmes, a UK-wide cross-sector project to nurture and develop aspiring leaders in learning disabilities nursing will be led by the four UK health departments.

4.2 Promoting the profession

Where we are now

Learning disabilities nursing has traditionally had a low profile among the general population and has received less focus than other nursing fields in policy over recent years. The demographic and policy challenges described throughout this report nevertheless mean that raising the profile of learning disabilities nursing is now more important than ever.

Learning disabilities nurses have historically embraced networking, and the strong existing networks for learning disabilities nurses across the UK provide a powerful platform from which to celebrate and promote their unique contribution.

Where we want to be

It is important that the profession is promoted to ensure all sectors are aware of the unique contribution and added value that learning disabilities nurses offer and that learning disabilities nursing is presented as a positive and rewarding career choice.

Promoting the image of the learning disabilities nursing profession therefore has an important part to play in encouraging recruitment, but it goes further than that. It is also about demonstrating to people with learning disabilities, their families and carers, the wider public, fellow professionals and policy-makers the advantages that learning disabilities nurses bring and developing their understanding of what they can deliver.

As part of that endeavour, partnership working with the RCN focusing on how the profession can be promoted to wider professional and lay audiences is being progressed, with a promotional resource under development. This work is expected to be completed in 2012.

The health and social care agenda provides further opportunities for developing networks that could strengthen partnership working across the profession in all sectors. Investment in forward-thinking, high-quality networks could support many of the initiatives outlined in this report.

Positive practice example

Managed Knowledge Network Learning Disability Portal, NHS Education for Scotland (NES)

The Managed Knowledge Network (MKN) Learning Disability Portal, supported by NES Knowledge Services, supports the health and social care workforce working with people with learning disabilities.

The MKN portal provides a sustainable, flexible and responsive means of ensuring that contemporary information on health needs and learning disabilities is available to the workforce quickly and efficiently, providing a platform for sharing best practice, promoting educational opportunities and hosting resources. The link to the Knowledge Network allows access to online journals and 500 bibliographic databases.

The portal also serves to bring together organisations and people with a common interest in finding, sharing and using knowledge to support people with learning disabilities. It includes online opportunities for accessing and sharing knowledge alongside support for development of skills and behaviours in finding and sharing knowledge effectively.

The development of the portal provides a unique opportunity for learning disabilities nursing to engage across all areas of practice and specialties and interface with other professional groups. The rapidly changing health and social care environment requires the learning disabilities nursing workforce to be responsive to change in practice, service alignment and integration.

The portal is designed for workforce use, but it also allows people with learning disabilities, their families and carers to access information and contribute to debates, helping to build confidence and influence in developing practice. The interactive model requires and encourages learning disabilities nurses to take ownership, engage and develop new initiatives and discussions, creating communities of practice.

This developing portal has the ability to network and engage across the UK, consequently linking national initiatives and helping translate them into local practice. The portal can respond, grow and adapt to changing technology, practice and policy.

For further information, contact Tommy Stevenson at [redacted].
The portal can be accessed at **www.knowledge.scot.nhs.uk/learningdisabilities**

Recommendation 16

Learning disabilities nurses need mechanisms to share best practice and develop the evidence base to continue to advance as a profession. Services must support learning disabilities nurses to participate in appropriate networks. A UK academic network for learning disabilities nursing will be created to support this drive.

4.3 Research and evidence

Where we are now

While the amount of research concerning learning disabilities nursing is increasing (25), there is still scope to further develop robust evidence. Learning disabilities nursing therefore requires support for:

- research activity
- research training
- implementation of research findings in practice.

Clinical–academic research careers have been promoted as one approach to developing partnerships between education and practice. A greater orientation towards evidence-based and evidence-informed practice can be achieved where educationalists have a clinical commitment within their portfolios and clinicians retain a strong education and research focus in their practice. Clinical–academic posts can promote greater integration between practice, education and research by supporting the enhancement of the evidence and education focus of practice and promoting a strong practice orientation in education and research. Currently, however, there are inconsistencies in the development and appointment of learning disabilities clinical–academic posts across the UK.

Where we want to be

Exciting opportunities nevertheless exist within the NHS and independent/voluntary sector to develop a broader range of clinical–academic roles that would strengthen and sustain practice, education and research provision. These roles should include researchers and educationalists maintaining links with clinical practice through clinical work, supervision of practitioners and joint working on particular practice development projects, and practitioners linking into education and research through teaching, research and initiatives that support education in practice. Clear organisational commitment is required to create models to develop sustainable roles such as these.

Research activity should be directly related to informing the practice of learning disabilities nursing and should focus on areas that add value and provide clear benefits to people with learning disabilities, their families and carers. Collaborative research studies involving higher education institutions that cover a range of geographic areas are required to facilitate larger-scale and comparative studies that can highlight differences and similarities in terms of need and developments. Existing links within the learning disabilities research community in the UK and internationally should facilitate this.

Most important, collaborative working with people with learning disabilities is essential to ensure that research is relevant to their needs and experiences. Learning disabilities nursing already has some good examples in this area and could lead on engaging, enabling and facilitating people with learning disabilities, their families and carers to participate in research.

Positive practice example

Learning disabilities nurses' involvement in research

The Confidential Inquiry into Deaths in People with Learning Disabilities is a three-year research study funded by the Department of Health and the Learning Disability Public Health Observatory in England. It is led by the Norah Fry Research Centre at the University of Bristol and is being carried out across Avon and Gloucestershire. The Inquiry is investigating all deaths among people with learning disabilities over the age of four years with the aim of adding to the current limited body of evidence, detecting any potentially avoidable and modifiable features involved in deaths and learning from positive practice.

The Mencap report *Death by Indifference* (7) highlighted the importance of involving families when evaluating care. In designing the Inquiry, the research team wanted to enable carers to be included and acknowledged that appropriately skilled staff were required to ensure that their views on the deceased were sought, understood and appropriately recorded. At the same time, it was important that their needs, as grieving carers, were also sensitively met.

As person-centred practitioners skilled in communicating with families and possessing sound understanding of the systems of care and complex health problems experienced by people with learning disabilities, a team of 11 learning disabilities nurses, supported by a lead nurse, were recruited to work part time as members of the Inquiry team. The nurses are seconded from their substantive posts to work with families of people who have died, conducting interviews, supporting them and signposting them to bereavement support agencies, if required. In addition, they advocate for the families at multi-agency local review panels held to discuss all death investigations.

For further information, contact Lesley Russ at [redacted]

Recommendation 17

Learning disabilities nursing research should be extended to ensure practice now and in the future is evidence based and the impact of interventions can be demonstrated. Services and education providers must ensure that all existing and future schemes for clinical–academic careers have appropriate representation of learning disabilities nursing.

"The learning disabilities nurse has always been aware of the needs of the whole family and the fact that it continued from childhood into adulthood is very reassuring."

Family carer

Conclusion and next steps



Conclusion and next steps

The UK Modernising Learning Disabilities Nursing Review involved wide engagement with key stakeholders. It heard the hopes, aspirations and concerns of practitioners, managers, educators and researchers and, most importantly, it heard what qualities people with learning disabilities, their families and carers value most in nurses.

While this report could never capture all the learning that emerged from the engagement process, it has attempted to focus on actions that will have the greatest positive impact for people with learning disabilities, their families and carers, the nurses who care for them and the services who support them.

The foundation for these actions and the developments they represent is the underpinning principles and values base of learning disabilities nursing. It is these principles that have served learning disabilities nursing well and which are cherished by people with learning disabilities, their families and carers.

Learning disabilities nurses now have an opportunity to take their services forward to a new level.

This report has set out recommendations across a wide range of areas that reflect the complexity and the importance of modern learning disabilities nursing. The four countries are now invited to consider these recommendations and progress them as appropriate within their own contexts. Some of the recommendations will benefit from implementation at UK level, and a UK Implementation Group is being set up to support the groups that will be established at country level to oversee the development of action plans and onward progression.

The recommendations are set out in Table 2, which shows which agencies/individuals need to take account of, and respond to, each recommendation.

It is important to stress that while the recommendations are central to the modernisation of learning disabilities nursing in the UK and consequently may receive heightened attention, readers should engage fully with the whole report – there are many key messages that should be considered in addition to the recommendations.

Table 2

Recommendation summary

Recommendation	Action at UK level	Action at country level	Action at service level	Action at education level	Action at commissioning level	Action at individual practitioner level
1. The four UK health departments and the independent/voluntary sector should establish a national collaborative to enable better understanding of, and planning for, a high-quality and sustainable registered learning disabilities nursing workforce across all sectors.	√		√		√	
2. Systems to collect workforce data are required in each country, with links across the UK, for workforce planning for future provision of learning disabilities nursing. These should be able to capture information on service provision, educational and research requirements and should cover the independent/ voluntary sector.		√	√	√	√	
3. The development of new, specialist and advanced role opportunities should be considered in light of workforce planning, service development and education provision. In particular, this should focus on the roles of non-medical prescribing, psychological therapies and telehealth and in specific settings such as the criminal justice system, mental health services (particularly dementia) and autism services.		√	√	√	√	
4. Each of the four countries should consider aligning their existing post-registration career frameworks for learning disabilities nursing to clearly articulate the knowledge and skills required by learning disabilities nurses at all levels and across all settings. These developments could be utilised across sectors (with appropriate adaptation) to give a coherent career framework.		√	√			
5. Commissioners and service planners should have a clear vision for how they ensure the knowledge and skills of learning disabilities nurses are provided to the right people, in the right places, and at the right time in a way that reflects the values- and rights-based focus of learning disabilities nurses' work.			√		√	√
6. Commissioners and providers of health and social care should ensure the skills, knowledge and expertise of learning disabilities nurses are available across the lifespan. This should be enabled through effective collaborative working across health and social care structures.		√	√		√	
7. Commissioners and providers of health and social care should ensure that learning disabilities nurses are able to collaborative effectively with general health services, including mental health services, to address the barriers that exist for people with learning disabilities to improving their health. This should include proactive health improvement, prevention, whole-family and public health approaches.			√		√	√

Recommendation summary

Recommendation	Action at UK level	Action at country level	Action at service level	Action at education level	Action at commissioning level	Action at individual practitioner level
8. Commissioners and service providers should ensure that specialist learning disabilities services for complex and intensive needs (including assessment and treatment services across all sectors) employ sufficient numbers of appropriately prepared and supported registered learning disabilities nurses. This highlights the need to support and develop the availability of specialist and advanced clinical skills and knowledge of learning disabilities nurses in all settings.			√		√	√
9. Learning disabilities nurses, their managers and leaders should develop and apply outcomes-focused measurement frameworks to evidence their contribution to improving person-centred health outcomes and demonstrating value for money. This may require a specific piece of work to scope current frameworks.			√			√
10. Learning disabilities nurses should strengthen their involvement and links to transformational work, productivity improvement and practice development.			√			√
11. Those who commission, develop or deliver education should ensure that all learning disabilities nursing education programmes reflect the key values, content and approaches recommended in this report. They should also ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services.			√	√	√	
12. Updated, strategic plans for pre- and post-registration learning disabilities nursing programmes are necessary for each country of the UK to support flexibility and ensure an efficient and sustainable model of delivery for the long term. This highlights the need for appropriate numbers of places on pre-registration learning disabilities nursing programmes to meet future workforce requirements.		√	√	√		
13. Education providers and services must work in partnership to ensure that educational and developmental opportunities for nonregistered staff are developed and strengthened and their benefits are evidenced through appraisal systems, and that educational and development opportunities are available for registered learning disabilities nurses to support their ongoing development, reflecting the needs of people with learning disabilities.			√	√		
14. Services should provide systems to ensure that learning disabilities nurses have access to regular and effective clinical supervision and that this its impact is monitored and evaluated on a regular basis.			√			√

Recommendation summary

Recommendation	Action at UK level	Action at country level	Action at service level	Action at education level	Action at commissioning level	Action at individual practitioner level
15. Leadership in learning disabilities nursing needs to be strengthened in practice, education and research settings with robust, visible leadership at all levels, including strategic and national levels. Services must ensure all learning disabilities nurses in clinical practice have access to a dedicated professional lead for learning disabilities nursing. In addition to existing leadership and development programmes, a UK-wide cross-sector project to nurture and develop aspiring leaders in learning disabilities nursing will be led by the four UK health departments.	√		√	√		√
16. Learning disabilities nurses need mechanisms to share best practice and develop the evidence base to continue to advance as a profession. Services must support learning disabilities nurses to participate in appropriate networks. A UK academic network for learning disabilities nursing will be created to support this drive.			√	√		√
17. Learning disabilities nursing research should be extended to ensure practice now and in the future is evidence based and the impact of interventions can be demonstrated. Services and education providers must ensure that all existing and future schemes for clinical–academic careers have appropriate representation of learning disabilities nursing.			√	√		

Appendix 1. Key policy and professional drivers within the four countries

England

Department of Health (2001)
Valuing People: a new strategy for learning disability for the 21st century - a White Paper.
London: Department of Health.

Department of Health (2002)
Action for Health, Health Action Plans and Health Facilitation: detailed good practice guidance on implementation for learning disability partnership boards.
London: Department of Health.

Department of Health/Department for Children, Schools and Families (2003)
Together from the Start: practical guidance for professionals working with disabled children (birth to third birthday) and their families.
London: Department of Health.

Department of Health (2007)
Good Practice in Learning Disability Nursing.
London: Department of Health.

Department of Health (2008)
Healthcare for All: report of the independent inquiry into access to healthcare for people with learning disabilities.
London: Department of Health.

Department of Health (2009)
Valuing People Now: a new three-year strategy for people with learning disabilities.
London: Department of Health.

Department of Health (2009)
World Class Commissioning for the Health and Wellbeing of People with Learning Disabilities.
London: Department of Health.

Department of Health (2009)
The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system.
London: Department of Health.

Department of Health/Department for Children, Schools and Families (2009)
Healthy Lives, Brighter Futures. The strategy for children and young people's health.
London: Department of Health.

Department of Health (2010)
Raising Our Sights: services for adults with profound intellectual and multiple disabilities. A report by Professor Jim Mansell.
London: Department of Health.

Gates B (2011)
Learning Disability Nursing: task and finish group: report for the Professional and Advisory Board for Nursing and Midwifery.
London: Department of Health.

Emerson E, Baines S, Allerton L, Welch V (2011)
Health Inequalities & People with Learning Disabilities in the UK: 2011.
Improving Health and Lives: Learning Disabilities Observatory.

Northern Ireland

Department of Health, Social Services and Public Safety (2005)
Equal Lives: review of policy and services for people with a learning disability in Northern Ireland: the N. I. Bamford Review.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2005)
A Healthier Future: a twenty year vision for health and well being in Northern Ireland 2005–2025.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2006)
The Bamford Review of Mental Health and Learning Disability (NI): forensic services.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2007)
Complex Needs – the nursing response to children & young people with complex physical healthcare needs.
Belfast: DHSSPS.

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 Disability action plan (2009–2011).
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2009)
Integrated Care Pathway for Children & Young People with Complex Physical Healthcare Needs.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2009)
Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09–2010/11.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2010)
Living Matters, Dying Matters – a strategy for palliative and end of life care for adults in Northern Ireland.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011)
Improving Dementia Services in Northern Ireland: a regional strategy.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2010)
A Partnership for Care: Northern Ireland strategy for nursing and midwifery 2010–2015.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011)
Learning Disability Service Framework. Consultation document.
Belfast: DHSSPS.

Guidelines and Audit Implementation Network (2010)
Guidelines: caring for people with a learning disability in general hospital settings.
Belfast: DHSSPS.

Scotland

NHS Health Scotland (2004)
Health Needs Assessment Report: people with learning disabilities in Scotland.
Edinburgh: NHS Health Scotland.

NHS Quality Improvement Scotland (2006)
Best Practice Statement: promoting access to healthcare for people with learning disabilities.
Edinburgh: NHS Quality Improvement Scotland.

NHS Quality Improvement Scotland (2009)
Tackling Indifference: healthcare services for people with learning disabilities national overview.
Edinburgh: NHS Quality Improvement Scotland.

Scottish Executive (2000)
The Same as You? A review of services for people with learning disabilities.
Edinburgh: Scottish Executive.

Scottish Executive (2002)
Promoting Health, Supporting Inclusion: the national review of the contribution of nurses and midwives to the care and support of people with learning disabilities.
Edinburgh: Scottish Executive.

Scottish Government (2007)
Equally Well. The report of the Ministerial Task Force on Health Inequalities.
Edinburgh: Scottish Government.

Scottish Government (2008)
Better Health, Better Care: action plan. What it means for you.
Edinburgh: Scottish Government.

Scottish Government (2008)
Achieving our Potential: a framework to tackle poverty and income inequality in Scotland.
Edinburgh: Scottish Government.

Scottish Government (2010)
Getting it Right for Every Child.
Edinburgh: Scottish Government.

Scottish Government (2010)
The Healthcare Quality Strategy for NHSScotland.
Edinburgh: Scottish Government.

Scottish Government (2010)
Towards an Autism Strategy for Scotland.
Edinburgh: Scottish Government.

Wales

Learning Disability Implementation Advisory Group and Welsh Assembly Government (2011)
Practice Guidance on Developing a Commissioning Strategy for People with Learning Disabilities.
Cardiff: Welsh Assembly Government.

National Assembly for Wales (2002)
Inclusion, Partnership and Innovation.
Cardiff: National Assembly for Wales.

Public Health Wales and Welsh Government (2011)
Good Practice Framework for People with Learning Disabilities Requiring Planned Secondary Care.
Cardiff: Public Health Wales and Welsh Government.

Welsh Assembly Government (2004)
Learning Disability Strategy. Section 7: guidance on service principles and service responses.
Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2007)
Statement on Policy and Practice for Adults with Learning Disabilities.
Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009)
A Community Nursing Strategy for Wales.
Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009)
Post Registration Career Framework for Nurses in Wales.
Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009)
We Are on the Way. A policy agenda to transform the lives of disabled children and young people.
Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2010)
Setting the Direction. Primary and community services strategic delivery programme.
Cardiff: Welsh Assembly Government.

Welsh Government (2011)
Together for Health. A five year vision for the NHS in Wales.
Cardiff: Welsh Government.

Appendix 2. Steering group memberships

Co-production Steering Group (supported by Scottish Consortium for Learning Disability)
Ann Burke, Bainsford

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Angela Halpin, West Dunbartonshire

Lorraine MacKenzie, West Dunbartonshire

Rona Membury, Highland

Ian Stones, Aberdeen

Alexander Thomson, Fraserburgh

England

Allyson Kent, Deputy Head of Nursing, Humber Mental Health Teaching NHS Trust

Alison Giraud Saunders, Independent Consultant, Policy into Practice

Alison Armstrong, Director of London Wide Programmes (Mental Health, Prison Health and Substance Misuse)

Amanda Platts, Self Advocate

Geoff Hodgson (supporting Amanda Platts), Supporter Centre Events

Ann Norman, Professional Nurse Adviser: Learning Disabilities/Prison Nursing, Royal College of Nursing

Professor Ben Thomas, Professional Advisor, Department of Health

Daniel Marsden, Practice Development Nurse for Patients with Learning Disabilities, East Kent Hospitals University NHS Foundation Trust

Deborah Hussey, Lincolnshire Partnership NHS Foundation Trust
Team Leader, Learning Disability Services

Felicity Howdle, Information Analyst, Centre for Workforce Intelligence (CfWI)

Gweneth Moulster, Nurse Consultant, Haringey Learning Disability Partnership

Helen Laverty, Lecturer, Nottingham University

Helen Mycock (representing Mencap until January 2012)

Jacky Vincent, Lead Nurse, Learning Disability & Forensic Services, Hertfordshire

Janet Cobb (Chair), Independent Consultant, Jan-Net Ltd

Jean Willson OBE, family carer

Joanna Goddard, Specialist Midwife for Safeguarding Children and Vulnerable Women

Susan Bernhauser, Dean of the School of Human and Health Sciences, University of Huddersfield

Lisa Gregg Herrett, Assistant Director Quality and Staff Development, Choice Support

Marc Pratt, Intensive Health Outreach Team, NHS Gloucestershire

Matthew Hoghton, Champion in Learning Disabilities, Royal College of General Practitioners Clinical Innovation and Research Centre

Paula Brayinon, Director of Operations and Nursing, Calderstones

Peter Hasler, Deputy Director of Nursing, South London and Maudsley NHS Foundation Trust

Professor Robert Gates, Professional/Academic Lead, University of Hertfordshire

Stephan Brusch, Health Access Manager and Head of Learning Disability Development Team, NHS London

Steven Hardy, Training and Consultancy Manager, Estia Centre

Steven Rose, Chief Executive, Choice Support

Sue Hudson, Practice Development Lead, Suffolk Mental Health Partnership

Sue Turner, Improving Health and Lives Project Lead, National Development Team for Inclusion

Sue Beacock, Associate Dean Learning and Teaching, Hull University

Terri Dorman, Practice Development Nurse, Bedfordshire & Luton Partnership NHS Trust

Tricia Handley, Nursing Manager Adult Social Care, Camden

Vicky Stobbart, Service Manager - Learning Disability, Southwark

Northern Ireland

Anne Campbell, Operations Manager, Belfast Health & Social Care Trust

Barry Mills, Clinical & Therapeutic Service Manager, Belfast Health & Social Care Trust

Claire Knox, carer

Damian McAleer, Nurse Education Consultant, Beeches Management Centre

Donna Morgan, Locality Manager & Lead Nurse, Northern Health & Social Care Trust

Fiona Rowan, carer

Francis Rice (Chair), Director of Nursing, Southern Health & Social Care Trust

Garvin McKnight, Staff Nurse, Muckamore Abbey Hospital, Belfast Health & Social Care Trust

Gillian McMullen, Project Manager Bamford Monitoring Group, Patient Client Council (PCC)

Glynis Henry, Chief Executive, Northern Ireland Practice & Education Council (NIPEC)

John Mc Eleney, Assistant Director, Praxis Care NI

Maurice Devine, Nursing Officer (Mental Health, Learning Disability and Older People), Department of Health, Social Services and Public Safety

Maureen Piggot, Director, Mencap Northern Ireland

Molly Kane, Regional Nurse Consultant Mental Health & Learning Disability, Public Health Agency

Neil Kelly, Operations Manager, Belfast Health & Social Care Trust

Professor Owen Barr, Head of School of Nursing, University of Ulster

Paula McLorinan, Consultant Child & Adolescent & Learning Disability Psychiatrist, Belfast Health & Social Care Trust

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Thomasina Duff, Staff Nurse, Belfast Health & Social Care Trust

Scotland

Andy Graham, Chair of the Scottish Community Learning Disability Nurses Network

Billy Pate, Scottish Community Learning Disability Nurses Network

Carol Dobson, Chief Nursing Officer, Mental Welfare Commission for Scotland

David Currie, Development Manager, Castlebeck Group Ltd

Elaine Kwiatek, Project Manager, Learning Disabilities Managed Care Network

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Margaret Serrels, Clinical Services Development Manager, NHS Lanarkshire

Mark Gillespie, Nurse Consultant Forensic Mental Health and Learning Disabilities, NHS Greater Glasgow and Clyde

Melanie Hornett (Chair), Nurse Director, NHS Lothian

Michael Brown, Nurse Consultant and Reader in Health and Social Care, NHS Lothian/ Edinburgh Napier University

Rosemary Duffy, Scottish Prison Services

Selina Clinch, Programme Manager, Healthcare Improvement Scotland

Susanne Forrest, Programme Director, NHS Education for Scotland

Tommy Stevenson, Educational Project Manager, NHS Education for Scotland

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Christopher Griffiths, Consultant Nurse/Lecturer, Abertawe Bro Morgannwg University Health Board

Dave Hawkins, Lead Nurse Learning Disabilities, Hywel Dda Health Board

Hayley Tarrant, Head of Learning Disability Services, Powys Teaching Health Board

Jenifer Clarke, Nursing Officer/Public Health and Health Professions Department, Welsh Government

Julie Kendall (Chair), Lead Nurse for Learning Disability Services, Aneurin Bevan Health Board

Ian Mansell, Senior Lecturer, University of Glamorgan

Pete Jones, Clinical Governance Co-ordinator, Betsi Cadwaladr University Health Board

Dr Robert Jenkins, Divisional Head of Learning Disability, University of Glamorgan

Ruth Northway, Professor of Learning Disabilities, University of Glamorgan

Ruth Wyn Williams, Lecturer in Learning Disability Nursing/Lecturer (Welsh medium) in Nursing, Bangor University

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NICE National Institute for Health and Care Excellence

NICE guideline

Autism spectrum disorder in adults: diagnosis and management

Clinical guideline

Published: 27 June 2012
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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

Overview 4
Who is it for? 4
Introduction 5
Key priorities for implementation 7
General principles of care 7
Identification and assessment 8
Interventions for autism 9
Organisation and delivery of care 10
Recommendations 11
1.1 General principles of care 11
1.2 Identification and assessment 17
1.3 Identifying the correct interventions and monitoring their use 24
1.4 Interventions for autism 25
1.5 Interventions for behaviour that challenges 29
1.6 Interventions for coexisting mental disorders 32
1.7 Assessment and interventions for families, partners and carers 33
1.8 Organisation and delivery of care 34
Terms used in this guideline 38
Recommendations for research 41
1 Facilitated self-help for anxiety and depression in autistic adults 41
2 The structure and organisation of specialist teams 42
3 Augmentative communication devices for autistic adults 42
Finding more information and committee details 44
Update information 45

This guideline is the basis of QS51.

Overview

This guideline covers diagnosing and managing suspected or confirmed autism spectrum disorder (autism, Asperger's syndrome and atypical autism) in people aged 18 and over. It aims to improve access and engagement with interventions and services, and the experience of care, for people with autism.

Who is it for?

- Health and social care professionals (including those in the independent sector)
- Commissioners and providers
- Adults with autism and their families, partners and carers

Introduction

Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities (also called 'intellectual disabilities'). Autistic people also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.

A significant proportion of autistic adults across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, autistic people are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised.

There is wide variation in rates of identification and referral for diagnostic assessment, waiting times for diagnosis, models of multi-professional working, assessment criteria and diagnostic practice for adults with features of autism. These factors contribute to delays in reaching a diagnosis and subsequent access to appropriate services.

When the diagnostic assessment process works well, professionals, the autistic person and their family, partner or carer(s) communicate right from the start and the autistic person is involved in the decisions relating to their care. This lays the foundation for a long-term understanding between the autistic person, their family, partner or carer(s) and the professionals supporting their needs. However, many adults have difficulties accessing a diagnostic assessment. Even if they manage to obtain a diagnosis they may receive no follow-up support because of the absence of appropriate services or an agreed care pathway.

In this guideline 'autism' refers to 'autism spectrum disorders' encompassing autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not

otherwise specified). The Guideline Development Group recognises, however, that different individuals and groups prefer a variety of terms for autism including autistic spectrum condition, autistic spectrum difference and neurodiversity (in recent Department of Health, National Audit Office and Public Accounts Committee documents, 'autism' is used to cover all of these terms).

This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, autistic adults.

A number of recommendations in this guideline have been adapted from recommendations in other NICE clinical guidelines. Where this occurred, the Guideline Development Group was careful to preserve the meaning and intent of the original recommendations. Changes to wording or structure were made in order to fit the recommendations into this guideline.

The guideline will assume that prescribers will use a drug's summary of product characteristics (SPC) to inform decisions made with individual patients. In this guideline, recommendations are marked with a note if drugs do not have a UK marketing authorisation for the indication in question at the time of publication. Prescribers should check each drug's SPC for current licensed indications.

Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

General principles of care

- All staff working with autistic adults should:
  - work in partnership with autistic adults and, where appropriate, with their families, partners or carers
  - offer support and care respectfully
  - take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.
- In order to effectively provide care and support for autistic adults, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from autistic people and their families, partners and carers.

Identification and assessment

- Consider assessment for possible autism when a person has:
  - one or more of the following:
    - ◇ persistent difficulties in social interaction
    - ◇ persistent difficulties in social communication
    - ◇ stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**
  - one or more of the following:
    - ◇ problems in obtaining or sustaining employment or education
    - ◇ difficulties in initiating or sustaining social relationships
    - ◇ previous or current contact with mental health or learning disability services
    - ◇ a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.
- For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10). (If a person has reading difficulties, read out the AQ-10.) If a person scores 6 or above on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism.

- When assessing behaviour that challenges carry out a functional analysis (see recommendation 1.5.3) including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:
  - physical disorders
  - the social environment (including relationships with the family, partner, carer(s) and friends)
  - the physical environment, including sensory factors
  - coexisting mental disorders (including depression, anxiety disorders and psychosis)
  - communication problems
  - changes to routine or personal circumstances.

Interventions for autism

- For autistic adults without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

Organisation and delivery of care

- Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:
  - developing clear policy and protocols for the operation of the pathway
  - ensuring the provision of multi-agency training about signs and features suggesting possible autism, and training and support on the operation of the pathway
  - making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
  - supporting the integrated delivery of services across all care settings
  - supporting the smooth transition to adult services for young people going through the pathway
  - auditing and reviewing the performance of the pathway.

Recommendations

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 NICE's information on 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 prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 General principles of care

Principles for working with autistic adults and their families, partners and carers

1.1.1 All staff working with autistic adults should:

- work in partnership with autistic adults and, where appropriate, with their families, partners and carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

1.1.2 All staff working with autistic adults should have an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning

- impact of the social and physical environment.

1.1.3 All health and social care professionals providing care and support for autistic adults should have a broad understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of and interaction with the social and physical environment
- impact on and interaction with other coexisting mental and physical disorders and their management
- potential discrepancy between intellectual functioning as measured by IQ and adaptive functioning as reflected, for example, by difficulties in planning and performing activities of daily living including education or employment.

1.1.4 All health and social care professionals providing care and support for autistic adults should:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy read, and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate.

1.1.5 All health and social care professionals providing care and support for autistic adults and their families, partners and carers should:

- ensure that they are easily identifiable (for example, by producing or wearing appropriate identification) and approachable
- clearly communicate their role and function
- address the person using the name and title they prefer

- clearly explain any clinical language and check that the autistic person understands what is being said
- take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the autistic person) if required.

1.1.6 All health and social care professionals providing care and support for autistic adults and their families, partners and carers should ensure that they are:

- familiar with recognised local and national sources (organisations and websites) of information and/or support for autistic people
- able to discuss and advise on how to access and engage with these resources.

1.1.7 Encourage autistic adults to participate in self-help or support groups or access one-to-one support, and provide support so that they can attend meetings and engage in the activities.

1.1.8 In all settings, take into account the physical environment in which autistic adults are assessed, supported and cared for, including any factors that may trigger behaviour that challenges. If necessary make adjustments or adaptations to the:

- amount of personal space given (at least an arm's length)
- setting using visual supports (for example, use labels with words or symbols to provide visual cues about expected behaviour)
- colour of walls and furnishings (avoid patterns and use low-arousal colours such as cream)
- lighting (reduce fluorescent lighting, use blackout curtains or advise use of dark glasses or increase natural light)

- noise levels (reduce external sounds or advise use of earplugs or ear defenders).

  Where it is not possible to adjust or adapt the environment, consider varying the duration or nature of any assessment or intervention (including taking regular breaks) to limit the negative impact of the environment.

1.1.9 All health and social care professionals providing care and support for autistic adults should:

- be aware of under-reporting and under-recognition of physical disorders in autistic people
- be vigilant for unusual likes and dislikes about food and/or lack of physical activity
- offer advice about the beneficial effects of a healthy diet and exercise, taking into account any hyper- and/or hypo-sensory sensitivities; if necessary, support referral to a GP or dietician.

1.1.10 All staff working with autistic adults should be sensitive to issues of sexuality, including asexuality and the need to develop personal and sexual relationships. In particular, be aware that problems in social interaction and communication may lead to the autistic person misunderstanding another person's behaviour or to their possible exploitation by others.

1.1.11 Ensure that autistic adults who have caring responsibilities receive support to access the full range of mental and physical health and social care services, including:

- specific information, advice and support to parents about their parenting role, including parent training if needed, by professionals experienced in the care of autistic adults and children
- social support, such as childcare, to enable them to attend appointments, groups and therapy sessions, and to access education and employment.

Structures for the organisation and delivery of care and

interventions

1.1.12 In order to effectively provide care and support for autistic adults, the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from autistic people and their families, partners and carers.

1.1.13 In each area a specialist community-based multidisciplinary team for autistic adults (the specialist autism team) should be established. The membership should include:

- psychologists with training and experience in working with autistic adults
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

1.1.14 The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for autistic adults (as not all may be in the care of a specialist team)

- support in accessing, and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for autistic adults living in specialist residential accommodation
- training, support and consultation for staff who care for autistic adults in residential and community settings.

Involving families, partners and carers

1.1.15 Discuss with autistic adults if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have (see recommendation 1.1.5).

1.1.16 If the autistic person wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate between the autistic person and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis
- explain how families, partners and carers can help support the autistic person and help with care plans
- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the autistic person and their family, partner or carer(s).

1.1.17 Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a carer's assessment of their own physical and mental health needs, and how to access this (see the NICE guideline on supporting adult carers).

1.1.18 If an autistic person does not want their family, partners or carer(s) to be involved in their care:

- give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care
- bear in mind that autistic people may be ambivalent or negative towards their family or partner. This may be for many different reasons, including a coexisting mental disorder or prior experience of violence or abuse.

1.2 Identification and assessment

Principles for the effective assessment of autism

1.2.1 Staff who have responsibility for the identification or assessment of autistic adults should adapt these procedures, if necessary, to ensure their effective delivery, including modifications to the setting in which assessment is delivered (see recommendation 1.1.8) and the duration and pacing of the assessment.

Identification and initial assessment of possible autism

1.2.2 Consider assessment for possible autism when a person has:

- one or more of the following:
  - persistent difficulties in social interaction
  - persistent difficulties in social communication
  - stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, **and**

- one or more of the following:
  - problems in obtaining or sustaining employment or education
  - difficulties in initiating or sustaining social relationships
  - previous or current contact with mental health or learning disability services
  - a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

1.2.3 For adults with possible autism who do not have a moderate or severe learning disability, consider using the Autism-Spectrum Quotient – 10 items (AQ-10). (If a person has reading difficulties, read out the AQ-10.) If a person scores 6 or above on the AQ-10, or autism is suspected based on clinical judgement (taking into account any past history provided by an informant), offer a comprehensive assessment for autism. [amended 2021]

1.2.4 For adults with possible autism who have a moderate or severe learning disability, consider a brief assessment to ascertain whether the following behaviours are present (if necessary using information from a family member, partner or carer):

- difficulties in reciprocal social interaction including:
  - limited interaction with others (for example, being aloof, indifferent or unusual)
  - interaction to fulfil needs only
  - interaction that is naive or one-sided
- lack of responsiveness to others
- little or no change in behaviour in response to different social situations
- limited social demonstration of empathy
- rigid routines and resistance to change

- marked repetitive activities (for example, rocking and hand or finger flapping), especially when under stress or expressing emotion.

  If two or more of the above categories of behaviour are present, offer a comprehensive assessment for autism.

Comprehensive (diagnostic, needs and risks) assessment of suspected autism

1.2.5 A comprehensive assessment should:

- be undertaken by professionals who are trained and competent
- be team-based and draw on a range of professions and skills
- where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development.

1.2.6 At the beginning of a comprehensive assessment, discuss with the person the purpose of the assessment and how the outcome of the assessment will be fed back to them. Feedback should be individualised, and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback.

1.2.7 During a comprehensive assessment, enquire about and assess the following:

- core autism features (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood
- early developmental history, where possible
- behavioural problems
- functioning at home, in education or in employment
- past and current physical and mental disorders
- other neurodevelopmental conditions

- hyper- and/or hypo-sensory sensitivities and attention to detail.

  Carry out direct observation of core autism features especially in social situations.

1.2.8 To aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as:

- the following tools for people who do not have a learning disability:
  - the Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ])
  - the Autism Diagnostic Interview – Revised (ADI-R)
  - the Autism Diagnostic Observation Schedule – Generic (ADOS-G)
  - the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)
  - the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)
- the following tools in particular for people with a learning disability:
  - the ADOS-G
  - the ADI-R.

1.2.9 To organise and structure the process of a more complex assessment, consider using a formal assessment tool, such as the Diagnostic Interview for Social and Communication Disorders (DISCO), the ADOS-G or the ADI-R.

1.2.10 During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as:

- other neurodevelopmental conditions (use formal assessment tools for learning disabilities)

- mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder)
- neurological disorders (for example, epilepsy)
- physical disorders
- communication difficulties (for example, speech and language problems, and selective mutism)
- hyper- and/or hypo-sensory sensitivities.

1.2.11 Do not use biological tests, genetic tests or neuroimaging for diagnostic purposes routinely as part of a comprehensive assessment.

1.2.12 During a comprehensive assessment, assess the following risks:

- self-harm (in particular in people with depression or a moderate or severe learning disability)
- rapid escalation of problems
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others.

Develop a risk management plan if needed.

1.2.13 Develop a care plan based on the comprehensive assessment, incorporating the risk management plan and including any particular needs (such as adaptations to the social or physical environment), and also taking into account the needs of the family, partner or carer(s).

1.2.14 Provide a 'health passport' (for example, a laminated card) for autistic adults, which includes information for all staff about the person's care and support needs. Advise the person to carry the health passport at all times.

1.2.15 As part of a comprehensive assessment consider developing a 24-hour crisis management plan, where necessary in conjunction with specialist mental health services, which should detail:

- the likely trigger(s) for a crisis
- the nature and speed of the reaction to any trigger(s), including details about the way in which autism may impact on a person's behaviour leading up to and during a crisis
- the role of the specialist team and other services (including outreach and out-of-hours services) in responding to a crisis
- advice to primary care professionals and other services on their responsibilities and appropriate management in a crisis
- advice for families, partners and carers about their role in a crisis
- the nature of any changes or adaptations to the social or physical environment (see recommendation 1.1.8) needed to manage a crisis.

1.2.16 Consider obtaining a second opinion (including referral to another specialist autism team if necessary), if there is uncertainty about the diagnosis or if any of the following apply after diagnostic assessment:

- disagreement about the diagnosis within the autism team
- disagreement with the person, their family, partner, carer(s) or advocate about the diagnosis
- a lack of local expertise in the skills and competencies needed to reach diagnosis in autistic adults
- the person has a complex coexisting condition, such as a severe learning disability, a severe behavioural, visual, hearing or motor problem, or a severe mental disorder.

1.2.17 On an individual basis, and using information from the comprehensive assessment and physical examination, and clinical judgement, consider further investigations, including:

- genetic tests, as recommended by the regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of a learning disability
- electroencephalography if there is suspicion of epilepsy
- hearing or sight tests, if there is suspicion of hearing or visual impairment
- other medical tests depending on individual signs and symptoms (for example, sudden onset of behaviour that challenges, change in usual patterns of behaviour, sudden change in weight, or suspicion that the person might be in pain and is unable to communicate this).

1.2.18 Offer all adults who have received a diagnosis of autism (irrespective of whether they need or have refused further care and support) a follow-up appointment to discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require.

Assessment of behaviour that challenges

1.2.19 Assessment of behaviour that challenges should be integrated into a comprehensive assessment for autistic adults.

1.2.20 When assessing behaviour that challenges carry out a functional analysis (see recommendation 1.5.3) including identifying and evaluating any factors that may trigger or maintain the behaviour, such as:

- physical disorders
- the social environment (including relationships with family members, partners, carers and friends)
- the physical environment, including sensory factors
- coexisting mental disorders (including depression, anxiety disorders and psychosis)
- communication problems
- changes to routines or personal circumstances.

1.3 Identifying the correct interventions and monitoring their use

1.3.1 When discussing and deciding on interventions with autistic adults, consider:

- their experience of, and response to, previous interventions
- the nature and severity of their autism
- the extent of any associated functional impairment arising from the autism, a learning disability or a mental or physical disorder
- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- the presence, nature, severity and duration of any coexisting disorders
- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed.

1.3.2 When discussing and deciding on care and interventions with autistic adults, take into account the:

- increased propensity for elevated anxiety about decision-making in autistic people
- greater risk of altered sensitivity and unpredictable responses to medication
- environment, for example whether it is suitably adapted for autistic people, in particular those with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)
- presence and nature of hyper- and/or hypo-sensory sensitivities and how these might impact on the delivery of the intervention
- importance of predictability, clarity, structure and routine for autistic people
- nature of support needed to access interventions.

1.3.3 When discussing and deciding on interventions with autistic adults, provide information about:

- the nature, content and duration of any proposed intervention
- the acceptability and tolerability of any proposed intervention
- possible interactions with any current interventions and possible side effects
- the implications for the continuing provision of any current interventions.

1.3.4 When deciding on options for pharmacological interventions for behaviour that challenges or coexisting mental disorders in autistic adults:

- be aware of the potential for greater sensitivity to side effects and idiosyncratic responses in autistic people **and**
- consider starting with a low dose.

1.3.5 For any intervention used in autistic adults, there should be a regular review of:

- the benefits of the intervention, where feasible using a formal rating of the target behaviour(s)
- any adverse events
- specific monitoring requirements of pharmacological interventions as highlighted by the summary of product characteristics
- adherence to the intervention.

1.4 Interventions for autism

Psychosocial interventions for the core features of autism

1.4.1 For autistic adults without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- a group-based social learning programme focused on improving social interaction

- an individually delivered social learning programme for people who find group-based activities difficult.

1.4.2 Social learning programmes to improve social interaction should typically include:

- modelling
- peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- discussion and decision-making
- explicit rules
- suggested strategies for dealing with socially difficult situations.

1.4.3 Do not provide facilitated communication for autistic adults.

Psychosocial interventions focused on life skills

1.4.4 For autistic adults of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles.

1.4.5 For autistic adults without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

- a group-based structured leisure activity programme
- an individually delivered structured leisure activity programme for people who find group-based activities difficult.

1.4.6 A structured leisure activity programme should typically include:

- a focus on the interests and abilities of the participant(s)
- regular meetings for a valued leisure activity

- for group-based programmes, a facilitator with a broad understanding of autism to help integrate the participants
- the provision of structure and support.

1.4.7 For autistic adults without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of autistic adults.

1.4.8 Anger management interventions should typically include:

- functional analysis of anger and anger-provoking situations
- coping-skills training and behaviour rehearsal
- relaxation training
- development of problem-solving skills.

1.4.9 For autistic adults without a learning disability or with a mild learning disability, who are at risk of victimisation, consider anti-victimisation interventions based on teaching decision-making and problem-solving skills.

1.4.10 Anti-victimisation interventions should typically include:

- identifying and, where possible, modifying and developing decision-making skills in situations associated with abuse
- developing personal safety skills.

1.4.11 For autistic adults without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

1.4.12 An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews
- training for the identified work role and work-related behaviours

- carefully matching the autistic person with the job
- advice to employers about making reasonable adjustments to the workplace
- continuing support for the person after they start work
- support for the employer before and after the person starts work, including autism awareness training.

Biomedical (pharmacological, physical and dietary) interventions and the core features of autism

1.4.13 Do not use anticonvulsants for the management of core features of autism in adults.

1.4.14 Do not use chelation for the management of core features of autism in adults.

1.4.15 Do not use the following interventions for the management of core features of autism in adults:

- exclusion diets (such as gluten- or casein-free and ketogenic diets)
- vitamins, minerals and dietary supplements (such as vitamin B6 or iron supplementation).

1.4.16 Do not use drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors) for the management of core features of autism or routinely for associated cognitive or behavioural problems in adults.

1.4.17 Do not use oxytocin for the management of core features of autism in adults.

1.4.18 Do not use secretin for the management of core features of autism in adults.

1.4.19 Do not use testosterone regulation for the management of core features of autism in adults.

1.4.20 Do not use hyperbaric oxygen therapy for the management of core features of autism in adults.

1.4.21 Do not use antipsychotic medication for the management of core features of autism in adults.

1.4.22 Do not use antidepressant medication for the routine management of core features of autism in adults.

1.5 Interventions for behaviour that challenges

1.5.1 Before initiating other interventions for behaviour that challenges, address any identified factors that may trigger or maintain the behaviour (see recommendation 1.2.20) by offering:

- the appropriate care for physical disorders (for example, gastrointestinal problems or chronic pain)
- treatment for any coexisting mental disorders, including psychological and pharmacological interventions (for example, anxiolytic, antidepressant or antipsychotic medication), informed by existing NICE guidance
- interventions aimed at changing the physical or social environment (for example, who the person lives with) when problems are identified, such as:
  - advice to the family, partner or carer(s)
  - changes or accommodations to the physical environment (see recommendation 1.1.8).

1.5.2 First offer a psychosocial intervention for the behaviour that challenges if no coexisting mental or physical disorder, or problem related to the physical or social environment, has been identified as triggering or maintaining behaviour that challenges.

1.5.3 When deciding on the nature and content of a psychosocial intervention to address behaviour that challenges, use a functional analysis. The functional analysis should facilitate the targeting of interventions that address the function(s) of problem behaviour(s) by:

- providing information, from a range of environments, on:
  - factors that appear to trigger the behaviour
  - the consequences of the behaviour (that is, the reinforcement received as a result of their behaviour)
- identifying trends in behaviour occurrence, factors that may be evoking that behaviour, and the needs that the person is attempting to meet by performing the behaviour.

1.5.4 In addition to the functional analysis, base the choice of intervention(s) on:

- the nature and severity of the behaviour
- the person's physical needs and capabilities
- the physical and social environment
- the capacity of staff and families, partners or carers to provide support
- the preferences of the autistic person and, where appropriate, their family, partner or carer(s)
- past history of care and support.

Psychosocial interventions for behaviour that challenges

1.5.5 Psychosocial interventions for behaviour that challenges should be based on behavioural principles and informed by a functional analysis of behaviour (see recommendation 1.5.3).

1.5.6 Psychosocial interventions for behaviour that challenges should include:

- clearly identified target behaviour(s)
- a focus on outcomes that are linked to quality of life
- assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour

- a clearly defined intervention strategy
- a clear schedule of reinforcement, and capacity to offer reinforcement promptly and contingently on demonstration of the desired behaviour
- a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)
- a systematic measure of the target behaviour(s) taken before and after the intervention to ascertain whether the agreed outcomes are being met.

Combined interventions for behaviour that challenges

1.5.7 Consider antipsychotic medication in conjunction with a psychosocial intervention for behaviour that challenges when there has been no or limited response to psychosocial or other interventions (such as environmental adaptations). Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

In June 2012 this was an off-label use of antipsychotic medication. See NICE's information on prescribing medicines.

Pharmacological interventions for behaviour that challenges

1.5.8 Consider antipsychotic medication alone for behaviour that challenges when psychosocial or other interventions could not be delivered because of the severity of the behaviour that challenges. Antipsychotic medication should be prescribed by a specialist and quality of life outcomes monitored carefully. Review the effects of the medication after 3–4 weeks and discontinue it if there is no indication of a clinically important response at 6 weeks.

In June 2012 this was an off-label use of antipsychotic medication. See NICE's information on prescribing medicines.

1.5.9 Do not routinely use anticonvulsants for the management of behaviour

that challenges in autistic adults.

1.6 Interventions for coexisting mental disorders

1.6.1 Staff delivering interventions for coexisting mental disorders to autistic adults should:

- have an understanding of the core features of autism and their possible impact on the treatment of coexisting mental disorders
- consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for autistic people.

Psychosocial interventions for coexisting mental disorders

1.6.2 For autistic adults and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder.

1.6.3 Adaptations to the method of delivery of cognitive and behavioural interventions for autistic adults and coexisting common mental disorders should include:

- a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')
- placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention
- making rules explicit and explaining their context
- using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations
- involving a family member, partner, carer or professional (if the autistic person agrees) to support the implementation of an intervention

- maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information).

Pharmacological interventions for coexisting mental disorders

1.6.4 For autistic adults and coexisting mental disorders, offer pharmacological interventions informed by existing NICE guidance for the specific disorder.

1.7 Assessment and interventions for families, partners and carers

1.7.1 Offer families, partners and carers of autistic adults an assessment of their own needs (see the NICE guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families, partners and carers).

1.7.2 When the needs of families, partners and carers have been identified, provide information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of autistic people. See the NICE guideline on supporting adult carers.

1.7.3 Offer information, advice, training and support to families, partners and carers if they:

- need help with the personal, social or emotional care of the family member, partner or friend **or**
- are involved in supporting the delivery of an intervention for their family member, partner or friend (in collaboration with professionals).

1.8 Organisation and delivery of care

Developing local care pathways

1.8.1 Local care pathways should be developed to promote implementation of key principles of good care. Pathways should be:

- negotiable, workable and understandable for autistic adults, their families, partners and carers, and professionals
- accessible and acceptable to all people in need of the services served by the pathway
- responsive to the needs of autistic adults and their families, partners and carers
- integrated so that there are no barriers to movement between different levels of the pathway
- outcome focused (including measures of quality, service user experience and harm).

1.8.2 Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about features of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway

- auditing and reviewing the performance of the pathway.

1.8.3 The autism strategy group should develop local care pathways that promote access to services for all autistic adults, including:

- people with coexisting physical and mental disorders (including substance misuse)
- women
- people with learning disabilities
- older people
- people from black and minority ethnic groups
- transgender people
- homeless people
- people from the traveller community
- people in the criminal justice system
- autistic parents.

1.8.4 When providing information about local care pathways to autistic adults and their families, partners and carers, all professionals should:

- take into account the person's knowledge and understanding of autism and its care and management
- ensure that such information is appropriate to the communities using the pathway.

1.8.5 The autism strategy group should design local care pathways that promote a range of evidence-based interventions at each step in the pathway and support autistic adults in their choice of interventions.

1.8.6 The autism strategy group should design local care pathways that respond promptly and effectively to the changing needs of all populations served by the pathways. Pathways should have in place:

- clear and agreed goals for the services offered to autistic adults
- robust and effective means for measuring and evaluating the outcomes associated with the agreed goals
- clear and agreed mechanisms for responding promptly to identified changes to people's needs.

1.8.7 The autism strategy group should design local care pathways that provide an integrated programme of care across all care settings. Pathways should:

- minimise the need for transition between different services or providers
- allow services to be built around the pathway and not the pathway around the services
- establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)
- have designated staff who are responsible for the coordination of people's engagement with the pathway.

Improving access to care

1.8.8 There should be a single point of referral (including self-referral) to specialist services for autistic adults.

1.8.9 Support access to services and increase the uptake of interventions by:

- delivering assessment and interventions in a physical environment that is appropriate for people with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)
- changing the professional responsible for the person's care if a supportive and caring relationship cannot be established.

1.8.10 Support access to services and increase the uptake of interventions by:

- ensuring systems (for example, care coordination or case management) are in place to provide for the overall coordination and continuity of care for autistic adults
- designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service).

Residential care

1.8.11 If residential care is needed for autistic adults it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation). The environment should be structured to support and maintain a collaborative approach between the autistic person and their family, partner or carer(s) for the development and maintenance of interpersonal and community living skills.

1.8.12 Residential care environments should include activities that are:

- structured and purposeful
- designed to promote integration with the local community and use of local amenities
- clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomy.

1.8.13 Residential care environments should have:

- designated areas for different activities that provide visual cues about expected behaviour
- adaptations to the physical environment for people with hyper- and/or hypo-sensory sensitivities (see recommendation 1.1.8)
- inside and outside spaces where the autistic person can be alone (for example, if they are over-stimulated).

1.8.14 Residential care staff should:

- understand the principles and attitudes underpinning the effective delivery of residential care for autistic adults
- work in collaboration with health and community care staff from a range of specialist services to support the delivery of a comprehensive care plan
- be trained in assessing and supporting the needs of autistic adults
- be consistent and predictable, but with some flexibility to allow change and choice
- be committed to involving families, partners and carers.

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline.

Augmentative communication

An alternative way of helping people with communication difficulties by using assistive technology such as computers or other devices, such as a speech output device.

Behavioural principles

Ideas, such as reinforcement and function of behaviour, that underlie behavioural therapies and underpin many interventions teaching adaptive skills for community living for autistic people, including those with behaviour that challenges.

Behaviour that challenges

A term used to describe behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety.

Care pathway

A system designed to improve the overall quality of healthcare by standardising the care process and promoting organised efficient service user care based on best evidence to optimise service user outcomes.

Chelation

A procedure that involves using one or more substances (chelating agents) to remove materials that are toxic, including heavy metals such as mercury, from the body.

Easy read

An accessible format for written communication designed for people with a learning disability. It uses simple jargon-free language, short sentences and illustrations.

Facilitated communication

A therapeutic intervention whereby a facilitator supports the hand or arm of an autistic person while using a keyboard or other devices with the aim of helping the person to develop pointing skills and to communicate.

Functional analysis

A method for understanding the causes and consequences of behaviour and its relationship to particular stimuli, and the function of the behaviour. The function of a particular behaviour can be analysed by typically identifying (1) the precursor or trigger of the behaviour, (2) the behaviour itself, and (3) the consequence of the behaviour.

Hyper- and hypo-sensory sensitivities

Being over-sensitive (hyper-sensitive) or under-sensitive (hypo-sensitive) to sound, light, colour, smell or taste, which can cause anxiety or even pain in an autistic person.

Informant

A family member, partner, carer or other third party known to the autistic person who is

able to provide information about the person's features and behaviour so that professionals can have a fuller picture of the person's developmental history. Some assessment tools for autism require information from informants.

Learning disability

Lower intellectual ability (usually defined as an IQ of less than 70) that leads to problems in learning, developing new skills, communication and carrying out daily activities. Learning disability severities are defined by the following IQ scores: mild=50–69, moderate=35–49 and severe=20–34. A person with a mild to moderate learning disability may only need support in certain areas. However, a person with a moderate to severe learning disability may have no speech or limited communication, a significantly reduced ability to learn new skills and require support with daily activities such as dressing and eating. Learning disabilities are different from 'learning difficulties', like dyslexia, which do not affect intellect. Learning disability is sometimes also called 'intellectual disability'.

Modelling

A technique used in behavioural therapy that utilises video and other media. The service user observes target behaviour on the video or computer screen, and repeats it.

Reinforcement

A technique used in behavioural therapy to teach 'rules' of social engagement through providing prompts for behaviour. Reinforcement may be by the autistic person or those working with or caring for them.

Recommendations for research

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group's full set of recommendations for research is detailed in the full guideline.

1 Facilitated self-help for anxiety and depression in autistic adults

What is the clinical and cost effectiveness of facilitated self-help for the treatment of mild anxiety and depressive disorders in autistic adults?

Why this is important

Anxiety and depressive disorders commonly coexist in autistic people and are associated with poorer health outcomes and quality of life. This may occur because of the direct impact of the anxiety or depression but also because of a negative interaction with the core features of autism. There is limited access and poor uptake of facilitated self-help by autistic people, largely due to limited availability but also because current systems for the delivery of such interventions are not adapted for use by autistic people. In adults without autism, facilitated self-help is an effective intervention for mild to moderate depression and anxiety. The development of novel methods for the delivery of facilitated self-help could make effective interventions available to a wider group of people.

The suggested programme of research would need to: (a) develop current methods for the delivery of self-help measures to take into account the impact of autism and possibly include developments in the nature of the materials, the methods for their delivery and the nature, duration and extent of their facilitation; (b) test the feasibility of the novel methods in a series of pilot studies; and (c) formally evaluate the outcomes (including symptoms, satisfaction and quality of life) in a large-scale randomised trial.

2 The structure and organisation of specialist teams

What structure and organisation of specialist autism teams are associated with improvements in care for autistic people?

Why this is important

The Department of Health's autism strategy (2010) proposes the introduction of a range of specialist services for autistic people; these will usually be built around specialist autism teams. However, there is little evidence to guide the establishment and development of these teams. There is uncertainty about the precise nature of the population to be served (all autistic people or only those who have an IQ of 70 or above), the composition of the team, the extent of the team's role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team's role and relationship with regard to non-statutory care providers. Therefore it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of autistic people. Given the significant expansion of services, this presents an opportunity for a large-scale observational study, which should provide important information on the characteristics of teams associated with positive outcomes for autistic people in terms of access to services and effective coordination of care.

3 Augmentative communication devices for autistic adults

What is the clinical and cost effectiveness of augmentative communication devices for autistic adults?

Why this is important

Many autistic people experience significant communication problems (for example, the absence of any spoken language or significant deficits in interpersonal skills), which have a profound effect on their ability to lead a full and rewarding life. It is probable that these problems are related to the core features of autism and are likely to persist for most people given the life-long course of autism and the lack of effective interventions for these

core features. A number of communication devices have been developed for autism but few, if any, have been subjected to a proper evaluation in adults. Despite this lack of formal evaluation, individual services have made considerable investments in augmentative communication devices. Research that provides high-quality evidence on the acceptability and the clinical and cost effectiveness of augmentative communication devices could bring about significant improvements in the lives of autistic adults.

The suggested programme of research would need to identify current devices for which there is: (a) some evidence of benefit (for example, case series and small-scale pilot studies); (b) some evidence that it meets a key communication need for autistic people (based on reviews of people's need in this area); and (c) indication that the device is feasible for routine use. The identified device(s) should then be formally evaluated in a large-scale randomised trial.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on autism.

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 amended recommendation 1.2.3 to clarify that when the Autism-Spectrum Quotient – 10 items (AQ-10) is used to assess for possible autism, the score at which the person should be offered a comprehensive assessment is 6 or above. Throughout the guideline we changed 'people with autism' to 'autistic people', 'challenging behaviour' to 'behaviour that challenges', and 'symptoms' to 'features' to align with current terminology.

August 2016: The following recommendations for research have been removed:

- What is the clinical and cost effectiveness of CBT for the treatment of moderate and severe anxiety disorders in autistic adults?
- What is the clinical and cost effectiveness of selective serotonin reuptake inhibitors (SSRIs) for the treatment of moderate and severe depression in autistic adults?

Minor changes since publication

January 2023: We have updated the link to the Autism-Spectrum Quotient – 10 items (AQ-10) tool.

March 2022: We have changed the description of psychologists in recommendation 1.1.13, in line with current practice and the British Psychological Society's best practice in psychology recruitment.

July 2020: We linked to the NICE guideline on supporting adult carers in recommendations 1.1.17, 1.7.1 and 1.7.2.

October 2015: Title changed from 'Autism: recognition, referral, diagnosis and management of adults on the autism spectrum' to 'Autism spectrum disorder in adults: diagnosis and management', for clarity and consistency with other guidance on this topic.

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People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services



Faculty Report FR/ID/03
July 2013

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Faculty of Psychiatry of Intellectual Disability

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Contents

Working group	4
Foreword	8
Executive summary and recommendations	9
Introduction	16
Learning disability, mental health morbidity and challenging behaviour	19
In-patient service provision for people with learning disability and mental health or behavioural problems	22
Monitoring standards and outcomes	36
Appendix 1. Studies describing acute admission units (category 2 and 3 beds)	40
Appendix 2. Service user and carer testimonies	51
References	55

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Foreword

The Faculty of Psychiatry of Intellectual Disability at the Royal College of Psychiatrists commissioned this report as a result of the abuse scandal at Winterbourne View Hospital. In that hospital there was an appalling standard of care that no one would condone. Since that time, there has been much debate about the place of specialist in-patient care for people with intellectual (learning) disabilities.

This report sets out the different types of specialist in-patient services that are currently provided, and describes the sort of difficult and challenging circumstances in which such services can be an appropriate intervention for a person with intellectual disability. These are always serious and challenging problems, where there are major risks to the person themselves and other people, so serious that compulsory treatment under the Mental Health Act is often required. As such, in-patient services can form an essential component of an overall integrated care pathway.

Some people refer to all specialist in-patient services for people with learning disabilities as 'assessment and treatment units' but this report explains why this is a flawed approach and does a disservice to the people who use the service.

Much has been said about the enhancement of community services that is required to reduce the use of specialist in-patient services, and we wholeheartedly support the development of better community services, particularly for those with challenging behaviour and other major mental health needs. However, as this report says, even if such improvements do deliver a reduction in the need for beds, a range of specialist in-patient services will still be required. Of course these must be of the highest quality, and fortunately there are assessment tools already in use (some developed by the College) that are very helpful in assessing quality. The universal adoption of such tools will go a long way to help prevent the abuse that happened at Winterbourne View from happening again.

Dr Ian Hall
Chair of the Faculty of Psychiatry of Intellectual Disability
Royal College of Psychiatrists

Executive summary and recommendations

The BBC Panorama programme 'Undercover Care: the Abuse Exposed' aired in May 2011, followed by the Serious Case Review from the South Gloucestershire Adult Safeguarding Board in July 2012, and the interim and final reports from the Department of Health in June and December 2012, have focused attention on the in-patient care of people with learning disability and mental health or behavioural problems. Describing 'assessment and treatment units' as a new form of institutional care which has no place in the 21st century, the reports set out national actions to deliver five goals, namely: more people with learning disability being supported to live at home; fewer people developing behaviour that challenged and those that did being kept safe in their communities; far fewer being sent away to hospitals; and proper planning, keeping such hospital stays as short as possible. On these goals, there can be little disagreement. By striving to deliver effective treatment in the least restrictive setting while paying due diligence to minimising risks, psychiatrists and other professionals working within the field of mental health in learning disability strive to achieve precisely these goals. However, in-patient services are a crucial part of the effort to achieve those goals. Although the majority of people with learning disability, mental health, behavioural and forensic difficulties will be supported within well-resourced community services, specialist hospital settings should remain available whenever there is good evidence that hospital is the best setting to enable their necessary assessment, treatment and care. This document describes the categories of in-patient care available, their purpose and how we monitor in-patient services to ensure safe and effective care.

Mental health, behavioural and other needs of people with a learning disability

People with a learning disability who come into contact with specialist learning disability mental health services often have a complex mix of learning disability, other developmental disorders, mental illnesses, personality disorders, substance misuse, and physical disorders including epilepsy. Some of these conditions present with challenging behaviours, others do not.

Challenging behaviour is a socially constructed, descriptive concept that has no diagnostic significance. It can range from pica, smearing and self-injury in a person with a profound learning disability, to unlawful killing in someone with a mild learning disability and forensic issues. It may be

unrelated to psychiatric disorder, but can also be a primary or secondary manifestation of it. Treatment for challenging behaviour emphasises the use of the least restrictive community resource wherever possible. In-patient admissions are required if the risk posed by the behaviour is of such a degree that it cannot safely be managed in the community. Alternatively, for some people an early admission may be required for diagnostic clarification and initiation of appropriate treatment. Some people with learning disability have multiple physical problems, and in some who present with challenging behaviour it can be difficult to tease out whether the presentation is because of an underlying organic (physical) condition. In many of these complex presentations, continuous nursing observation, investigations, medical and psychiatric input may be needed within an in-patient setting for an accurate diagnosis and effective treatment. Appreciating this complexity is important in determining the role that in-patient units play in diagnosis and treatment. Good in-patient care can only be delivered by multidisciplinary teams working very closely with Social Services to ensure person-centred planning and plans for appropriate provision to move on from hospital care. It is important that people have the right care and support packages to meet their individual needs with agreed outcomes for moving on through the pathways of care.

The range of in-patient service provision

Describing all types of specialist in-patient services for people with learning disability as 'assessment and treatment units for challenging behaviour' does not capture the spectrum of in-patient services and their different functions in meeting the needs of those with complex presentations. When this approach is used by governments, regulatory authorities and some service providers, it results in mixing up categories of beds that serve completely different functions. As a consequence, targets that aim solely on cutting the numbers of 'assessment and treatment units for challenging behaviour' will result in significant gaps in service provision that will disadvantage the very patients it is meant to help.

This report sets out, with representative case examples, six categories of in-patient beds and their close relationship with each other. Although all these categories do involve some assessment and treatment, they serve different functions. They can be best understood within the context of the tiered model, where tier 4 constitutes the in-patient part of a specialist learning disability service provision:

- category 1: high, medium and low secure forensic beds
- category 2: acute admission beds within specialised learning disability units
- category 3: acute admission beds within generic mental health settings
- category 4: forensic rehabilitation beds
- category 5: complex continuing care and rehabilitation beds
- category 6: other beds including those for specialist neuropsychiatric conditions.

From a patient care perspective, the narrative should be that of in-patient services complementing community teams to achieve good treatment outcomes and being part of the pathway of care for those who present with

complex needs. Indeed, depending on patient needs, an admission to an in-patient bed can sometimes be appropriate and beneficial early on in the care pathway, to undertake a multidisciplinary assessment and provide early interventions to prevent rapid deterioration.

High, medium and low secure forensic beds (category 1)

Category 1 refers to beds within forensic hospitals in conditions of high, medium or low security. The decision whether a person becomes a 'forensic patient' or not often depends on both clinical judgements about risks and the attitudes of professionals working in the criminal justice system. Both of these are inevitably shaped by the availability of services, and if less restrictive in-patient facilities are unavailable, more patients can end up in these restrictive settings.

Acute admission beds within specialised learning disability units (category 2) and acute admission beds within generic mental health settings (category 3)

Category 2 and 3 beds are acute admission beds intended for the assessment and treatment of severe mental health and/or behavioural problems, of an intensity which poses a risk that cannot be safely managed in a community setting, but which does not meet the risk threshold to be considered for a forensic bed. Category 2 serves this function within a specialised learning disability unit, whereas category 3 does it within a generic or mainstream mental health ward setting. There is a considerable body of published literature about the comparison between category 2 and 3 beds, but there is no evidence to suggest that any one model is superior. The two models serve different types of patients and generic psychiatric care may be unpopular, especially with carers and families.

Category 2 beds in specialist learning disability units are needed because although the equity of access that a policy of mainstreaming brings is very pleasing, it is meaningless if not accompanied by equity of outcome. Being treated by specialists in the mental health of people with learning disability, within settings that are particularly suitable for those with learning or developmental disadvantage, is a reasonable adjustment that allows people with learning disability and mental health or behavioural difficulties to achieve the same equity of outcome as people without learning disability with the same mental disorders. These beds, therefore, are not a reminder of inequality through segregation but a guarantor of equity through specialisation.

That is not to say that category 3 beds cannot deliver good outcomes for people with mild learning disability and mental illness. The College report *Enabling People with Mild Intellectual Disability and Mental Health Problems to Access Healthcare Services* (Royal College of Psychiatrists, 2012) explains how this can be effective, if there is substantial specialist support available to facilitate this from community learning disability teams.

Forensic rehabilitation beds (category 4)

Category 4 is for people who have stepped down from forensic units with enduring issues of risky behaviours. Their legal status and current risk assessments still emphasise the need for ongoing therapeutic input and

robust external supervision for the protection of the public. The availability of these hospital beds, often in locked or open community units, allows them to receive treatment in a less restrictive setting than a category 1 bed.

Complex continuing care and rehabilitation beds (category 5)

Category 5 is for people who have undergone the initial acute assessment and treatment process. For a variety of reasons, including enduring mental illnesses or severe behavioural problems that have not responded adequately to treatment, ongoing risks arising from neglect or vulnerability or persisting risks to the safety of others, a safe transition into the community has not been possible. The availability of these beds allows a process of rehabilitation and re-skilling in a safe, structured and therapeutic environment at a pace that patients can tolerate, and minimises the risk of 'revolving-door' patterns of hospital admissions to category 2 or 3 beds.

Category 4 and 5 beds are not unique to people with learning disability. They closely mirror the definition of the 'longer-term complex/continuing care units' contained in the recently published document *Defining Mental Health Services – Promoting Effective Commissioning and Supporting QIPP* (NHS Confederation, 2012). The definitions in that document have been endorsed by a range of organisations, including the Department of Health, the Care Quality Commission, the Audit Commission, the Association of Directors of Adult Social Services (ADASS), the NHS Information Centre, the Mental Health Network – NHS Confederation, the Royal College of General Practitioners, the Royal College of Psychiatrists, the Royal College of Nursing and mental health leads of the strategic health authorities.

Other beds including those for specialist neuropsychiatric conditions (category 6)

This includes specialist beds for some neuropsychiatric conditions such as epilepsy and movement disorders. At present, this service provision is limited to a few, very specialised national units.

Bed occupancy in learning disability in-patient services

Using data obtained from the Faculty of Psychiatry of Intellectual Disability's regional representatives, we found that at present there are around 3954 beds within the 10 strategic health authority regions of England. This is made up of approximately 2393 category 1, 814 category 2, 622 categories 4/5 and 125 category 6 beds (no specific data available for category 3 beds). This includes some, although not all, beds in specialist units designated for autism spectrum disorders. These figures include all National Health Service (NHS) and independent sector provision for forensic and non-forensic services and represent an almost 90% reduction from a high of over 33000 NHS beds in 1987–1988.

If, in the absence of significantly improved community services, the less restrictive in-patient facilities (categories 2–5) are further reduced because they are all uniformly described as assessment and treatment beds, then many more people will have unmet needs that compromise their mental health and safety. The result of this could be even more people ending up in far more restrictive forensic beds (category 1).

Stepping down from in-patient services

Currently, 70% of forensic (category 1) beds are in conditions of low security. Since the provision of relational and procedural security is often more important than physical security for people with learning disability, many patients currently in these beds could potentially move to the less restrictive rehabilitation beds (category 4 or 5). At present, this is problematic because the commissioning streams for secure beds (category 1) are different to those for all the other categories of hospital beds and the possibility of patients 'stepping down' creates financial pressures for clinical commissioning groups. In addition, there is significant geographic variation in the current distribution of in-patient beds. Although economies of scale may hamper the efforts to provide all categories of beds in every district, the emphasis should be on in-patient service provision as close to the person's place of residence as possible. It is therefore important to consider all in-patient beds, whether 'forensic' or 'non-forensic', as a whole while planning for future provision.

Although the aim is for all patients to move through to the community, it has to be recognised that not all will move at a predetermined pace all the way through the care pathway. For patients who stay in hospital for long periods, there should be demonstrable evidence of ongoing therapeutic input. This will include psychiatric input, nursing care, availability of psychological therapy, occupational therapy, rehabilitation activities that include educational and vocational opportunities, and supervised or independent access to the community. Even though the patient may choose sometimes not to engage in these activities, these therapeutic activities should nevertheless be available.

In-patient services' accreditation

Accreditation tools focus on process variables within in-patient units and ensure that clinical practice will be in keeping with standards that are accepted by peers. There are a range of such tools including the Royal College of Psychiatrists' Accreditation for Inpatient Mental Health Services in Learning Disability (AIMS-LD) and the peer review accreditation process (Quality Network for Forensic Mental Health Services). The measurement of these process variables will have to be supplemented with information about whether treatment provided in these settings works. A minimum data-set of outcome variables that cover measures of clinical effectiveness, patient safety and patient experience proposed in this report will help in benchmarking services nationally.

RECOMMENDATIONS

We make the following recommendations.

1 Lack of awareness about the six different categories of in-patient beds results in all of them being described incorrectly as 'assessment and treatment units'. When undertaking reviews of in-patient placements, service providers, commissioners and policy makers should be aware of these different categories and monitor their function against these categories. Inspection reports by regulatory authorities should specify these different bed categories.

Action: Care Quality Commission or equivalent, service providers and commissioners

2 A choice of both generic mental health and specialist learning disability mental health beds should be available for people with learning disability and mental health or behavioural problems who require acute in-patient treatment. This choice should be determined by clinical need, patient and carer preference and evidence-based practice.

Action: service providers, commissioners, service users, families and carers

3 Regional commissioning strategies should focus care pathways on well-developed community services and a spectrum of in-patient care as described by the six categories in this report.

Action: service providers, commissioners, service user and carer groups

4 Since there are local variations in the number of beds needed within each individual category, there should be discussion between patients, carers, professionals, providers and commissioners in each area about local need as part of a joint strategy in developing pathways of care for people with learning disability.

Action: service providers, commissioners, service users, families and carers

5 There should be an ongoing dialogue at a local level between learning disability health providers, mental health providers and local authorities to ensure that responsive local authorities and mental health services can help reduce the need for admission and shorten the length of stay in hospital. Commissioners and providers should plan from day one of admission to in-patient services for the person with learning disability to move back to community services.

Action: service providers, commissioners, local authorities and mental health services

6 Availability of multidisciplinary therapeutic input distinguishes good in-patient facilities from those that are no more than settings of containment. There should be regular monitoring of this availability through the care programme approach and other reviews.

Action: service users, parents, carers, service providers, commissioners, Care Quality Commission or equivalent

7 All in-patient units should be able to show evidence of having gone through an external accreditation process such as the Royal College of

Psychiatrists' peer review accreditation for forensic beds, the AIMS-LD project or any other equivalent.

Action: service providers, commissioners, Care Quality Commission or equivalent

8 All in-patient units should be able to show evidence of a minimum data-set of treatment outcomes that includes baseline descriptions of quality of care, measures for effective treatments, appropriate use of medication, patient safety, compliance with Mental Capacity Act, and patient experience.

Action: service providers, commissioners, Care Quality Commission or equivalent

9 A number of patients in category 4 and 5 beds (forensic rehabilitation and rehabilitation and continuing care) stay for very long periods in hospital because apart from therapeutic input, they also need continuous supervision for the protection of the public. If this type of continuous supervision was legally enforceable in the community, without it amounting to the legal standard for deprivation of liberty, then they could very well be managed outside hospitals. We recommend further scrutiny of this issue.

Action: government legislation or guidance

Introduction

Over the past 30 years, there has been a gradual reduction of hospital beds across all medical and surgical specialties in the NHS in England. This fall has been most dramatic in mental health and learning disability. Mental illness bed numbers have fallen from 67421 in 1987–1988 to 22403 in 2011–2012 (66.8% reduction) as compared to a reduction of learning disability beds from 33421 to 1800 in same time frame (95% reduction). Table 1 presents these numbers in more detail.

Government policy, the process of deinstitutionalisation and the development of a range of community services resulted in the closure of long-stay hospitals for people with a learning disability (Kingdon, 2005). As a result of this process, the number of in-patients in hospitals fell from a high of around 64000 in 1970, to well under 10000 by 2001 (Braddock *et al*, 2001; Department of Health, 2001). The latter included placements in residential accommodation within the NHS and with the campus closure programme (Department of Health, 2006), bed numbers fell further. The last remaining patients in NHS accommodation were moved out successfully to a range of community settings, such as nursing homes, residential group homes, supported living accommodation, family homes or independent living (Bhaumik *et al*, 2011). The closure of long-stay hospitals was accompanied by an increasing focus on community learning disability teams providing a range of services, including those for mental health and behavioural difficulties (Lindsey, 2000). Within this model, the purpose of in-patient beds changed from one that provided long-term residential accommodation, to one that was accessed for assessment and treatment of severe mental health and/or behavioural difficulties.

Table 1 Average daily number of available beds, England, 1987–1988 to 2012–2013 (NHS England, 2013)[a]

Year	All specialties	Mental illness	Learning disability
1987–1988	297364	67122	33421
1988–1989	282918	63012	30048
1989–1990	270301	59288	26406
1994–1995	211812	41827	13211
2000–2001	186091	34214	6316
2005–2006	175436	29802	3927
2009–2010	158461	25503	2809
2010-2011	142470	23159	2191
2011–2012	138574	23200	1800
2012–2013	138574	22403	1859

a. No data available for years 1995–2000, 2001–2005 and 2006–2009.

The Department of Health's interim report (2012*a*) in the aftermath of the abuse scandal at Winterbourne View Hospital (BBC One Panorama, 2011) stated that there were 1252 occupied beds in in-patient services designated as assessment and treatment units dealing with challenging behaviour; 500 of those had lengths of stay of more than 6 months (Care Quality Commission, 2011). Concluding that there were too many people staying for too long within these units, the report suggested that only 300–400 assessment and treatment beds, the equivalent of 2 to 3 per local authority area, were needed across England. (That figure does not appear to be correct, since with 326 districts there are far more local authorities in England than the report assumes. We now understand that the report was referring not to all local authorities, but only the upper tier ones that number around 120.)

In a strongly worded foreword to the interim report (Department of Health, 2012*a*), the then Minister of State for Care Services described assessment and treatment units as a new form of institutional care. It was a theme that continued in the conclusions of the report where these units were described as a model of care that has no place in the 21st century. Quoting extensively from the Mansell report (Department of Health, 2007) and the *Valuing People* policy documents (Department of Health, 2001, 2009), this report recommended 14 national actions and gave a list of 5 goals that would be achieved were these actions to be taken. These were that more people with learning disability would be supported to live at home; fewer people would develop behaviour that challenged; those who did would be kept safe in their communities; far fewer would be sent away to hospitals; and when that happened, proper planning would mean that their stay would be as short as possible. The final report (Department of Health, 2012*b*) stated that many people who should be supported in communities were in hospital for too long. There was a widespread failure to design, commission and provide services locally and a failure to assess the quality and outcomes being delivered in hospitals. It broadly endorsed the goals set out in the interim report and established a programme of action and a concordat towards achieving that.

On the goals that are thus set out, there can be little disagreement. Indeed, psychiatrists and other professionals working within the field of mental health in learning disability strive to achieve precisely these goals, namely deliver effective treatment in the least restrictive setting, while paying due diligence to minimising and managing the risks that pose a danger either to the patients themselves or to others. We suggest, however, that in-patient units are a crucial part of the effort to achieve these goals. Far from being institutions that have no place in the 21st century, they are vital to ensure that people with learning disability and mental health or behavioural difficulties get the treatment they require. The response to abuse in any such unit should be renewed efforts to stamp out poor practice, enhance governance structures and punish criminal activity, rather than seeking to shut down a crucial part of patient care altogether. In this, we suggest that the response should be exactly similar to how abuse scandals have been dealt with elsewhere in the health system within general hospitals.

Although the majority of people with learning disability, mental health, behavioural and forensic difficulties will be supported within well-resourced community services, specialist hospital settings should remain available whenever there is good evidence that hospital is the best setting to enable their necessary assessment, treatment and care.

Coming as they did in the aftermath of the Winterbourne scandal, the Department of Health reports, perhaps understandably, focused on issues around 'challenging behaviour' and 'assessment and treatment units'. We suggest that this is too narrow a focus. Effective planning requires a fuller examination of the whole issue of in-patient service provision rather than a particular subtype. It would be useful to examine this within the tiered model of service provision that describes the patient journey between hospital and community settings (Royal College of Psychiatrists, 2011*a*). Such an exercise can delineate why in-patient services are needed, the types of those services, the different models of that service provision and the ways of measuring and monitoring them. In the absence of such a fuller examination, targets that focus solely on the number of 'assessment and treatment beds for challenging behaviour' will result in service cuts that far from delivering equality to a marginalised population will only serve to further disadvantage them.

This report is prepared on behalf of the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists and focuses on adults with a learning disability. It is primarily based on statistics from England, but wherever available, in-patient information from Wales, Scotland and Northern Ireland is given. The models of healthcare that are described would apply equally to all jurisdictions. The report examines the following points:

1 learning disability, mental health morbidity and challenging behaviour

2 in-patient service provision for people with learning disability, mental health and behavioural problems: categories of beds and service models

3 monitoring of standards and outcomes.

Learning disability, mental health morbidity and challenging behaviour

Learning disability

The UK government uses the term learning disability, yet the international classificatory systems, DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization, 2008), currently use the term mental retardation. The Royal College of Psychiatrists recently decided to use the term intellectual disability. Since governmental organisations and commissioning bodies in the UK are still using the term learning disability, this report uses that terminology throughout.

Learning disability is a condition characterised by significant impairments of both intellectual and adaptive functioning and an onset before the age of 18 (World Health Organization, 2008). About 1–2% of the general population will have a learning disability (Emerson *et al*, 2011). In England, the Learning Disabilities Public Health Observatory estimated that in 2011 just below 1 million adults aged 18 or above had that condition (Emerson *et al*, 2011). The degree of learning disability can be mild, moderate, severe or profound, with over 90% of those affected falling within the mild range (Department of Health, 2001). Since their functional abilities are very close to the lower end of normality, those with a mild learning disability often may not come to the attention of specialist learning disability health services at all.

Mental health morbidity

People with a learning disability have high rates of mental health comorbidity (Deb *et al*, 2001). Epidemiological studies have suggested a prevalence rate of 31–41% (Cooper *et al*, 2007; Morgan *et al*, 2008). For those in contact with specialist learning disability health services, a recent study (Kiani *et al*, 2013) offers a good demonstration of this point. The counties of Leicestershire and Rutland (including the city of Leicester) have a total population of just under 1 million and one would expect around 10 000–20 000 people with a learning disability there. The long-established Leicestershire Learning Disability Register (McGrother *et al*, 1993) has only 3062 people on it and of these 2713 receive help from the specialist learning disability services of the local NHS trust (Kiani *et al*, 2013). Of this 2713,

between 33 and 35% (about 920 people) have a diagnosable mental disorder based on ICD-10 criteria.

For those who are treated within hospital settings, figures from 9 specialist in-patient unit studies (Hurst *et al*, 1994; Singh *et al*, 1994; Trower *et al*, 1998; Raitassuo, 1999; Alexander *et al*, 2001; Tajuddin *et al*, 2004; Xeniditis *et al*, 2004; Hall *et al*, 2006*a*) show rates of major mental illness comorbidity ranging from 50 to 84%. This is in addition to other comorbid conditions such as autism spectrum disorders, attention-deficit hyperactivity disorder, personality disorders and substance misuse. For individuals treated within or referred to forensic (i.e. secure) hospital services for those with learning disability, similarly high figures are reported. Up to half have a personality disorder, up to a third have an autism spectrum disorder, about a third to half have a major mental illness, about a third to half have substance misuse/dependence and about a fifth have epilepsy (Alexander *et al*, 2002, 2006; Plant *et al*, 2011). It is thus clear that of those people with a learning disability who come into contact with psychiatrists, whether they are in the community or in specialist hospitals, it is not learning disability alone that is the focus of treatment. Their clinical presentations are often a complex mix of learning disability, mental illnesses, other developmental disorders, personality disorders, substance misuse, and physical disorders including epilepsy. Some of these conditions present with challenging behaviours, whereas others do not. Appreciating this complexity is important in determining the role that in-patient units play in diagnosis and treatment. Good in-patient care can only be delivered by multidisciplinary teams working very closely with Social Services to ensure person-centred planning and plans for appropriate provision to move on from hospital care. It is important that people have the right care and support packages to meet their individual needs with agreed outcomes for moving on through the pathways of care.

Challenging behaviour

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion (Royal College of Psychiatrists *et al*, 2007). Challenging behaviour is a socially constructed, descriptive concept that has no diagnostic significance, and makes no inferences about the aetiology of the behaviour. It covers a heterogeneous group of behavioural phenomena across different groups of people; for example, oppositional behaviour in children, faecal smearing in those with a severe learning disability, and self-harm in adult mental illness. Challenging behaviour may be unrelated to psychiatric disorder, but can also be a primary or secondary manifestation of it (Xeniditis *et al*, 2001). For people with learning disability who come into contact with health services, it can range from stereotypies and self-injury in a person with a profound learning disability, to unlawful killing in someone with a mild learning disability and forensic issues. A meta-analysis of risk markers for challenging behaviour that looked at 86 studies described four types of challenging behaviours: self-injury, aggression, stereotyped behaviours and destruction of property (McClintock *et al*, 2003). Suggesting that male gender, severe learning disability and autism were possible risk markers, this comprehensive paper commented

about the lack of data on the incidence, prevalence and chronicity of challenging behaviours in this population. The recent report from the Department of Health (2012*a*) states that there are a total of 15 000 people in England with learning disability or autism and behaviour that challenges. Data provided by the Leicestershire Learning Disability Register studies would suggest that the numbers may be higher (Tyrer *et al*, 2006; Kiani *et al*, 2013). In an area with a population of around 1 million, there are 540 people with some form of problem behaviour, including 443 with physical aggression of more than 3 episodes per week and/or severe intensity. Extrapolating from this, it appears that between 22 000 and 26 000 people with a learning disability in England are likely to have some form of behaviour that challenges.

Treatment for 'challenging behaviour' does not necessarily require an in-patient setting. Indeed, the therapeutic approach to it has been well described and emphasises the use of the least restrictive community resource wherever possible (Royal College of Psychiatrists *et al*, 2007). In-patient admissions are required only if the risk posed by the behaviour is of such a degree that it cannot safely be managed in the community. Persistent challenging behaviour, which poses a level of risk that is unmanageable in a community setting, may be the manifestation of some other underlying mental health difficulty that requires careful assessment and treatment in the safe setting of an in-patient resource. Equally, there may be many people with a learning disability who require an in-patient admission for further assessment, diagnosis and treatment of mental disorders that do not necessarily present with challenging behaviour. Indeed, admission to a specialist unit can sometimes be appropriate and beneficial early on in the care pathway, rather than as a last resort. Suffice to say that the purpose of admitting a person with a learning disability to a specialist in-patient setting is not merely because that person has 'challenging behaviour'.

In-patient service provision for people with learning disability and mental health or behavioural problems

Why are in-patient beds needed?

The assumption that all behaviours were a consequence of institutional lifestyles, which would diminish once community care was introduced, may be flawed (Holland *et al*, 2002). There are several reasons why people with a learning disability and mental health/behavioural difficulties need access to specialist in-patient provision.

1 Behaviours previously hidden or tolerated within institutions become more visible in the community and lead to adverse consequences (Moss *et al*, 2002).

2 An increased societal aversion to risk (Carroll *et al*, 2004) makes this dynamic more potent. Behaviour, whether it is aggression or self-injury, can pose a level of risk that is deemed unacceptable in a community setting. In this situation, in-patient settings of varying degrees of security are needed for varying periods of time. The guiding principle is to go for the least restrictive within those options.

3 Any patient who is seen as 'liable to be detained' under the Mental Health Act will by law require a hospital bed (*R v Hallstrom ex p W* [1986]).

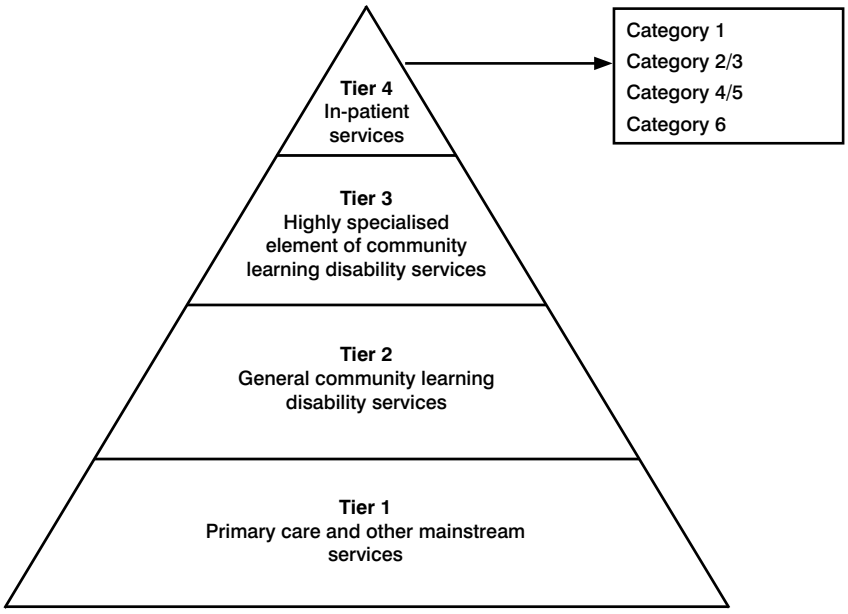
4 Just as in the general population, people with learning disability also develop mental ill health. As discussed in detail in the previous chapter (p. 19), they have in fact higher rates of psychiatric and developmental morbidity. For those who come into contact with specialist or generic mental health services, this is not just because they have a learning disability. Their clinical presentations are usually a complex mix of learning disability, mental illnesses and other developmental disorders. The natural course of these mental disorders suggests that there may be both crisis situations and situations where symptoms or behavioural disturbance persist in spite of adequate treatment. During those times, they need a safe setting with professionally qualified staff who can treat them.

5 People with learning disability and mental health problems also have an extraordinary range of physical disorders including epilepsy (Emerson

& Baines, 2012) that makes their presentation even more complex. For some people who present with challenging behaviour, physical and mental health issues are intricately linked with each other and often it can be difficult to tease out whether the presentation is because of an underlying organic (physical) condition. In many of these complex presentations, continuous nursing observation, physical investigations, medical and psychiatric expertise may be needed within an in-patient setting for an accurate diagnosis and effective treatment.

What are the types of in-patient beds?

A number of authors have described or summarised different categories of in-patient beds (Dickinson & Singh, 1991; Alexander *et al*, 2001; Chaplin, 2004, 2009, 2012; Hall *et al*, 2006*a*,*b*). All in-patient services for this group of patients can be best understood within the context of the tiered model of service provision, with tier 4 constituting the in-patient part of a specialist learning disability service provision (Fig. 1).



Tier 1 encompasses primary care and other mainstream services. It is the tier of service provision that serves the general health, social care and educational needs of people with learning disability and their families. The community learning disabilities team and the psychiatrist have limited direct clinical contact in this tier. Nevertheless, they are involved in activities which may influence patients' care and interacting with this tier is essential to the training of learning disability psychiatrists.

Tier 2 is general community learning disability services. At this level the person with learning disability starts to use specialist learning disability services. Most specialist services are provided jointly between health and social services or are moving towards such a model.

Tier 3 is a highly specialised element of community learning disability service. This includes areas of specialised needs such as epilepsy, dementia, challenging behaviour, pervasive developmental disorders and out-patient forensic services.

Tier 4 is specialist in-patient services. It includes all specialist in-patient services for people with learning disabilities, ranging from local assessment and treatment services to high secure forensic services.

Fig. 1 Tiered/stepped model of care for learning disability services (adapted from Royal College of Psychiatrists, 2011*a*).

Based on discussions with stakeholders (service users, family members, carers, general practitioners, psychiatrists in various subspecialties, nurses, psychologists, speech therapists, social workers, occupational therapists, physiotherapists and service commissioners) we describe six categories of in-patient beds for people with learning disability and mental health and behavioural difficulties (Box 1).

Inspection reports on so called 'assessment and treatment units' (Care Quality Commission, 2012) tend to group bed categories 2, 3, 4 and 5 together. Consequently, it is not surprising that there is a very wide range in the length of stay mentioned in these reports. This in turn leads to stringent criticism about the inappropriate use of assessment and treatment beds (Scottish Executive Joint Improvement Team, 2006; Department of Health, 2012*a*,*b*). It is absolutely imperative to tease out these differing categories of beds using the typology we describe, to inform appropriate commissioning.

Category 1 (high, medium and low secure forensic beds)

At the most restrictive end, there are the forensic beds. These are for patients who pose a level of risk assessed as requiring the physical, relational and procedural security of a high, medium or low secure unit (Box 2). The general characteristics of these units have been described elsewhere (Kennedy, 2002; Royal College of Psychiatrists, 2007*a*,*b*; R. Alexander & H. Boer, personal communication, 2013). Although all patients accessing these beds tend to be detained under the Mental Health Act 1983 (amended 2007), not all may have gone through the criminal justice system and hence may not be detained under Part 3 of the Mental Health Act (in practice, therefore, these patients may be detained on sections ranging from Section 3 to Section 37 or Section 41).

There is a tendency among those responsible for health planning and indeed some clinicians to see these forensic beds as somehow completely different from the other in-patient provision. Admittedly, this approach may be problematic in all areas of mental health, but it is particularly so in learning disability. This is because the way the criminal justice system manages law-breaking behaviour by people with learning disability is variable (R. Alexander & H. Boer, personal communication, 2013). A person with a more severe learning disability is unlikely to ever come before the courts unless the criminal act is very serious. Even for those with a milder degree

Box 1 Categories of in-patient beds within tier 4 for people with learning disability and mental health and/or severe behavioural problems

- Category 1: high, medium and low secure forensic beds
- Category 2: acute admission beds within specialised learning disability units
- Category 3: acute admission beds within generic mental health settings
- Category 4: forensic rehabilitation beds
- Category 5: complex continuing care and rehabilitation beds
- Category 6: other beds including those for specialist neuropsychiatric conditions and short breaks

Box 2 Case vignette: category 1 typical patient story

Kylie is a 30-year-old woman with a mild learning disability who has had a childhood history of being sexually abused. She was in and out of local authority care, left school without any qualifications, never had any productive employment and was never in any stable relationship. By early adulthood, she was misusing alcohol and illicit drugs, and had a range of difficulties. The most problematic were impulsive behaviour, a tendency to become aggressive when these impulsive acts were thwarted in any way, a persistent pattern of self-harm (overdosing, slashing herself and inserting objects into her body), marked instability of mood, and uncontrolled bursts of anger resulting in aggression targeted towards acquaintances, professionals and members of the public. The aggression often resulted in her being evicted from various placements. In her late 20s, she also appeared to develop an episodic depressive illness associated with psychotic features. These episodes would last for 3–4 months at a time. Her index offence was one of assaulting a fellow resident at an emergency placement with a knife. Arrested by the police, she was assessed and initially admitted to the local psychiatric ward under Section 3. In hospital, her psychotic features improved with medication, but there was little engagement in any other therapy. The police and Crown Prosecution Service decided to drop charges because they felt that she was already receiving treatment in hospital and the victim was not considered a reliable witness. As discussions were going on about discharging her, she got into another argument and repeatedly stabbed a fellow patient with a dinner knife causing serious injury. This time, she was charged with grievous bodily harm, the case went through the courts and she was placed under Section 37 in a specialist medium secure unit for people with learning disability. Her clinical diagnosis on admission was one of mild learning disability with significant impairment of behaviour (ICD-10 code F70.1), emotionally unstable personality disorder (ICD-10 code F60.3), recurrent depressive disorder, currently in remission (ICD-10 code F33.4) and harmful use of alcohol (ICD-10 code F10.1). Her treatment plan included diagnostic clarification, appropriate psychotropic medication, a psychological formulation and dialectical behaviour therapy adapted for people with learning disability, an occupational therapy-led life skills and education programme, nursing care, supervised community access and a graded transition into a supported living setting within the community through gradually reducing level of therapeutic security.

of learning disability only a small minority end up being formally charged, prosecuted or convicted. This means that the decision whether a person becomes a 'forensic patient' or not often depends on clinical judgements about risks and the attitudes of professionals working in the criminal justice system. These attitudes and decisions are inevitably shaped by the availability of resources. If less restrictive in-patient facilities are unavailable, either because they were shut down or not commissioned, these patients end up in far more restrictive forensic beds (R. Alexander & H. Boer, personal communication, 2013). There could hardly be a better demonstration of the law of unintended consequences. Similarly, an absence of appropriate step-down facilities including forensic rehabilitation beds, rehabilitation and continuing care beds and appropriate community placements can also result in patients remaining for longer periods than necessary in medium or low secure settings. It is therefore important to consider all in-patient beds, whether 'forensic' or 'non-forensic', as a whole while planning for future provision. Many patients in these beds have a mild learning disability and fall between the boundaries of 'mainstream' mental health and learning disability

services in the community – too disabled for one and too disordered for the other. Although admission to 'mainstream' forensic units may achieve the aim of equity of access, that achievement is meaningless in the absence of equity of outcome. A low IQ often excludes people from treatment programmes (Beech *et al*, 1998; Talbot, 2007). This happens not necessarily because these 'mainstream' forensic units are overcome by prejudice, but because for those with learning disability the treatment content needs to be delivered in a way that is appropriate for their developmental and intellectual level. Economies of scale, as well as availability of a critical mass of expertise may mean that these developmental-level specific treatment programmes are best delivered in specialised forensic learning disability units (Alexander *et al*, 2010).

Category 2: acute admission beds in specialist learning disability units, and category 3: acute admission beds provided within acute mental health wards or such wards with a specialist learning disability function

Both these categories of beds are intended for the assessment and treatment of severe mental health and/or behavioural problems, of an intensity which poses a risk that cannot be safely managed in a community setting, while not meeting the risk threshold to be considered for a forensic bed. Category 2 beds provide this function within the setting of a specialised learning disability unit (Box 3), whereas category 3 would do that within a generic or mainstream mental health ward setting (Box 4, p. 28).

The philosophy of normalisation that underpinned the move to community care emphasised that people with learning disability live their lives in a similar way to others in society (Bhaumik *et al*, 2011). In terms of in-patient care for mental health difficulties, the implication would be that they should access mainstream psychiatric services the same way as they would access generic services for physical health (Department of Health, 2001; Alexander *et al*, 2002; Chaplin, 2004, 2009; Cole & Gregory, 2004). The logical extension of that argument would be to say that there is no place for category 2 beds and anyone with a learning disability who needs in-patient treatment for mental health or behavioural difficulties should access category 3 beds in generic mental health wards. The clinical reality, informed not just by the views of clinicians, but also those of patients, their relatives and carers, is considerably different and much more nuanced.

There is a considerable amount of literature published over the past 20 years that has explored treatment outcomes from these two types of in-patient provision for assessment and treatment. The main studies are summarised in Appendix 1. This extensive evidence base has been well summarised in two elegant structured reviews (Chaplin, 2004, 2009); the first examined 24 studies and the second 28. The studies included were controlled trials or descriptive surveys drawn from the UK, the USA, Canada and Australia. The main conclusions can be summarised as:

- there is no conclusive evidence to favour either model (category 2 or category 3 beds)
- the two models serve different types of patients and this would partially explain the differences in length of stay

Box 3 Case vignette: category 2 typical patient story

Mark is a 33-year-old man with mild to moderate learning disability secondary to tuberous sclerosis, childhood autism and generalised epilepsy (well controlled on multiple anti-epileptic medications). He has a history of minor self-injury (head banging) and various challenging behaviours (e.g. property destruction and smearing faeces). Over the past 3 weeks, since a well-liked staff member left, the team at his supported home struggled to manage his increasingly difficult and aggressive behaviour. On the day of admission he was constantly crying and banging his head. He seemed more disoriented and did not respond to well-known staff. He frequently visited the toilet and at one time may have collapsed. In the evening he assaulted three people and required police intervention. After a Mental Health Act assessment he was admitted under Section 2. Assessment included physical examination with prompt physical health screening (urine dip test and microbiology, ultrasound scan of renal tract, computed tomography of the head) and observations for an adjustment disorder. He was managed with nursing support and minimal use of as required medication while a formulation was agreed. He required treatment for a urinary tract infection and his acute behaviours settled gradually. His other tests showed little change from scans performed some years ago. A health action plan was agreed to include longer-term specialist renal and neurological review. The speech therapist revised his communication passport for him and the occupational therapist completed a sensory processing assessment. He agreed to stay informally after 3 weeks, to further assess and manage his minor behaviour problems, and his Section 2 order was rescinded. After a further 4 weeks with his home staff working with him on the unit, he started to go out on leave to his home. After a total of 8 weeks he was discharged with an enhanced care package, action plans for future risk management and ongoing review by a community nurse and psychiatrist (who also managed his epilepsy).

- people with severe learning disability were not well served by generic services (category 3 beds)
- there was a worse outcome for people with learning disability in generic settings, particularly in the older studies; this could change once a specialist learning disability component was introduced into that generic setting
- generic psychiatric care is unpopular, especially with carers; this could be improved by specialist input
- the provision of general psychiatric care without specialist learning disability input is not sufficient to meet the needs of people with learning disability.

Patient and carer experiences submitted to us strongly reflect some of these points (Appendix 2) and consistently favour category 2 beds as opposed to category 3 beds. This could be due to several factors, which include: lack of expertise of staff in the assessment and management of mental health problems in people with learning disability; lack of availability of therapeutic approaches which are accessible and appropriate; and inappropriateness of the physical environment and patient mix on wards. It is important to stress, however, that category 2 beds are needed not merely because mainstream mental health units do not care or are prejudiced, or are staffed by people with no training. If these were the only issues, they

Box 4 Case vignette: category 3 typical patient story

Martha is a 34-year-old woman who lives at home with her mother and has mild learning disability and bipolar affective disorder. She is monitored by her care coordinator, who is employed by the learning disability services. However, she presented with symptoms of a manic relapse: irritability, elation, overspending, vulnerability and grandiose and persecutory delusions. Despite the support she was receiving, as well as treatment with lithium carbonate and olanzapine, her mental state deteriorated to the point that she needed admission for assessment under the Mental Health Act 1983. She was assessed by the psychiatrist from the learning disability team. A bed was found on the local acute general psychiatric admission unit where she was admitted following discussion with the general psychiatric consultant responsible for her sector. On admission, an assessment was made of her physical health needs in conjunction with her general practitioner, mother and care coordinator. Her communication and self-care needs were also assessed and staff from the community learning disability service gave advice to the in-patient staff on how to meet those needs. The general adult consultant assumed responsible clinician status during her in-patient stay but ward rounds were conducted jointly with her community learning disability consultant and care coordinator. Doses of her medication were optimised and she had periods of leave, initially accompanied by her care coordinator, as she started to recover. Prior to discharge she underwent assessment which involved her mother, care coordinator, learning disability psychiatrist, general adult psychiatrist, and in-patient nurse. She was discharged from section, returned home and was followed up by her care coordinator and the consultant psychiatrist in learning disability.

Adapted from Royal College of Psychiatrists, 2012.

could of course be put right by good governance and adequate training. Category 2 beds are needed because although the equity of access that a policy of mainstreaming brings is very pleasing, it is meaningless if not accompanied by equity of outcome. It has been suggested that 'equal' does not always mean 'the same' and that the 'reasonable adjustments' that are needed to make services equally accessible to people with learning disability are not particularly difficult to make (Department of Health, 2008). Being treated by specialists in the mental health of people with learning disability within settings that are particularly suitable for those with learning or developmental disadvantage is a reasonable adjustment that allows people with learning disability and mental health or behavioural difficulties to achieve the same equity of outcome as others with the same mental disorders. These beds therefore are not a reminder of inequality through segregation but a guarantor of equity through specialisation.

That is not to say that category 3 beds cannot deliver good outcomes for people with mild learning disability and mental illness. College report CR175 (Royal College of Psychiatrists, 2012) explains how this can be effective if there is substantial specialist support available from community learning disability teams to facilitate this.

Speaking in a different context, the comment has been made about how an insistence on treating everyone as equal when they are obviously unequal not only perpetuates inequality but also leads to injustice (BBC Radio 4, 2012). The same situation could happen for people with learning disability and mental health problems if they are all forced into mainstream mental health services regardless of their unique needs. There is the

lingering worry that the agenda of inclusion is merely being used as a means of disguising cuts to these specialist services which were crucial in delivering good and equitable outcomes for people with learning disability and mental health or behavioural difficulties in the first place (Cumella, 2010). We recommend that people with learning disability and mental health or behavioural problems and their families should have the choice to determine the most appropriate service for their needs.

Category 4: forensic rehabilitation and category 5: complex continuing care and rehabilitation

These two categories refer to in-patient provision for a number of patients whose mental health problems and behavioural difficulties remain intractable in spite of optimum treatment. These patients continue to need the structure, security and care offered by a hospital setting for long periods of time.

Category 4 is mostly people who have stepped down from forensic units with enduring issues of risky behaviours towards others or self (Box 5 and 6). Many of these patients have committed serious offences in the past and may sometimes be under restrictions from the Ministry of Justice. Although they have gone through offence-specific and other

Box 5 Case vignette: category 4 typical patient story (A)

John is 43 years old and has mild learning disability and a long history of behavioural difficulties, including physical and sexual aggression that started from late childhood and early adolescence. His victims included children of both genders as well as people with learning disability less able than him. After many incidents that did not result in prosecution he was, at the age of 30, convicted of a serious sexual offence against a child. He received a Section 37 order and spent 4 years in a high secure and 3 years in a medium secure hospital. He had one or two depressive episodes during this time but these were treated and he responded well.

After initial reluctance, he engaged in a range of therapies including the adapted sex offender treatment programme. Although his insight and behaviour within supervised settings improved, professionals involved in his care were unanimous that ongoing supervision was an integral part of his treatment plan, not least because his active sexual interest in children remained problematic. At the same time, it was felt that he could be in a less restrictive setting that guaranteed an adequate level of therapeutic input, albeit with less physical security. He was hence transferred from the medium secure unit to a locked rehabilitation setting. The treatment plan there included monitoring of his mental state, treatment of depression when relevant, nursing support, supportive therapy with a relapse prevention focus from psychology, regular supervised access to the community, an occupational therapy-led rehabilitation service and a voluntary work placement with staff supervision. Unescorted leave remains problematic; there were at least two incidents when he was the subject of complaints from members of the public, although it did not lead to prosecution. Psychology work continues to focus on these issues. He has been an in-patient in locked rehabilitation for 6 years and is still detained under the Mental Health Act.

Box 6 Case vignette: category 4 typical patient story (B)

> Robert is 21 years old and has a mild learning disability. He was charged with grievous bodily harm and was in prison on remand where he was vulnerable and suffered from low mood and suicidal ideation. Initially transferred to a low secure unit on remand, he later received a hospital order under Section 37. Robert engaged well with the therapy programmes in the low secure unit and after 18 months was transferred to a locked rehabilitation facility closer to his home.
>
> During his stay in locked rehabilitation, Robert's mental and physical health was monitored and work on his offending behaviour continued with psychology and nursing involvement. He enrolled in an education course and started a work placement in the community. He soon started having unescorted leave and developed a good relationship with his family. After a period of 1 year, he was discharged to the community. He lives in a flat with a support package. He continues with his work placement and has developed a good network of friends.

programmes, their current risk assessments still emphasise the need for robust external supervision and ongoing therapeutic input. Within a structured therapeutic environment provided by a category 4 bed, they are able to stay out of trouble with the law. They tend to have long durations of stay often running into years, but it is the availability of these beds, often in locked or open community units, that allows them to receive treatment in a less restrictive setting than a secure unit. It does appear that the need for continuous supervision for the protection of the public is the primary reason for their long hospital stay. This degree of supervision where a capacitous individual's right to access the community is rigidly controlled at all times by a supervising staff member would, under the current legislative framework, amount to a deprivation of liberty and hence be legally untenable. If there was a way of making this continuous supervision legally enforceable in the community without it amounting to the current standard for deprivation of liberty in capacitous individuals, then they could very well be managed outside hospitals. We recommend further legal or legislative scrutiny of this issue.

Category 5 is mostly for people who have undergone the initial intensive treatment process. Their diagnostic and psychological formulations are available and they have had access to a range of biopsychosocial treatments (Box 7). There are some who argue that there is no place for this continuing care category and that all these patients should be treated in the community. However, we suggest that these beds are required for a small number of patients because of a variety of reasons. This can include enduring mental illnesses not responsive to treatment, severe behavioural challenges that have not responded adequately to treatment approaches, ongoing risks arising from neglect or vulnerability and persisting risks to the safety of others similar to that posed by people in category 4 beds. Because of this, a safe transition into the community has not been possible even with adequately resourced community provisions.

The provision of a stable, structured and predictable environment with qualified staff who can continue to offer physical and psychosocial treatments that incorporate positive risk-taking offers the best quality of life. It is thus

Box 7 Case vignette: category 5 typical patient story

Linda is a 35-year-old woman with a moderate learning disability secondary to anoxic brain damage, limited speech, a recurrent depressive disorder and a range of challenging behaviours. During her school years, the challenging behaviours included pulling other students' hair, kicking, hitting out and scratching. This behaviour resulted in her being excluded several times. By her late teens, it appears that she developed an episodic depressive illness characterised by low mood, social withdrawal, weight loss and other somatic symptoms. Her parents, however, for whom she was an only daughter, appeared to manage her at home with minimal contact with health or social services.

By the time she was 23, Linda was having several of these episodes associated with aggressive acting-out behaviours. She was then referred to the learning disability psychiatry service. An additional stress factor at the time was her parents' decision to divorce. Her depressive disorder was treated with various psychotropic medications and she received input from the psychology team, but she remained unmanageable in the community and her mother with whom she stayed was increasingly unable to cope. Because of Linda's depression, agitation and periods of unpredictable, impulsive and severe aggression, she was admitted to the assessment and treatment unit (a category 2 bed). Assessments suggested that although some of her behaviour was related to the depression, a substantial part was an integral part of her communication style. She lacked the verbal ability to express her feelings and often relied on her behaviours to express them. In hospital, she had access to a range of psychological and behavioural interventions.

Several attempts were made to identify appropriate placements, however, service providers felt unable to cope with her challenging behaviours and she was promptly returned to the unit. Given the long-standing nature of her behaviours and the need for an environment which could provide ongoing treatment as well as re-skill her to live back in the community, she was transferred to the continuing care unit of the learning disability service (a category 5 bed). Within the stable environment of the facility it was possible to undertake a further review of her medication. She also received ongoing input from a speech and language therapist and occupational therapist, who were able to develop and contribute to behavioural management plans put forward by the psychologist.

On a combination of an antipsychotic, mood stabiliser and antidepressant medication along with the other interventions, there was a significant improvement in her mood and an overall reduction in her challenging behaviours. She began accessing the community with staff support and enjoyed going to clubs with other patients as a group accompanied by staff on an evening out. She benefitted from the stable and quieter environment of the unit where it was possible for her to engage with the multidisciplinary team, including art therapy and drama therapy. This period of stability meant that placements could be explored and providers were willing to offer suitable accommodation and staff support. The multidisciplinary team then worked with the staff from the residential home, ensuring that they were well equipped with the skills to manage both her vulnerability and behaviours. She was tried on an extended period of leave into the new placement and eventually discharged successfully.

a process of rehabilitation and re-skilling for a transition to community settings. This may, however, be at a pace these patients can cope with and therefore duration of stay tends to be long. If these beds were not available, the consequence could potentially be revolving-door patterns of hospital admissions to category 2 or 3 beds. Category 5 also includes a very small number of people with a significant learning disability, an autism spectrum disorder and a marked, violent sensitivity to the novel, unexpected or untoward. The management of this group requires a skilled, multidisciplinary staff group who are not only familiar with the person with autism spectrum disorder, but also have the training and skills to react non-intuitively in providing an unusually structured, predictable and consistent environment.

Category 4 and 5 beds are not unique to people with learning disability. The description of these beds closely mirrors the definition of the longer-term complex/continuing care units contained in *Defining Mental Health Services – Promoting Effective Commissioning and Supporting QIPP*, a recently published document from the NHS Confederation's Mental Health Network (NHS Confederation, 2012). The definitions in that document have been endorsed by a range of organisations including the Department of Health, Care Quality Commission, Audit Commission, ADASS, NHS Information Centre, Royal College of General Practitioners, Royal College of Psychiatrists, Royal College of Nursing and the mental health leads of strategic health authorities (NHS Confederation, 2012).

Arguably, the provision of relational and procedural security is more important than physical security for people with learning disability and hence many patients currently in forensic units, particularly in conditions of low security, could potentially move to the less restrictive rehabilitation beds (category 4 or 5). At present, this is problematic because the commissioning streams for forensic beds are different to those for all the other categories of hospital beds and the possibility of patients 'stepping down' creates financial pressures for local health commissioners. There is therefore a need for a wider regional commissioning of in-patient to community care pathways that will include all the six categories of in-patient beds. Service providers should be able to demonstrate clear evidence of ongoing therapeutic activity. This will include psychiatric input for monitoring of mental state and appropriate treatment, nursing care, availability of psychological support and therapy, an occupational therapy-led rehabilitation service, which may include educational and vocational opportunities, and supervised or independent access to the community on a regular basis. Although the patient may choose sometimes not to engage in these activities, these therapeutic activities should be available and accessible. It is this that will distinguish good in-patient facilities from those that are no more than 'settings of containment'. Relatives, carers, commissioners and regulating authorities should be able to monitor this through regular reviews.

There will have to be an acceptance, however, that not all patients move at a predetermined pace all the way through the care pathway. At all times, there should be demonstrable evidence that patients are in the least restrictive setting appropriate for their clinical state.

Category 6: other types of beds

This includes specialist beds for some neuropsychiatric conditions such as epilepsy and movement disorders. At present, this service provision is limited to a few, very specialised national units.

Numbers of beds and optimising their use

A striking feature is the different figures that are available for bed numbers in this area. Figures given by various sources may be different because of the variations in counting forensic and non-forensic beds or NHS and independent sector beds. The Winterbourne interim report from the Department of Health (2012*a*) states that there are 1252 assessment and treatment beds. It is not clear whether this includes all the non-forensic beds (i.e. categories 2–6). A survey of forensic learning disability beds (i.e. category 1) estimated that there were 48 high, 414 medium and 1356 low secure beds for people with learning disability in 2009 within the 10 strategic health authority regions of England (Alexander *et al*, 2011). It showed a very uneven distribution of these beds, with some regions not having any medium or low secure unit within its borders. These data included both NHS and independent sector beds. A more up-to-date comprehensive survey was undertaken as part of this report in 2012/2013 by the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists, acquiring data from NHS trusts and independent sector hospitals across all categories in the ten strategic health authority regions in England. The survey showed that there were about 3954 beds in England: 2393 category 1, 814 category 2, 622 categories 4/5 and 125 category 6 beds. A further breakdown of beds by NHS or independent sector and by region is detailed in Table 2. This includes some beds in specialist units designated as those for people with autism spectrum disorders. A separate survey of these units may give a more accurate number and the proportion of these beds occupied by people without a learning disability whose needs and presentations may be different. This figure includes all NHS and independent sector provision for forensic and non-forensic services and represents an over 90% reduction from a high of more than 33 000 NHS beds in 1987–1988.

The occupancy figure of the currently available beds, though difficult to elicit precisely, is estimated to be about 80%. This figure is in keeping with the best practice guidelines for bed occupancy within in-patient mental health settings (Royal College of Psychiatrists, 2011*b*). Thirteen years ago, research suggested that the total bed requirement (in all the 1–6 categories) was 14–29 per 100 000 population (Bailey & Cooper, 1997). Based on our survey and consultation, we would now estimate that the total bed requirement taking all six categories of in-patient beds together is only about 6 to 7 per 100 000. We must stress, however, that this figure is only intended as a broad guideline and may vary significantly based on local realities. In any case, this number represents a substantial reduction from before and has been possible because of significant improvements in community learning disability services and better working arrangements with generic mental health teams.

The total number of in-patient beds currently available across the six categories therefore represents an appropriate number. This is with due regard to clinical needs, government policies on risk management and current legislation. If the less restrictive in-patient facilities (categories 2–5) are cut down further, many more patients could end up in far more restrictive forensic beds (category 1).

There is scope for some people currently in category 1, 2 or 3 beds to move to less restrictive options within categories 4 and 5. The precise number of beds in each category therefore can vary depending on local factors and this should be a subject of discussion between patients, carers,

Table 2 Royal College of Psychiatrists, Faculty of Psychiatry of Intellectual Disability survey of in-patient beds (2012–2013)

	Category 1						Category 2		Categories 4 & 5				Category 6	
	High secure		Medium secure		Low secure		Acute admission beds		Forensic rehabilitation		Continuing care		Other	
Regions	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non NHS
North East	0	0	42		155	8	97		59	139		19		
North West	0	0	52	13	127	28	64	0	85	0	0	0	18	o
Yorkshire and Humber	0	0	32	88	44	142	73	0	0	15	14	76	0	0
East Midlands	48	0	0	150	16	189	46	0	0	0	19	0	48	0
West Midlands	0	0	15	0	71	123	69	60	16	0	25	0	53	0
Eastern	0	0	52	67	25	465	64	0	5	17	9	0	0	0
London	0	0	67	0	25	127	146	108	0	0	10	78	0	0
South East Coast	0	0		16		57	10							
South Central	0	0	10	0	28	71	52	0	9	0	14	0	6	0
South West	0	0	0	0	28	12	25	0	0	0	13	0	0	0
Total NHS/ independent sector	48	0	270	334	519	1222	646	168	174	171	104	173	125	0
Total		48		604		1741		814		345		277		125
Total in each category				2393				814			622			125
Total in-patient beds in England	3954													

NHS, National Health Service.

BT Mod 3 Witness Stmt 20 Mar 2023 PART 2 OF 9 Exhibit Bundle (1 of 8) (T01-T02) (pp195-2639 of 20966) (this part 2445 pages)

professionals, providers and commissioners in each area. However, not all patients may move at a predetermined pace all the way through the care pathway. The emphasis at all times has to be on the least restrictive setting that is clinically indicated at that point, with evidence of ongoing therapeutic input. This would be a better approach than the introduction of arbitrary time scales.

In-patient service provision should be as close to the person's place of residence as possible to facilitate the link with local community learning disability teams. Although arguments regarding economies of scale and the availability of a critical mass of professional expertise, particularly for category 1 beds, may hamper efforts to provide all categories of beds in every district, the emphasis should be on in-patient service provision as close to the person's place of residence as possible. We recommend that commissioning for in-patient services should therefore include all six categories of beds, be focused on care pathways from hospital to the community and may have to be regional (covering neighbouring health districts).

For a community learning disability team to function optimally, it is important to have the backup of these categories of in-patient provision. Whereas further development of community services in the form of intensive outreach services may reduce the use of in-patient beds, the numbers of such beds have now been reduced to a very low level. There is little evidence that in this situation any further reduction of bed usage can be achieved in a good service. The UK 700 study carried out in adult mental health services had suggested that those with borderline learning disability may require less in-patient provision if combined with intensive case management (Hassiotis *et al*, 1999, 2001). In the only randomised controlled trial of service provision that compared standard and assertive styles of community team functioning in learning disability (the latter characterised by more intensive professional input) (Oliver *et al*, 2005), there was little difference between the number of days of in-patient stay for patients in the two groups. Service planners need to consider the factors that affect the number of in-patient beds needed in a region. These include eligibility criteria for admissions to these units, types of intervention provided in these units, the role of community learning disability teams in the prevention of admissions and in facilitating discharges, and availability of specialised providers of community placements (with pro-active commissioning from health and Social Service commissioners).

Close monitoring and review of 'out-of-area' and indeed 'within-area' placements by health and local authorities is required, not just as a guarantee for preserving standards but also to tackle any issues around delayed discharges that may compromise the optimal use of in-patient beds. Discharge planning should start at the beginning of the admission with identification of a community care coordinator within the care programme approach framework. Health commissioners have an active role to play in liaising with their local authority counterparts to expedite this process.

The figures provided in Table 2 are best estimates submitted by the College's regional representatives. Some bed categories may have changed or may be incomplete. In many cases, it includes beds designated as those for specialist autism services.

This survey also showed that in Scotland there were an estimated 50 beds in category 1, 158 in categories 2 and 3, 44 in category 4 and 58 in category 5. In Northern Ireland there were 19 in category 1, 67 in categories 2 and 3, and 84 in category 5.

Monitoring standards and outcomes

In measuring service delivery, there are two key questions (Brugha & Lindsay, 1996). First, is the treatment carried out to an adequate standard as defined by current clinical practice? Second, does such treatment actually work?

Standards

Standard is defined as a level of quality or attainment. There are several standards available through various professional organisations, some of which are mentioned below. The evaluation of whether a service achieves a level of standard can be done through the process of audit.

For category 1 beds, the peer review accreditation process for forensic beds from the Royal College of Psychiatrists (2007*a*,*b*; Tucker *et al*, 2012) offers a set of standards that can be rated through peer review.

For category 2 and 3 beds, the Royal College of Psychiatrists published the second edition of AIMS-LD in November 2010 (Cresswell *et al*, 2010). That manual of standards was written primarily for non-forensic assessment and treatment beds for adults of working age with a learning disability, where the person is admitted for a short to medium term and is then discharged. These standards were drawn from a range of key documents from the National Institute for Health and Care Excellence and the Care Quality Commission, and were finalised after extensive discussions with a range of stakeholders including psychologists, psychiatrists, nurses, academics, regulators, commissioners, service users, carers, service managers, charities and interested individuals. The AIMS-LD has standards that cover five broad areas: general standards; timely and purposeful admission; safety; environment and facilities; and therapies and activities. To support the accreditation process, each standard has been categorised:

- 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 ward would be expected to meet
- type 3: standards that an excellent ward should meet.

This accreditation process is widely regarded as a gold standard and wards that are compliant with these standards could not conceivably be the settings of containment rather than personalised care that some fear assessment and treatment units may become.

For beds under category 4 the forensic peer review standards could apply and for those in category 5 and 6, the AIMS-LD standards could apply.

These accreditation standards cover the process variables within in-patient units and ensure that clinical practice will be in keeping with standards accepted by peers as appropriate.

Outcomes

Outcome is defined as an end result or consequence. In health services, it is a measure of what happens to the health of the patient as a result of the treatment and care they receive. Outcome measures need to relate to the three domains of quality: effectiveness, patient safety and patient experience (Department of Health, 2008). For category 1 or forensic beds, there were a total of two outcome studies from low (Day, 1988; Reed *et al*, 2004), four from medium (Halstead *et al*, 2001; Alexander *et al*, 2006, 2011; Gray *et al*, 2007) and two from high secure hospitals (Butwell *et al*, 2000; Morrissey *et al*, 2007). There have not been any from category 4 forensic rehabilitation beds, although some of the low and medium secure unit studies listed do talk about care pathways to rehabilitation. The most common outcome variable described was duration of stay. Others included direction of care pathway, institutional aggression, reoffending, reconviction and readmission to hospital. None of the outcome studies have looked at the cost of placements and this means that discourse about costs in this area is often based on anecdote and opinion rather than objective evidence. Based on this evidence, for categories 1 and 4, a minimum data-set of outcome measures that cover baseline measures and the domains of clinical effectiveness, patient safety and patient experience is set out in Table 3.

For bed categories 2, 3 and 5, there have been over 30 published studies that describe outcomes and some of them are listed in Appendix 1. In addition, the Royal College of Psychiatrists (2011*a*,*b*) has recommended the use of patient-identified goals, Health of the Nation Outcome Scales (HoNOS), physical health measures (e.g. blood pressure, body mass index), social outcomes (e.g. employment, accommodation, community engagement), symptom-specific scales, benchmarking incident reporting, suicide and self-harm rates, harm caused to others, in-patient safety measures and validated measures drawn up using patient and carer expertise. Based on this evidence, a minimum data-set of outcome measures that cover the domains of clinical effectiveness, patient safety and patient experience is set out in Table 4.

Table 3 Minimum data-set of outcome variables for in-patient beds in categories 1 and 4

Measures at baseline	
Essential	▪ Diagnoses on ICD-10 criteria or equivalent: include degree of learning disability, pervasive developmental and other developmental disorders, personality disorders, mental illnesses, substance misuse or dependence and physical disorders (Gray *et al*, 2007; Alexander *et al*, 2011) ▪ IQ score on WAIS–IV or equivalent (Wechsler, 2008) ▪ Coded forensic history: index offence, nature of detention, past convictions for offences of violence, sex, arson and other offences, history of aggression towards other people, property and self (Alexander *et al*, 2006, 2011; Gray *et al*, 2007) ▪ HoNOS secure score (Dickens *et al*, 2007)
Desirable	▪ PCL:SV score (Hart *et al*, 1995; Morrissey, 2003, 2007, 2011; Gray *et al*, 2007; Fitzgerald *et al*, 2011) ▪ HCR-20 (Webster *et al*, 1995; Gray *et al*, 2007; Fitzgerald *et al*, 2011) ▪ VRAG score (Gray *et al*, 2007; Quinsey *et al*, 2006; Fitzgerald *et al*, 2011) ▪ START score (Webster *et al*, 2004)
Measures of effectiveness	
Essential	▪ Global measures or measures of symptom severity: HoNOS secure, yearly and at discharge (Dickens *et al*, 2007) ▪ Progress measures: community leave status (no leave/escorted leave/unescorted leave) ▪ Progress measures: length of stay ▪ Progress measures: direction of care pathway (whether moved to a less restrictive setting)
Desirable	▪ Symptom-specific assessment scales (e.g. measures of anger, depression/anxiety, other psychopathology) ▪ HCR-20: yearly and at discharge ▪ START score: regular intervals (e.g. 2-monthly and at discharge) ▪ Clinical Global Impression (CGI) scale (Guy, 1976)
Measures of patient safety	
Essential	▪ Proxy measures of aggression: index of the number of restraints and seclusions (total number divided by length of stay) (Alexander *et al*, 2010) ▪ Proxy measures of self-injury/self-harm: index of the number of incidents (total number divided by length of stay) ▪ Number of alerts regarding patient safety ▪ Any 'never' incidents: escapes, suicide
Measures of patient experience	
Essential	▪ Evidence of patient participation in treatment planning: My Shared pathway (NHS Networks; Esan *et al*, 2012) ▪ Patient satisfaction surveys ▪ Evidence of carer/family participation in treatment
Desirable	▪ Measures of social climate: Essen Climate Evaluation Schema or equivalent (Schalast *et al*, 2008) ▪ Quality of Life measure: EQ-5D-3L or equivalent, yearly and at discharge (EuroQol Group, 1990)

Table 4 Minimum data-set of outcome variables for in-patient beds in categories 2, 3 and 5

Measures at baseline	
Essential	▪ Comorbid diagnoses on ICD-10 criteria or equivalent: include degree of learning disability, pervasive developmental and other developmental disorders, personality disorders, mental illnesses, substance misuse or dependence and physical disorders ▪ IQ score on WAIS–IV or equivalent (Wechsler, 2008) ▪ HoNOS learning disability score
Desirable	▪ Measure of symptom severity using TAG (Slade *et al*, 2000), Reiss Screen Test (Reiss, 1988), PIMRA (Matson, 1988), PASADD checklist (Moss *et al*, 1998), MOAS (Oliver *et al*, 2007) and symptom-specific assessment scales (e.g. measures of anger, depression/anxiety, other psychopathology)
Measures of effectiveness	
Essential	▪ Global measures or measures of symptom severity: HoNOS learning disability, on admission, discharge and at regular intervals ▪ Progress measures: community leave status (no leave/escorted leave/unescorted leave) ▪ Progress measures: length of stay ▪ Progress measures: direction of care pathway (whether moved to a less restrictive setting)
Desirable	▪ Measure of symptom severity using TAG, Reiss Screen Test, PIMRA, PASADD checklist, MOAS and symptom-specific assessment scales (e.g. measures of anger, depression/anxiety, other psychopathology). ▪ CGI scale
Measures of patient safety	
Essential	▪ Proxy measures of aggression: index of the number of restraints and seclusions (number divided by length of stay) ▪ Proxy measures of self-injury/self-harm: index of the number of incidents (number divided by length of stay) ▪ Number of alerts regarding patient safety ▪ Any 'never incident' (e.g. suicide)
Measures of patient experience	
Essential	▪ Evidence of patient participation in treatment planning ▪ Evidence of community participation: education, work experience and leisure ▪ Patient satisfaction surveys ▪ Evidence of carer/family participation in treatment
Desirable	▪ Measures of social climate: Essen Climate Evaluation Schema or equivalent (Schalast *et al*, 2008) ▪ Quality of Life measure: EQ-5D-3L or equivalent, yearly and at discharge (EuroQol Group, 1990)

Appendix 1. Studies describing acute admission units (category 2 and 3 beds)

Study	Sample	Measures used	Comments
Hurst *et al*, 1994	■ 157 patients (97 male, 60 female) ■ Age on admission: range 15–63 years, mean 30	■ Level of disability according to DSM criteria ■ Primary psychiatric diagnosis ■ Length of stay ■ Whether the patient was readmitted	■ Category 2 beds ■ Case-note review, testing treatment effectiveness for the dually diagnosed ■ Outcomes are more unfavourable in patients with borderline learning disability as they resent this type of placement or those with pervasive developmental disorder ■ Median length of stay 68 days (94% returned to the community, with the remainder returning to the psychiatric hospital which had originally referred them; 37% were readmitted, of whom 62% had one readmission and the remainder had multiple readmissions) ■ Patients with learning disability respond well to treatment in an environment which is attuned to their level of communication skill
Singh *et al*, 1994	■ 11 patients (5 male, 6 female) ■ Average age 38 years	■ Demographic data ■ Length of stay ■ Reason for admission ■ Past psychiatric care ■ Level of handicap ■ DSM diagnosis and treatment ■ Other social factors deemed important to note at admission	■ Category 3 beds ■ A description of the first 18 months of the Hillingdon district service where admission facilities for people with dual diagnosis were made available on a general psychiatric ward ■ Case-note analysis ■ Average length of stay was 8 weeks; longer admissions which are appropriate for this client group are less likely to be tolerated on a general psychiatric ward ■ There was a trend in individuals with major psychiatric illness for the illness to become more chronic ■ Learning disability admissions to a general psychiatric ward are problematic for a number of reasons. Lack of staff training and experience. Occupational therapy may not be developmentally appropriate for this client group ■ It is doubtful whether this model of treatment can work
Raitasuo *et al*, 1999	■ 40 in-patients staying in a specialist psychiatric unit in Finland	■ Brief Psychiatric Rating Scale (BPRS) ■ Diagnostic Assessment for the Severely Handicapped (DASH) scale ■ Visual Analogue Scale (VAS) – patients and their primary carers were asked to independently estimate the patient's psychiatric state ■ Living place at discharge evaluated in order of most supportive to least supportive	■ Category 2 beds ■ Study describes the psychiatric in-patient treatment ('need-adapted treatment' – individually tailored treatment plans) of those with dual diagnosis in a specialist psychiatric unit ■ Patients' psychotic symptoms improved greatly on the BPRS during their in-patient stay, but not during aftercare ■ 4 patients' psychiatric symptoms were recorded on the DASH scale, 1 of the patients' symptoms were significantly reduced and 3 patients' symptoms remained the same ■ Patients and their primary carers considered their condition to have improved significantly during their in-patient stay ■ Living place at discharge: 33 patients' living arrangements were the same at admission and at discharge, 3 needed a less supportive placement and 4 a more supportive placement ■ The mean treatment time in the unit was 2.91 months (range 0.16–12.3, s.d.=3.35)

Alexander *et al*, 2001	■ 56 in-patient admissions to Hillingdon and Westminster over 3 years (63% *v.* 59% male respectively) ■ Mean age, years: Hillingdon 24, Westminster 32	■ Length of stay ■ ICD-10 diagnostic categories were used throughout ■ Level of learning disability ■ Demographic data	■ Comparison of category 2 and category 3 beds in two London districts ■ Retrospective case notes-based survey – a descriptive comparison of the sociodemographic and clinical variables of 3 years of in-patient admissions in Hillingdon and Westminster ■ Mean length of stay was 369 days in the specialist learning disability unit and 79 days in the general psychiatry ward ■ The only significant predictor variable for the duration of stay was residential status at the time of admission (those from residential homes tend to stay longer) ■ Difficulty in discharging back to the same place as that at time of admission would predict 'new long-stay'
Tajuddin *et al*, 2004	■ 72 individuals (49 male, 23 female) ■ Age: range 18–63 years, mean 34	■ Demographic information ■ Diagnoses/severity of learning disability ■ Length of stay ■ Readmission ■ Residence before and after admission ■ Reiss Screen for Maladaptive Behaviour before and after admission ■ Individual clinical outcomes	■ Category 2 beds ■ Aimed to evaluate the use of the acute specialist in-patient unit for adults with dual diagnosis: retrospective case-note review of all admissions over 2 years ■ Mean length of stay was 70.8 days (range 2–215) ■ Long-stay patients were more likely to be males with mild learning disability and a primary diagnosis of schizophrenia, behaviour disorder or personality disorder ■ 22% of the individuals were admitted on more than one occasion (69% of this group had a behaviour disorder or a personality disorder) ■ Significant reduction on the Reiss score suggests an improvement in overall patient presentation ■ 76% of patients were successfully treated and discharged to their original residence; on 22 occasions patients had to be discharged elsewhere as their initial placements were unwilling to accept them back
Xentidis *et al*, 2004	■ 84 admissions recorded in time period studied (36 male, 48 female): 39 in specialist unit, 45 in generic settings ■ Age: mean 34.55 years	■ Key variables of gender, age, ethnic group, presence of autism, epilepsy ■ Primary psychiatric diagnosis ■ Length of stay ■ Readmissions ■ Level of learning disability ■ Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) checklist ■ Global Assessment of Functioning (GAF) Scales ■ Disability Assessment Scale (behavioural functioning) ■ Threshold Assessment Grid (TAG)	■ Comparison of category 2 and category 3 beds ■ The study aimed to describe the patient characteristics and treatment outcomes of patients admitted to the specialist unit using standardised measures; admissions to the specialised unit are also compared with admissions to generic psychiatric wards ■ No significant differences in key variables between the admissions ■ Readmission rates were similar in both groups: 5 patients in the specialist group were readmitted twice, in the generic group 3 patients were admitted twice, 1 patient had 3 admissions and 1 patient was readmitted 4 times ■ Highly significant difference in that length of stay was much longer for patients in the specialist unit (mean 23.2 weeks, s.d.=14.1; in the generic group mean 11.1 weeks, s.d.=13.6) ■ Statistical differences were yielded on all four measures of treatment outcomes: TAG score halved; significant reduction in severity of mental health problems; GAF score almost doubled, indicating an increase in overall level of functioning; PAS-ADD symptoms were reduced by almost half ■ Significant improvements were demonstrated within the specialist unit cohort; specialist units are an effective care option for this patient group

Hall *et al*, 2006	▪ 37 participants from 50 eligible patients	▪ Assessment of psychiatric symptoms ▪ Risk ▪ Needs ▪ Level of functioning	▪ Category 2 beds and community patients ▪ Community and in-patient groups were compared across three time points using a range of clinical outcome measures that assessed psychiatric symptoms, risk, needs and level of functioning ▪ In-patients and community groups had similar mental health problems, however, patients living in an in-patient setting had higher unmet needs, lower functioning and were also higher risk ▪ There were significant improvements across the range of outcome measures in both groups ▪ Effective mental healthcare for people with learning disability is provided when learning disability, social care and mental health services work collaboratively
Seager *et al*, 2000	▪ 154 people with learning disability		▪ Category 2 beds ▪ People with learning disability who were discharged from hospital to community care were studied (using information from care staff and case notes) with a view to establishing the number of readmissions and exploring the reasons for these ▪ A readmission rate of 8.4% was found, which was broadly in line with previous studies in this area ▪ Severe problem behaviour was a prominent reason for hospital readmission, with physical aggression to staff and peers a factor in each of these cases ▪ Relapsing mental illness was thought to be a factor in a number of the admissions precipitated by physical aggression ▪ Physical deterioration featured highly as a cause of readmission to the learning disability hospitals, demonstrating their continuing role in providing physical healthcare for a group of patients who were not being provided for by generic services
Kent & Bird, 1994	▪ 20 young people with learning disability (14 male, 6 female) ▪ Age: mean 23.50 years, range 17–34	▪ Level of intellectual functioning as assessed by the WAIS-R or WISC-R ▪ Adaptive Behaviour Scale (ABS) ▪ Length of stay ▪ Severity of challenging behaviour ▪ 3 questionnaires designed specifically for this project measuring characteristics (Q1), characteristics of follow-up placement (Q2) and patient and carer feelings towards the placement (Q3, more qualitative)	▪ A pilot follow-up study of a behavioural programme for 20 young people with learning disability and challenging behaviour; the study was designed to identify behavioural problems which can most successfully be addressed in this type of unit, and to provide outcome measures ▪ Between admission and discharge 18 out of 20 participants had increased their adaptive points by a mean of 40; of these, 9 had continued to improve at follow-up, 1 showed no change and 6 had decreased slightly; 2 participants' scores had decreased by 37 and 40 points, taking their adaptive scores to lower than before admission ▪ Between admission and discharge 18 out of 20 participants had made good progress with regard to their challenging behaviour; 7 of the 13 who displayed self-injurious behaviour had improved significantly ▪ Participants were divided into two groups: the good-outcome group and the poor-outcome group; those in the good-outcome group were: younger on admission, scored lower on adaptive skills and higher on challenging behaviours; they had remained on the treatment programme for 12–18 months and had been discharged from the unit for longer

Kent & Bird, 1994 cont.			■ The overall level of independent living had increased from pre-admission and the majority of patients were living in a less restrictive placement ■ Length of stay on the treatment programme was 3–66 months (mean 20.30); 10 young people moved to the rehabilitation unit for 3–28 months (mean 14.30) ■ Minimum of 5 months' follow-up
Trower *et al*, 1998	■ 113 new admissions into a specialist in-patient unit over a 2-year period, accounted for by 80 individuals (52 male, 28 female) ■ Age: mean 33.5 years, range 18–66	■ Demographic data ■ Level of learning disability ■ Duration of admission ■ Section/informal admission ■ Seclusion episodes ■ Residency before and after discharge ■ ICD-10 psychiatric or behavioural disorder was also ascertained with the clinically responsible consultant ■ Presence of active epilepsy also recorded	■ Category 2 beds ■ Case-note analysis evaluating the use of an acute admission unit over a 2-year period ■ Generic mental health services are mostly accessed by patients with mild learning disability ■ Mean duration of stay was 46.6 days (range 2–194); 4 had been in-patients for more than 1 year and could be described as 'new long-stay' – this study's findings suggest that such an outcome is not inevitable ■ Most individuals were discharged back to the residence they were from, only a minority had to be found alternative accommodation, for a variety of reasons ■ Findings suggest that a specialised in-patient unit is able to meet the needs of those adults with a learning disability and a psychiatric problem who need short-term in-patient assessment and treatment; the authors argue that the expertise of the multidisciplinary care team makes the specialist unit the treatment of choice for learning disability patients
Clare & Murphy, 1993	■ 6 patients who had left the mental impairment evaluation and treatment service	■ American Association for Mental Deficiency (AAMD) Adaptive Behaviour Scale (ABS) ■ Vineland Social Maturity Scale ■ Client's quality of care prior to entering the service established via staff interviews ■ Client's quality of life during receipt of the service established using the Residents' Opinions Schedule	■ Category 2 beds ■ Between entering and leaving, all 6 patients had made gains in their level of skills and social functioning; 5 had also reduced their challenging behaviours for which referral had been sought ■ All were living in less restrictive residential facilities than when they had entered
Chaplin, 2004	■ Review article	■ Literature review using a variety of electronic sources plus hand-searching to identify all studies which evaluate the outcomes of people with learning disability and mental illness using general psychiatric services	■ Although 27 studies were located, only 2 were of randomised controlled trials; the evidence is poor quality and therefore further service evaluation is necessary to provide more robust evidence as to which services are preferred ■ Results referred to: general *v*. specialised services, novel intervention *v*. standard treatments, home-based treatments, people with learning disability *v*. people without learning disability and other methodologies ■ No conclusive evidence to favour the use of general or specialist psychiatric services

Chaplin, 2009	■ Review article	■ Literature review aiming to establish differences in treatment outcomes for patients with learning disability and mental disorders treated in general or specialised learning disability mental health services ■ Conducted using electronic databases and websites of learning disability and mental healthcare	■ People with learning disability, particularly severe, have reduced access to general psychiatric services ■ Generic services are unpopular, particularly with carers, however, services can be improved by providing trained staff and in-reach from community teams ■ Hall *et al* (2006*a*,*b*) describe a service in which people with learning disability were admitted to beds on a general psychiatric ward with a specialised learning disability function and cared for by nurses who have received learning disability training ■ General psychiatric services without help are not sufficient to meet the needs of people with learning disability
Bouras & Holt, 2004	■ Review article		■ The specialisation of mental health services for people with learning disability, provided by mainstream mental health services at a tertiary care level, offers a way forward
Burge *et al*, 2002	■ 62 individuals with developmental disabilities	■ Non-parametric statistics were used to compare the median length of stay between the two samples ■ Associations between length of stay and other covariates were explored within the sample of patient admissions with learning disability	■ Category 3 beds ■ A retrospective chart review on all individuals with developmental disabilities who were psychiatric in-patients at a Canadian general psychiatric hospital over a 4-year period (1994–1998); a comparison sample of admissions of patients without learning disability was chosen ■ When individuals with learning disability are psychiatric in-patients, their length of stay is affected by some factors that have been identified in previous studies not specific to learning disability (e.g. referral source and diagnosis) ■ Male patients with learning disability have longer lengths of stay than do female patients in the same sample
Gustafsson, 1997	■ The study sampled adult people with learning disability receiving special services and admitted to in-patient psychiatric care in one Swedish county		■ Category 2 and 3 beds ■ The results show a low frequency of psychiatric care utilisation among people with learning disability and coexisting psychiatric disorders in comparison with the proportion of psychiatric care utilisation among people with psychiatric disorders in the general population ■ The results are discussed in terms of how the level of learning disability might influence referral or diagnosis, the length of admissions, and the support provided within the special services to people with learning disability and psychiatric disorders
Hall *et al*, 2006*a*	■ 37 participants	■ Global Assessment of Functioning (GAF) ■ Mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Mini PAS-ADD)	■ Category 3 beds ■ In-patients and community groups had similar mental health problems, but in-patients had higher unmet needs and lower functioning, and were at greater risk ■ There were significant improvements across the range of outcome measures in both groups

Hall *et al*, 2006*a* cont.		■ Threshold Assessment Grid (TAG) ■ Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD) ■ Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities short version (CANDID-s)	■ Working with mainstream mental health services and across health and social service boundaries delivers effective mental healthcare for people with learning disability. A specialised learning disability input into the ward was necessary
Lyall & Kelly, 2007	■ 348 admission episodes	■ To examine the use of specialist psychiatric beds for people with learning disability, created following the closure of a long-stay institution ■ Admission and discharge data were examined, including history of previous institutional admission, diagnosis at discharge and number of subsequent readmissions	■ Category 2 beds ■ Out of 348 admission episodes, 59 were accounted for by 40 patients who were previously resident in the long-stay institution; most admissions were for new patients from the community ■ Over time, admissions to the specialist unit decreased when occupancy reached and persisted at 100%, coinciding with a significant rise in admissions of adults with learning disability to general adult psychiatric wards ■ Resettlement after closure of long-stay learning disability institutions has not been accompanied by a high readmission rate for former residents, but neither has there been a decreasing need for psychiatric beds for those with learning disability and severe psychiatric disturbance ■ Most of these admissions are for people with learning disability who are relatively new to the service ■ There has been a persistent problem with full occupancy of these beds, which reflects delayed discharges indicating a lack of community resources and an increasing demand for admission
Mackenzie-Davies & Mansell, 2007	■ 333 people from 38 units	■ A questionnaire was sent to all NHS trusts that had learning disability in-patient beds, and all private or voluntary healthcare establishments providing services for people with mental health problems or learning disability; it asked for information about the unit, its residents and the views of the unit manager	■ Questionnaire study that targeted category 2 beds ■ 44 agencies confirmed that they provided assessment and treatment units, of which 38 returned questionnaires ■ These units served 333 people of whom 75% had mild or moderate learning disability; a quarter had been in the units more than 2 years; 40% of residents had a discharge plan and 20% had this and the type of placement considered ideal for them in their home area ■ The main strengths of the units were identified as the knowledge and experience of the staff and having sufficient staff; the main problems as inappropriate admissions, bed-blocking and the relationship with other services, difficulties with recruiting and retaining staff, the location and environment of the unit and the mix of residents ■ There has been an increasing rate of provision of special units, which now predominantly serve people with moderate or mild learning disability; this model of service provision is becoming more widespread but the potential problems are still present ■ Areas are identified for further research

Nawab & Findlay, 2008	■ 130 admissions over a 6-year period	■ Cases were identified using the ward admission register and Patient Information Management System (PIMS) ■ Demographic data ■ Admission and discharge processes ■ Length of stay ■ Diagnosis (recorded in case notes)	■ Category 2 beds ■ There is a need for a small number of specialist assessment and treatment beds for those with a learning disability; it is up to services (healthcare, social care, justice and carer organisations) to coordinate their expertise to ensure that individuals' needs are appropriately met and that they do not remain in-patients after their need for this level of care has diminished ■ Joint protocols, robust risk assessments and interagency working recommended
Ashaye *et al*, 1997	■ 26 long-stay elderly patients in a psychogeriatric ward *v*. 23 long-stay patients with learning disability aged 65+ and 40 long-stay patients with learning disability aged 50–65 years	■ HoNOS	■ On the HoNOS, the elderly psychiatric patients scored significantly higher for problems with mood, relationships and occupation/activities. There were no significant differences for any of the scales rated between the 50- to 65-year-old and >65-year-old patients with learning disability ■ The similarities between the three groups of patients would suggest that for some patients the same services may be utilised; this could reduce the cost of the care in the community and entail more economical use of the facilities and staff ■ The HoNOS proved to be a concise and simple instrument, which could become a useful tool in monitoring the outcome of healthcare in long-stay patients
Chan *et al*, 2004	■ 2 case studies		■ The case studies illustrate the difficulties in accessing mental health services for this 'invisible' group of individuals with learning disability, and demonstrate the gaps in service delivery and clinical practice ■ The paper argues that mental health concerns should be considered when challenging behaviours are present in persons with learning disability
Cowley *et al*, 2005	■ 752 adults		■ Category 2 beds ■ Predictors of admission for a cohort of 752 adults living in community settings; 83 were admitted ■ Schizophrenia spectrum disorders and mild learning disability independently predicted admission for the total cohort ■ The presence of symptoms associated with psychosis and the presence of physical aggression predicted admission in the subsamples
Driessen *et al*, 1997		■ Determinants of (1) referral to psychiatric services and (2) the amount of mental healthcare consumed were analysed in a population of individuals with learning disability, using data from a cumulative mental health case register in a defined geographical area	■ Category 2 and 3 beds ■ Associations between level of disability, gender, age and social environment on the one hand, and psychiatric referral and service consumption on the other were expressed as odds ratios (ORs) ■ Being older (OR=1.9, 95% CI 1.5–2.5), having milder learning disability (OR=1.4, 95% CI 0.9–2.3) and living alone (OR=5.8, 95% CI 2.8–11.9) predicted a higher probability of receiving psychiatric treatment ■ Living alone (OR=15.3, 95% CI 1.7–136.1) was also associated with higher level of mental health service consumption

Gustafsson, & Sonnander, 2004	■ Samples from two Swedish counties	■ The Reiss Screen for Maladaptive Behaviour ■ Psychopathology Inventory for Mentally Retarded Adults	■ The overall occurrence of mental health problems in adults with learning disability ranged from 34 to 64% ■ The most common mental health problems were aggressive, self-injurious behaviours, signs of depression, anxiety or adjustment problems ■ The occurrence of adults with learning disability among patients receiving out- or in-patient psychiatric care was approximately 1%; between 70 and 90% of these persons had a mild level of learning disability ■ The overall occurrence of mental health problems was similar to reported overall figures in comparable studies conducted in the USA, the UK and Denmark. The number of adults with learning disability registered for out- or in-patient psychiatric care was low compared with the occurrence of mental health problems based on the screening results
Holden & Neff, 2000	■ 28 adults with mental retardation and severe psychiatric disorder		■ Category 3 beds ■ The impact of intensive out-patient mental health interventions (in a dual-diagnosis clinic) on the hospitalisation rate and length of stay was examined for 28 adults with mental retardation and severe psychiatric disorder; they were selected on the basis of frequent use of mental, medical and social services ■ Charts were reviewed for the 12-month periods before and after referral to the programme to compare service utilisation; a single group pre- and post-test design with no control group was employed ■ Correlated *t*-tests comparing the pre- and post-program number of hospitalisations and lengths of stay indicated significant decreases in both hospitalisations and lengths of stay after programme entry, which may result in significant reductions in hospital costs
Lohrer *et al*, 2002	■ 64 people with dual diagnosis		■ Category 3 beds ■ Anecdotal reports suggest that persons with a dual diagnosis (mental retardation and psychiatric illness) admitted to acute psychiatric hospitals stay longer and require more services than individuals without mental retardation. To test these hypotheses, a questionnaire was completed for 64 people with dual diagnosis admitted to 10 psychiatric hospitals over 3 months ■ Multivariate analysis revealed that a diagnosis of mental retardation was not a predictor of length of stay. Use of 1:1 staffing was more likely, whereas arrangement of different community placement at discharge was less likely for persons with than without dual diagnosis. Additionally, age, diagnosis, symptomatology, living arrangements, insurance status and service use distinguished the patient groups. Implications are discussed in the context of a need for further examination and training focused towards this population

Metcalfe *et al*, 2005	▪ Patients with severe psychosis were randomly allocated to intensive case management (ICM) or standard case management. For each patient group with complex needs the effect of ICM is compared with that in the rest of the cohort	▪ The UK700 trial failed to demonstrate an overall benefit of ICM in patients with severe psychotic illness. This does not discount a benefit for particular subgroups, and evidence of a benefit of ICM for patients of borderline intelligence (NART error score of 40 or above) has been presented. The aim of this study is to investigate whether this effect is part of a general benefit for patients with severe psychosis complicated by additional needs. Outcome measures are days spent in psychiatric hospital and the admission and discharge rates ▪ ICM may be of benefit to patients with severe psychosis complicated by borderline intelligence or depression, but may cause patients using illicit drugs to spend more time in hospital. There was no convincing evidence of an effect of ICM in a further seven patient groups. ICM is not of general benefit to patients with severe psychosis complicated by additional needs. The benefit of ICM for patients with borderline intelligence is an isolated effect which should be interpreted cautiously until further data are available
Patterson *et al*, 1995	▪ Patients with learning disability and mental illness who were admitted to a state hospital. Exact numbers not available	▪ Category 3 beds ▪ Clients with developmental disability and a concomitant mental illness are often underserved or inappropriately treated because of interorganisational barriers, leading to unnecessary hospitalisation and lengthy delays in community placement. To overcome these barriers, agencies responsible for developmental disabilities and mental health services in Spokane County in Washington State developed a collaborative system of care in 1989. An interagency consortium was established to promote coordination of services between the community mental health centre, the state hospital, the county human services agency, the state's regional developmental disability service agency, the state institution for the people with developmental disability, and several community agencies serving this group of patients ▪ Between 1990 and 1992, admissions of persons with developmental disability to the state hospital were more likely to be appropriate admissions of persons with a mental illness, patients were discharged more efficiently, and crisis respite services were used in place of hospitalisation. In addition, anecdotal reports indicated a reduction of interagency tensions
Lunsky *et al*, 2006	▪ Secondary analysis of data from the 1999–2003 Colorado Client Assessment Record (CCAR), and all tertiary psychiatric hospitals in Ontario, Canada	▪ Category 3 beds ▪ Patients with both mental retardation and a psychiatric diagnosis differed from those who did not have mental retardation in terms of demographic characteristics, diagnostic and symptom profile, resources and recommended level of care. More specifically, patients with both mental retardation and a psychiatric diagnosis had significantly worse ratings across nearly all CCAR functional domains and were assessed as requiring more than the recommended levels of care compared with other patients

Lunsky *et al*, 2006 cont.	■ Random sample of 3927 cases, representing 12470 patients receiving psychiatric services	■ Patients who have both mental retardation and a psychiatric diagnosis constitute a sizeable subgroup of an already underserved psychiatric hospital population. Greater attention is required to meet the unique clinical and service needs of this challenging group
Saeed *et al*, 2003	■ All psychiatric admissions of people with developmental disabilities over a 5-year period were selected (*n*=294), and were compared using survival analysis to a random sample of admissions from the general psychiatric population (*n*=287)	■ Category 3 beds ■ This study investigated associations between the presence of developmental disabilities and length of in-patient stay for mental healthcare ■ Overall, people with developmental disabilities stayed in hospital longer than those without developmental disabilities, and this extra stay was partially attributed to case-mix differences between the cohorts. Sub-analysis in both cohorts showed that those going back to their usual living arrangement stayed a shorter period than those who were discharged elsewhere, and that people with developmental disabilities were less likely to be discharged to their usual living arrangement than were people without the disability ■ This study highlighted the importance of specialised residential and personal supports for people with developmental disabilities and a coexisting mental disorder
Lunsky *et al*, 2011	■ 246 out-patients identified as having learning disability, from both specialised and general programmes	■ Category 2 and 3 beds ■ Individuals with learning disability in specialised programmes differed from patients with learning disability in general programmes with regard to demographics, diagnostic profile, symptom presentation and recommended level of care. Further research is required to determine why individuals access some services over others

Appendix 2. Service user and carer testimonies

Mrs J, parent of a son with learning disability and mental health problems:

'I am a carer for my son who has learning disability and mental health problems. I strongly support the need for specialised in-patient services for people with learning disability and mental health problems.

My experience of specialist in-patient learning disability services has been positive. Staff are available when needed and they understand people with learning disabilities. The environment is also structured for the needs for people with learning disability. I felt confident that learning disability staff could care for my son and they were able to respond to his individual needs. I was able to speak to my son at any time over the phone and the staff always actioned anything they said they were going to do.

My son, himself, has never had any complaints about the services he received. Therapy staff were always available and my son looked forward to seeing other people and enjoyed the social side of things.

I have also had experience of my son accessing adult mental health services and accident and emergency department where my experience was not good. I felt that staff in generic services did not understand my son's needs and it was frightening for me and my son and the general public present in these places. It was an experience that I hope that I never have to go through again.'

Mrs P, carer:

'I am a paid carer for people with learning disability and mental health problems.

I have had several of my residents who have accessed specialist learning disability in-patient services over the years. I feel that staff working in learning disability services have specialist expertise to meet the needs of people with learning disabilities and mental health problems. The staff are welcoming and person-centred.

The admission process is good and the paperwork is always in place and there is a named nurse who is contactable. There is always a calm

feeling about the learning disability in-patient unit even if it is noisy. It has a good layout, and there are visitor rooms and there is excellent communication between staff and carers.

One of the strong points is the availability of therapy staff who engage very well with the patients. The in-patient and community teams liaise with each other for a smooth discharge from the in-patient unit. Staff and doctors have a very good rapport with patients and I would prefer the learning disability in-patient unit to the adult mental health unit for my residents.

I have also had experience of my residents being admitted to generic services where the environment is very busy and chaotic. There are no rooms available to discuss the patient's problems in private. I feel that generic staff do not have an understanding with people with learning disability and their needs. There was no therapy available in generic service, and there was poor communication between the staff and carers with regard to the patient's admission and discharge process. I have also had experience of patients being sent on home leave before it was checked whether it was safe to do so. I personally feel that generic services could learn a lot from learning disability in-patient services.'

FS, SERVICE USER:

'My name is FS. I have learning disabilities and mental health problems. I have received support and help from the learning disability service for many years and I have been admitted to the learning disability in-patient unit and also to adult mental health units in the past. I feel that learning disability in-patient units are better suited to me when I am unwell and need to be admitted to hospital.

I get admitted to get better. This is because I find it difficult to cope at home sometimes. When I am in the learning disability in-patient unit I have people to talk to and I feel safe. When I have been admitted to other mental health units in the past I have felt vulnerable from other patients who pick on me.

Staff on other mental health units do not spend much time with me and the environment is also noisy and very busy. The chairs and beds are nailed to the floor and there are no wardrobes or cupboards in the room. I feel even if staff do spend more time with me and even if the environment is much better, other patients will still pick on me on mental health wards. This is why I prefer to be admitted to a learning disability in-patient unit if I become unwell.'

MRS CAROL TILLEY, CARER:

'My son has now been an in-patient at the learning disability assessment and treatment unit for 15 weeks and I would like to tell you how very different this experience has been for both my son and myself compared with his previous experience as an in-patient in an assessment ward in a psychiatric hospital.

My son is 37 years of age. He was born with a learning disability and Asperger syndrome and over the years has experienced depression,

anxiety, psychotic depression, catatonia, and more recently been diagnosed with bipolar disorder. In October 2010, he was admitted to our local psychiatric hospital for assessment following the onset of catatonia and psychotic depression. At this time he was an extremely unwell, vulnerable person and his family were very concerned that the assessment ward in a general mixed psychiatric centre would be the wrong environment for him. Our fears were justified when it became clear that although staff did their best to support him, they were having difficulties because they had very little knowledge of, or training in, learning disability. This lack of knowledge and experience extended to the consultant psychiatrist and the ward manager. They were all in difficulty.

The family tried very hard to locate somewhere more suitable for him and although we did identify a specialist centre, we were unable to get the local authority to agree to work with us to improve his hospital placement. After a very difficult period, he was discharged to my care. By March 2011, he was able to take up his normal life again and we hoped that all would be well. However, we remained very concerned that if his mental health was to break down again, there would not be any suitable provision available to help him as a person with learning disability and mental health problems.

Towards the end of 2011 my son's mental health was causing concern and by mid-January 2012 he needed hospitalisation. This time it was suggested by his psychiatrist that a specialist learning disability assessment and treatment unit would be more appropriate for his care and treatment and I visited the centre to learn more about it. I was reassured straight away by meeting the manager, who spent time with me outlining how the unit works and informing me that, with agreement from our local commissioners with regard to cost, they had a bed available and would be able to admit my son. Within 48 hours he was admitted and I felt entirely different this time about his safety and the ability of staff in understanding his needs.

I have long been concerned about the use of psychiatric medication for those with learning disabilities, and am pleased to see that a holistic and health-centred approach is taken alongside the use of medication. During my son's time in the unit he has had a complete check of his physical health, plus visits to the dentist and optician. He has had regular meetings with the psychologist and psychiatrist. Other appropriate activities are organised, available and offered to him. I am also reassured that the medication, and its effect on him, is closely monitored.

The outstanding difference about this unit is that it is specifically to help those with a learning disability who also have mental health problems, and it is this difference that makes it so important that units like this should continue to be available for these most vulnerable members of our society when they are needed.

I do find myself wondering already what will happen when and if my son needs in-patient service again, what will happen to him if the specialist learning disability assessment and treatment unit is unable to provide a bed? There is clearly a shortage of specialist mental health services for those with a learning disability and this worries me greatly.

I hope that you will have the opportunity to bring this to the attention of the commissioners or providers of services and as a professional working in this field stress the need for these services to continue to be provided, and for these services to be more widely available.

Mental illness is common in people with learning disability, although not always recognised, and improved support for some of the most vulnerable members of our society is an area that still needs more work.'

Comments from Service User Mental Health Advocacy Group supported by the Estia Centre, London

Mr Peter Cronin, service user, peer reviewer and ward visitor to report on quality:

'Staff were polite and friendly (on the learning disability ward). The learning disability ward was more understanding. Some people were aggressive [on the acute mental health ward]. It was unsettling. On the [acute mental health ward] communication isn't so good. The learning disability ward had lots of leaflets, some on medication. They were good at communication. I did an audit on the learning disability ward. They were doing lots of activities. Some patients were playing cricket with the staff, some were doing cooking with the [occupational therapist].'

Yolanda Zimock, service user, on the in-patient experience on a learning disability ward:

'There are lots of things to do, like gym, relaxation class, cooking. The staff really helped me. Sometimes it's too noisy.'

Quotes from service users who do not wish to be named:

'The nurses listen to me (learning disability ward). They help me with my worries. They made a book for me, it's with worries. It has pictures in it, it's easy to read.'

'People understand me here. They are good at working with people with learning disabilities. They take time to tell you about things. There are lots of things to do. I feel safe, there is no bullying. It's better to be on a ward for people with learning disabilities.'

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WINTERBOURNE VIEW – TIME FOR CHANGE

Transforming the commissioning of services for people with learning disabilities and/or autism

A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014



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CONTENTS

Foreword 6

Executive summary 8

About this report 12

The problem we are confronting 14

- Where we are now 14
- Where we need to get to 15
- Why has there not been more progress? 17

Recommendations 20

- Strengthening rights 20
- Forcing the pace on commissioning 24
- Closures 28
- Building capacity in the community 31
- Holding people to account 36

Appendix 1
Membership of the steering group 37

Appendix 2
'We have the right' statement 38

Appendix 3
Challenging Behaviour National Strategy Group Charter 40

Appendix 4
Summary of Recommended Social Investment Structures from *Winterbourne View and Social Investment* (2014) 42

FOREWORD

The Winterbourne View scandal, exposed by the Panorama programme, shocked the nation. It led to the Government pledge to move all people with learning disabilities and/or autism inappropriately placed in such institutions into community care by June this year. Not only has there been a failure to achieve that movement, there are still more people being admitted to such institutions than are being discharged. This has caused anger and frustration.

In light of the need to achieve progress Simon Stevens, the CEO of NHS England, asked me to consider how we might implement a new national framework , locally delivered, to achieve the growth of community provision needed to move people out of inappropriate institutional care.

Only by a big expansion of such community provision can we achieve a move from institution to community. So we need a mandatory national commissioning framework that delivers that expansion, pooled budgets, and a focus on the individual's needs not the system boundaries. The role of the many voluntary and community organisations that both advocate for and provide services for people with learning disabilities and/or autism is crucial to that aim, as are the individuals themselves, their families, clinicians, managers and professionals across the health service and in local councils, who need to work together to achieve a dramatic turn-around.

In tackling this challenge it became clear to me that we need both a major expansion of community delivery driven by better commissioning but also, crucially, the empowerment of people with learning disabilities and/or autism and their families. That means a clear and robust Charter of Rights and an effective "Right to Challenge", backed by strong advocacy and support, that enables citizens to demand change. We also propose that community based providers have the right to propose alternatives to inpatient care from commissioners. And we support a major expansion of the right to request a personal budget; again we believe this underpins an empowerment of the individual citizen to have care and support appropriate to them.

In other words we need to drive change from the top through better commissioning and from the bottom up through empowering people and families to challenge the system.

Underpinning a shift to community provision and away from inappropriate institutional care are exciting proposals for workforce development and a new social finance fund. In developing community provision we need social finance to support capital development so we propose a "life in the community social investment fund" which will support the provision of working capital, investment in housing and an investment readiness partnership fund. This is a new proposal but we recognised that developing community provision needs the funding that social finance can provide and I urge Government and NHS England to push ahead with funding to make this happen promptly.

The steering group were clear about the crucial importance of workforce and skills development. This must happen alongside developing community facilities. We were particularly impressed with the momentum around the idea of the Academy set out on this Report. We must ensure that momentum for change is built on by all those involved.

And finally, as well as a mandatory national framework for commissioning that is locally delivered we must have active decommissioning of inappropriate institutional care and closures of such institutions. The timetable and process requires further discussion but a twenty-first century approach to the care and support of people with learning disabilities cannot be based on long-term care in an institution.

In putting together this report I want to thank all my colleagues on the steering group, and all those I have met or spoken to, and those who submitted many comments and documents. Even when critical we recognised this came about through the anger of those who have seen a system fail them.

In 1851, the American physician and philanthropist Samuel Gridley Howe wrote about the "evils" of institutional care. He wrote, "all such institutions are unnatural, undesirable and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society."

That essential truth underpins our proposals for change and we know they have widespread support. We recognised that as a nation when we closed the old mental health asylums and we must recognise it again here.

I have recommended to the chief executive of NHS England that my steering group be brought together again in 6 months to review progress on our recommendations and that we have a formal stock take of actions taken in 12 months' time. We can act as a driver for change but clearly it is the institutions themselves that must deliver these recommendations. And deliver them they must.

Over the past few years people with learning disabilities and/or autism have heard much talk but seen too little action, and this forms the backdrop to our recommendations and our desire to see urgent action taken now to make a reality of the Winterbourne pledge. They deserve better and this Report provides recommendations on that essential road map for change.





Sir Stephen Bubb

EXECUTIVE SUMMARY

About this report

1. This report is the product of NHS England asking Sir Stephen Bubb, chief executive of charity leaders body ACEVO, to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism. This came after a pledge made in the wake the Winterbourne View scandal – to enable people with learning disabilities and/or autism inappropriately placed in hospital to move to community-based support by June 2014[1] – was missed.

2. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, providers and academics).

3. Whilst originally tasked with drawing up recommendations for a commissioning framework, it was clear to the steering group that any such framework formulated by NHS England would need to be accompanied by related action from others (including most obviously central and local Government), and our recommendations reflect this. Our starting point is that it is not acceptable in the twenty-first century for thousands of people to be living in hospitals when with the right support they could be living in the community, and that to force change we need both more 'top-down' leadership (from NHS England, local government, central government and other Arms-Length Bodies), and from the 'bottom up' more empowerment for people with learning disabilities and/or autism and their families. Our recommendations are aimed at both.

4. The failure to meet the Winterbourne View pledge above means there is now a great deal of anger and frustration surrounding this issue. In responding to this report, NHS England and its partners need both to act with urgency, and to be realistic about the timeline for success, so that they do not promise yet another 'false dawn'.

The problem

5. Some people with learning disabilities and/or autism who present challenging behaviour and/or complex mental health problems may need to be admitted to inpatient settings to be assessed and treated – particularly if they are liable to detention under the Mental Health Act on the recommendation of mental health professionals or a court. But many are admitted when their admission could have been prevented had they

1 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

received better support in the community, and many stay in hospital too long, when with the right support in the community they could be discharged. The result is that for many years too many people with learning disabilities and/or autism have been, and continue to be, in inappropriate inpatient settings – often a very long distance away from family and home.

6. We must see a step change on two fronts: a) putting in place the community-based support to safely discharge people currently in inpatient settings (of whom the latest NHS England data collection showed there were 2,600)[2], and crucially b) supporting children, young people and adults in the community to prevent admissions in the first place (focusing on a much larger number, most urgently perhaps some 24,000 adults in England who present severe challenging behaviour[3]).

7. By a very long way, this report is not the first time anyone has considered these issues. Many have done so, over many decades. So why has there not been more progress? Our view is that:

   - It is not that we don't know 'what good looks like'. That has been described many times, from Professor Mansell's[4] authoritative report in 1993 onwards.
   - Nor is it that we don't know what kind of commissioning we need to secure that good care. The Concordat published after the Winterbourne View scandal set out the necessary key steps very clearly (starting with pooled budgets and joint local commissioning plans), and has been followed by a range of further analysis and guidance.
   - Instead, it is that we make it too hard for stakeholders across the system to make change happen, and too easy to continue with the status quo. And we do not give enough power or support to the people most eager and best placed to make things change – starting with people with learning disabilities and/or autism themselves and their families.

8. Our recommendations therefore aim to make it easier (or mandatory) to do the right thing, harder (or impossible) to do the wrong thing, and to empower and support the agents of change.

Recommendations

Strengthening rights

1. **The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning.** The Charter should clarify existing rights, and set out new rights we propose below. The mandatory commissioning framework later in our recommendations should require all commissioners to invest in services that make these rights 'real' and easily used.

2 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/
3 K. Lowe et al, Challenging Behaviours: prevalence and topographies. *Journal of Intellectual Disability Research*, 51, 625–636 (2007)
4 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)

2. **The Government should respond to 'the Bradley Report Five Years On',**[5] to ensure that people with learning disabilities and/or autism are better treated by the criminal justice system.

3. **People with learning disabilities and/or autism and their families should be given a 'right to challenge' decisions to admit or continue keeping them in inpatient care.** They should receive independent expert support to exercise that right, including high-quality independent advocacy.

4. **NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism,** including all those in inpatient care and appropriate groups living in the community but at risk of being admitted to inpatient care.

5. **The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital,** so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.

Forcing the pace on commissioning

6. **The Government and NHS England should require all local commissioners to follow a mandatory commissioning framework.** The funding and responsibility for commissioning services for this group should be devolved as much as possible from NHS specialised commissioning to Clinical Commissioning Groups. Learning from the strengths (and weaknesses) of the Better Care Fund, a mandatory framework should then require the pooling of health, social care and housing budgets, and mandate NHS and local government commissioners to draw up a long-term plan for spending that funding in a way that builds up community services, makes the Charter of Rights above real, and reduces reliance on inpatient services. NHS England, central Government and local government representatives such as the Local Government Association and Association of Directors of Adult Social Services should support and assure the drawing up of local commissioning plans, and unblock systemic barriers (including Ordinary Residence rules and eligibility for Continuing Health Care). There should be a named lead commissioner in each area, working collaboratively with a provider forum and people with learning disabilities and/or autism and their families.

7. **Community-based providers should be given a 'right to propose alternatives' to inpatient care** to individuals, their families, commissioners and responsible clinicians.

Closures of inpatient institutions

8. **The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities.** This active decommissioning should be driven by a tougher approach from the Care Quality Commission, local closure plans, and closures led by NHS England where it is the main commissioner. NHS England should come to a considered, realistic view on what is possible – but then it should

5 G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* (2014)

set out a clear timetable not just for reductions in admissions or inpatient numbers, but for closures of beds and institutions.

Building capacity in the community

9. **Health Education England, Skills for Care, Skills for Health and partners should develop a national workforce 'Academy' for this field, building on the work already started by Professors Allen and Hastings and others**[6]**.** The Academy should bring together existing expertise in a range of organisations to develop the workforce across the system.

10. **A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services.** The Investment Fund, seeded with £30 million from NHS England and/or Government, could leverage some £200 million from other investors to make investment more easily accessible to expand community-based services.

Holding people to account

11. **Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.** Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning organisation) should be collected and published. Both local commissioners and national bodies (including NHS England, DH, the LGA and others) should be held to account for implementing our recommendations above – local named lead commissioners by local people, NHS England and central Government, and national bodies through existing governance structures (such as the Transforming Care Assurance Board chaired by the Minister for Care and Support).

6 Their proposal is outlined at https://drive.google.com/file/d/0B_At2T3XSWfTd2VOcTRrOURMZW8/edit?pli=1

ABOUT THIS REPORT

1. After the Winterbourne View scandal, the Government and a large number of partners signed a Concordat pledging action on care for people with learning disabilities and/or autism who present behaviour that challenges and/or complex mental health problems. The Concordat promised: "health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014". It envisaged a "rapid reduction in hospital placements for this group of people", and "the closure of large-scale inpatient services".[7] But that pledge was missed.

2. Following the failure to meet that pledge, NHS England developed a programme plan and asked Sir Stephen Bubb, chief executive of charity leaders body ACEVO, to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism.

3. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, Gavin Harding MBE as co-chair of the Department of Health's Transforming Care Assurance Board, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, voluntary sector organisations who work with and/or represent people with learning disability or autism and their families, providers and academics). The membership of the steering group is set out in the appendices.

4. When we refer to community based services we mean smaller more personalised services within a community setting where there is good access to local amenities and services. People supported are able to exercise choice and control over where they live, who they live with and who supports them and truly feel that where they live is their home. The label applied to the service – such as supported living or registered care – should in no way impact on the quality or feel of the service provided.

5. The steering group was supported through focus groups with individuals with learning disabilities and/or autism and their family carers, and by an expert reference group on social investment. The latter group was supported by research on the potential role for social investment from Resonance Ltd, which formed the basis for much of our thinking on social investment and which is being published alongside this report.[8]

7 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)
8 Resonance, *Winterbourne View and Social Investment* (2014)

6. In formulating this report, over several months the steering group met with or heard from a wide range of stakeholders. We held workshops with people with learning disabilities and/or autism, with providers and with commissioners. We looked at the considerable volume of work already undertaken on this issue – the reports by Professor Mansell of 1993 and 2007,[9] the review by the Department of Health undertaken after the Winterbourne View scandal,[10] the subsequent Concordat signed up to by stakeholders across the system,[11] *Ensuring Quality Services* by the LGA/NHS England,[12] and reports and guidance by a very wide range of organisations, including but not limited to the Joint Improvement Partnership hosted at the Local Government Association, Think Local Act Personal, the National Development Team for Inclusion(NDTI), the Royal College of Psychiatrists and the British Psychological Society, the Housing and Support Alliance, Skills for Care, the Challenging Behaviour Foundation, the Challenging Behaviour National Strategy Group and others. A number of organisations spoke to us or submitted evidence directly, including the Ideas Collective, CHANGE, Shared Lives Plus, and Prof. Richard Hastings at the University of Warwick. We have drawn heavily on their ideas and views, and are hugely grateful for their engagement.

7. Whilst we were originally tasked with making recommendations for a national commissioning framework for NHS England, it is clear to us that any such framework formulated by NHS England must be accompanied by related action from others – most obviously, local and central government – and by a stronger rights framework. Our recommendations reflect this.

9 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)
10 Department of Health, *Transforming Care: a national response to Winterbourne View hospital* (2012)
11 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)
12 LGA & NHS England, *Ensuring Quality Services* (2014)

THE PROBLEM WE ARE CONFRONTING

Where we are now

1. The problem we are dealing with is, we believe, well understood. It has been well described a number of times, by people with learning disabilities and/or autism themselves, their families, charities and campaign groups, the Department of Health, professional organisations, the Local Government Association and NHS England. We summarise it here for clarity, rather than as a new addition to the debate.

2. Some people with learning disabilities and/or autism who present challenging behaviour may need to be admitted to inpatient settings to be assessed and treated – particularly if they are liable to detention under the Mental Health Act on the recommendations of mental health professionals or a court. But

   a) many are admitted when that could have been prevented had they received better support in the community,

   b) many stay in hospital too long, when with the right support in the community they could be discharged.

   The result is that for many years, at any one time far too many people with learning disabilities and/or autism could (and still can) be found in inappropriate inpatient settings.

3. After the Winterbourne View scandal, the Government and a large number of partners signed a Concordat which promised: "health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014". It envisaged a "rapid reduction in hospital placements for this group of people", and "the closure of large-scale inpatient services".[13]

4. Since then, hundreds have been transferred out of inpatient care – NHS England's quarterly data collections show that between 30 September 2013 and 30 September 2014, 923 people were transferred out of inpatient care. But crucially, numbers admitted have been consistently higher than numbers transferred out – with 1,306 individuals admitted over the same period.[14]

5. Individuals with learning disabilities, their families, commissioners and clinicians, will still say that many of those inpatients could be discharged, or that their admission could have been prevented, if there were better

13 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)
14 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

support available in the community. And NHS England's care reviews are still finding significant numbers of people in inpatient settings who could and should be discharged with the right community-based support in place. Too often, people are still placed in inpatient settings a very long distance from family and home.

6. The pledge in the Concordat is still valid. We still need to do better both at

   a) Putting in place the community-based support to safely **discharge people** currently in inpatient settings (of whom the latest NHS England data collection showed there were 2,600),[15] and

   b) supporting people in the community to **prevent admissions** in the first place – with that early intervention starting at the earliest possible stage in childhood, but most urgently with better support provided to adults in the community with severe challenging behaviour (of whom there are much larger number, perhaps some 24,000 people in England[16]).

7. Stakeholders were clear to us that this latter need to focus on early intervention and prevention cannot be overlooked. The intense focus on the 2,000–3,000 people currently in inpatient settings is welcome, but it must not be at the expense of catering for the larger number at risk of admission. Failure to do better for them will result in failure to reduce inpatient numbers overall.

Where we need to get to

8. Again, there is broad consensus on what the world should look like for people with learning disabilities and/or autism who present behaviour that challenges. It has been described repeatedly by people with learning disabilities and/or autism themselves, their families, Professor Mansell (in 1993 and again in 2007),[17] the Department of Health (in its 'model of care' published after the Winterbourne View scandal),[18] the Winterbourne View Joint Improvement Programme (in *Ensuring Quality Services*),[19] the NDTI (in the DH-funded *Guide for commissioners of services for people with learning disabilities who challenge services*)[20] and others. Again, we summarise 'what good looks like' here for clarity rather than with the intention of adding anything new to the debate:

   - The presumption should be that people live in their own homes, not in hospitals. A hospital, whatever the quality of the care it provides, is not a home.
   - The system needs to respect and uphold the rights of people with learning disabilities and/or autism (general human rights and rights

15 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/
16 K. Lowe et al, Challenging Behaviours: prevalence and topographies. *Journal offfIntellectual Disability Research,* 51, 625–636 (2007)
17 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)
18 Department of Health, *Transforming Care: a national response to Winterbourne View hospital* (2012)
19 LGA & NHS England, *Ensuring Quality Services* (2014)
20 NDTI, *Guide for commissioners of services for people with learning disabilities who challenge services* (2010)

specific to people with disabilities), ensuring that they are able to exercise choice and control over their lives and that they are treated with dignity and respect.

- Services need to support people as human beings to lead whole lives (rather than simply as 'patients' who need to be treated for medical problems).
- Support needs to be provided over the whole life course, from birth to old age, and we should seek to intervene early to prevent crises rather than simply responding to them.
- The system needs to combine highly personalised support with reasonable adjustments that ensure access to universal services.
- Services need to incorporate building blocks that we know to be crucial to success, such as: multi-disciplinary community learning disability teams able to provide support with communication, physical and mental health and social needs; care coordinators; support for families to look after family members at home, including short break services; high-quality independent advocacy services; appropriate housing; access to education, work and meaningful activities; extra support in times of crisis; access to Positive Behavioural Support and highly-skilled staff throughout the system (all set out in more detail in the Mansell reports,[21] the joint report of the Royal College of Psychiatrists, British Psychological Society and the Royal College of Speech and Language Therapists in 2007,[22] or the NHS England/LGA guide *Ensuring Quality Services*[23]).
- Where a spell in inpatient settings is truly necessary, it should be as local as possible, and enable speedy resolution to crises in a way that builds resilience for the individual and their family.
- People with learning disabilities gave us a strong message that a good system will be co-designed with, and employ, people with learning disabilities and/or autism and their family members.

9. There is also broad agreement about some of the mechanisms required in commissioning practice if we are to have services that meet the above, and these were clearly spelt out in the Transforming Care Concordat that followed the Winterbourne View scandal. They included:

- Pooled budgets and joint commissioning, accompanied by strong local leadership. The Transforming Care Concordat stated: "the strong presumption will be in favour of pooled budget arrangements... CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area."[24]

21 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)
22 Royal College of Pyschiatrists, British Pyschological Society and Royal College of Speech and Language Therapists, *Challenging Behaviour: a unified approach* (2007)
23 LGA & NHS England, *Ensuring Quality Services* (2014)
24 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

- Personalisation. The Concordat pointed to the importance of personal care plans for each individual, and pledged that inpatients "should be receiving personalised care and support in community settings".[25] Subsequent work, such as Think Local Act Personal and the NDTI's 2014 report on personal health budgets for people with learning disabilities,[26] has pointed to the potential benefits of personal budgets as a tool for achieving personalised care.

- Contracts that incentivise or require best practice. The Concordat pledged a range of actions to make it easier to: reward best practice through the NHS commissioning for quality and innovation (CQUIN) framework, embed Quality of Health principles in NHS contracts and Quality of Life principles in social care contracts, and hold providers to account.[27]

- Support for commissioners. There has been widespread recognition that local commissioners do not always have the capacity or capability to lead the kind of service transformation hoped for, and the Concordat led to a range of actions to support commissioners, ranging from practical tools (such as toolkits or service specifications) to guidance (such as that by the Royal College of GPs and Royal College of Psychiatrists[28]) to workshops as currently being run by the Joint Improvement Programme. People with learning disabilities and/or autism and their families have argued strongly that they and their local groups should be partners in commissioning decisions.

- Provider and workforce development. Again, there has been widespread agreement that for more people with learning disabilities and/or autism who display challenging behaviour to be supported successfully in the community, community-based providers and workforces will need support and development. A large number of pledges in the Concordat focused on workforce development, with actions ranging from guidance for social workers to minimum training standards for healthcare support workers to guidance for commissioners on workforce development.[29]

Why has there not been more progress?

10. As the above makes clear, this steering group is not the first time anyone has thought about this issue, by a very long way. For decades people have argued for change and described what good care looks like, and how we can commission it. The Winterbourne View scandal made the need for change even clearer, and resulted in a wide range of commitments from Government and others. But the problem remains. Why?

25 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)
26 Think Local Act Personal & the NDTI, *Personal Health Budgets: including people with learning disabilities* (2014)
27 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)
28 Joint Commissioning Panel for Mental Health, *Guidance for commissioners of mental health services for people with learning disabilities* (2013)
29 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

11. Our view is that progress has been so slow not because we haven't described what good looks like, or how we need to get there, but because it has been too hard to do the right thing and too easy to do wrong thing, and the people most eager to change the system (people with learning disabilities and/or autism and their families, enthusiastic providers, clinicians and commissioners) have had too little power or support to do so.

12. Clinicians are being asked to admit fewer people who present challenging behaviour to inpatient settings, and to discharge others, on the basis that they can be appropriately supported in the community. Many clinicians would like to do just that, and some manage it – but too often they do so in spite of the system, not because of it. They are being asked to keep people in the community or discharge to the community when many will worry that the community-based support on offer is insufficient, or not there at all. They do not want to see individuals unsupported in the community, and many will have seen precisely that happen with subsequent placement breakdown and a need for readmission. They are being asked to take this approach when many work for providers that are not financially incentivised to have a culture and a drive to get people supported in the community, but that instead have an incentive to keep inpatient beds full. And clinicians are being asked to do this when the people who have the expertise to suggest to them realistic community-based alternatives are often unable to, because they lack access to information about the individual's needs.

13. Both health and social care providers are being asked to expand their community-based capacity to support people who present behavioural challenges in order that they are not admitted in the first place, or can be safely discharged from inpatient settings. Many would like to do just that, and some manage – but again, too often despite the system not because of it. Providers are being asked to invest significant sums of money in new staff, training and sometimes new or altered accommodation, months in advance of them taking on new clients and being paid for their care. They may not have the capital to make that upfront investment. Sometimes they are asked to put those services in place at impossibly short notice. And they are asked to make the upfront investment when they are fundamentally not confident that commissioning or clinical behaviour will change, and that there will be predictable revenue streams to pay for their investment.

14. People with learning disabilities and/or autism and their families are being asked to play a central role – speaking up for their rights, acting as partners in designing packages of support, perhaps managing personal budgets, challenging poor practice, being directly involved in the appointment of their care staff. Some do. But too often they experience it as an exhausting battle against the system. Others do not know what their rights are, don't have the support to express or use them. Still others do not know what good community-based potential alternatives could be created for them, and know only the community services that have failed them before.

15. Frontline staff are being asked to behave differently – to think more often of people as people and citizens with rights(not just patients with problems), to engage individuals or their families in care more, to be aspirational about what people can achieve, to make greater use of Positive

Behavioural Support. Many do – but again, less because of the system than in spite of it, because we are asking them to do so without a great deal of support or training, and without incentivising the organisations they work for to make it a priority.

16. And commissioners (CCGs, local councils and NHS specialist commissioners) are being asked to collaborate across organisational boundaries to transform a highly complex system, taking risks in the process. Some have, but again, too often in spite of the system not because of it. Because they are being asked to do all this when many have limited time and capacity to give to the issues, lack expert support, are constrained or slowed down by organisational disputes over who pays for what and whose responsibility an individual should be, and may lack the backing from local leaders that they need to push through change and negotiate compromise between different interests. And they are being asked not to put people in inpatient beds when often those beds have been paid for on a block contract, come at no marginal cost, and feel like the safe option.

17. We need to make it easier (or mandatory) for all these stakeholders to do what we are asking of them. We need to make it harder (or impossible) for them to settle for the status quo that we are agreed must stop. And we need to empower the agents of change – those commissioners, providers, clinicians and above all, people with learning disabilities and/or autism and their families, who are battling for things to be done differently. That is what any new commissioning framework needs to do, and what our recommendations aim to achieve.

RECOMMENDATIONS

Strengthening rights

1. **The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning**

1.1. We have heard, loud and clear, the message from people with learning disabilities and/or autism and their families that the system needs to do a better job of respecting and upholding their rights, and listening to what they have to say. This is about doing what is fundamentally the right thing, respecting people's human rights as a point of principle. But it is also about empowering people who could help change the way the system works for the better, but who too often struggle to make themselves heard. In the context of the problem described in the previous chapter, it is about empowering the agents of change.

1.2. People with learning disabilities and/or autism and their families have an array of rights in law or Government policy – through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on.

1.3. But in our engagement with stakeholders over the course of our work, we heard that the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.

1.4. In some cases, people with learning disabilities and/or autism and their families may not be aware of the rights they already have, or may not have access to the support they need to exercise those rights (such as access at the right time to an advocate or lawyer – for instance, during a crisis, at point of admission, or when in an inpatient setting).

1.5. In other cases, there are doubts over whether the rights of people with learning disability are being respected in practice as originally intended. For instance, as the Government has recognised,[30] there have been occasions where the safeguards in the Mental Health Act have not been properly applied, leading to the recent consultation on updating the Mental Health Act Code of Practice.

1.6. There are also serious concerns about the treatment of people with learning disabilities and/or autism by the criminal justice system, and whether their rights are being properly upheld.

30 Department of Health, *Stronger Code: Better Care. Consultation on proposed changes to the Code of Practice: Mental Health Act 1983* (2014)

In 2009, the 'Bradley Report'[31] described a widespread lack of awareness of the issues faced by people with a learning disability and communication difficulties in the criminal justice system. Since then, there has been significant progress, but the 'Bradley Report Five Years On',[32] published this year, found more needs to be done and made nine recommendations for action. This area was outside our remit to explore in detail, but we recognise how fundamentally important it is. We recommend that the Government respond to the recommendations of the 'Bradley Report Five Years On', setting out how cross-government action will tackle the issues raised.

1.7. To make the rights that people with learning disabilities and/or autism and their families already have feel real, we recommend that the Government should set out a Charter of Rights for people with learning disabilities and/or autism – and then require commissioners to shape local services around those rights.

1.8. Any such charter should build on existing work (such as the 'We Have the Right' statement put together by people with learning disabilities with support from CHANGE for the purposes of this report, or the Challenging Behaviour Charter drawn up by the Challenging Behaviour National Strategy Group, both of which can be found in the appendices). The Charter of Rights should clarify the rights people already have, and the support they can access to use them. It should clarify how professionals (commissioners, clinicians and others) should respect those rights – including in respect to upcoming changes to the Mental Health Act Code of Practice.

1.9. To give the Charter of Rights 'teeth', local commissioners should be required to base their local commissioning plans on it, and to set out how they will make those rights real – for instance, by:

- ensuring information is accessible and available in a range of formats (including easy read) and adapted for individual needs;
- commissioning high-quality independent advocacy services for people with learning disabilities (including people with complex needs), brokerage support, and supporting self-advocacy and family advocacy groups. Particularly for individuals who do not have family, or do not have a supportive family, such support is critical;
- offering personal budgets – and strong support for people with learning disabilities and/or autism and their families to use them;
- ensuring that at key moments (such as prior to admission) people with learning disabilities and/or autism and their families know their rights, know what support they can access to exercise them, and know how to access that support;

31 Lord Bradley, *The Bradley Report* (2009)
32 G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* (2014)

- employing and working in genuine partnerships with people with learning disabilities and/or autism and family carers throughout the system – in drawing up commissioning plans, in hiring staff, in ensuring providers meet high quality standards, in scrutinising and holding commissioners to account, sitting on provider boards of director, and so on. Some of this good practice commissioners could require through the contracts they let to providers, and NHS England should show leadership by employing people with learning disabilities and/or autism at a central level to help drive service transformation.

1.10. Action to make this Charter of Rights 'real' should be central to the mandatory commissioning framework we set out below.

2. People with learning disabilities and/or autism should be given a 'right to challenge' their admission or continued placement in inpatient care

2.1. In addition to making existing rights feel more 'real', we propose extending the rights of people with learning disabilities and/or autism and their families – starting with a 'right to challenge'.

2.2. A 'right to challenge' would allow a person with learning disabilities and/or their family to challenge a decision to admit them to hospital or keep them there, should they so wish. Such a right should be accompanied by free support from an independent, multi-disciplinary team, including 'experts by experience' – family carers or people with learning disabilities who have had experience of inpatient services or been at risk of admission themselves. Building on the process already developed through NHS England's existing programme of care and treatment reviews and reviews by NHS England's Improving Lives Team, together they would ask what assessment, treatment or safeguarding was to be undertaken/was being undertaken in an inpatient setting that could not feasibly be done in the community. The independent support would help individuals and families understand what community-based alternatives might be possible. Based on the presumption set out in the Mandate from the Department of Health to NHS England after the Winterbourne View Scandal ("the presumption should always be... that people remain in their communities"), the review triggered by this right to challenge would only recommend admission/continued placement in hospital if it concluded that the assessment, treatment or safeguarding could only be effectively and safely carried out in an inpatient setting.

2.3. We recognise that many individuals with learning disabilities and/or autism will not feel able to challenge the decisions taken regarding their care, particularly if they are in inpatient settings. In such cases, it is essential that the commissioners paying for their care take the responsibility to challenge the appropriateness of their admission or continued placement in inpatient settings. We expect all commissioners to ensure a care and treatment review is undertaken with the permission of the patient or their carer in order to confirm if inpatient treatment is appropriate.

3. NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism, along with support to manage those budgets

3.1. The 'right to challenge' outlined above should be allied to an extension of rights to have a personal budget (or personal health budget),[33] building on existing rights for those eligible for Continuing Health Care and social care funding. A right to have a personal budget (or personal health budget) should be considered for:

- **People who are inpatients and those at risk of admission**: If an independent review linked to a 'right to challenge' found that an individual could avoid admission or be discharged with the right package of assessment, treatment, support and safeguarding in the community, the individual and their family should have a right (but not an obligation) to a personal budget (or personal health budget) to put that package in place.
- **People with learning disabilities and mental health needs.** For instance, people with learning disabilities who are on the Care Programme Approach would be a readily identifiable group who might benefit.
- **Children and young people with learning disabilities.** Children and young people who have significant health needs could be offered personal budgets (or personal health budgets) to enable them to remain living in the community and avoid out of area placements.

3.2. Personal budgets and personal health budgets encourage a change in thinking. Instead of commissioning services for groups, support is designed for one person at a time, based on a whole-life care plan that focuses on what matters to the person and their family. As now, people should be able to take their budget in a variety of ways – as a direct payment, as a notional budget, or as a budget managed by a third party (known as an individual service fund in social care).

3.3. Local areas will need national support to make this extension a reality, and the centre (the Department of Health, NHS England and national partners) will need to invest in that support. This should include:

- Ensuring close links with the Integrated Personal Commissioning programme, to support local areas to pool funding across health and social care.
- Publishing the number of people taking up personal budgets (or personal health budgets) and the impact on their lives, so local health and social care commissioners understand progress and can be held to account.

33 The term personal health budget is used where care is funded by the NHS, while personal budget is used in social care.

- Putting in place a national support programme for local commissioners, to enable them to actively promote personal budgets (or personal health budgets) as an option for these groups.
- Ensuring that the other recommendations of this report are implemented in ways that encourage and promote uptake of personal budgets and personal health budgets.

4. **The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital,** so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.

4.1. We heard that on being admitted to hospital, it is common for people with learning disabilities and/or autism to lose their tenancy. Not only can that be distressing for the individual, the need further down the line to find suitable accommodation can cause delays to discharge. It was not in our remit to look into this issue in detail, but we recommend that the Government explore ways to protect the tenancies of people with learning disabilities and/or autism when they are admitted to hospital, so that they can return to the same home on discharge if they wish to.

Forcing the pace on commissioning

5. **The Government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework**

5.1. The basic pillars of what is required at a local level from NHS and local authority commissioners has already been described (and committed to by a range of partners) through the Transforming Care Concordat and elsewhere, namely:

- One shared vision, driven forward by active senior leadership, based on the presumption that hospitals are not homes, and that people should be supported to live in the community.
- One pooled budget, allowing maximum flexibility for commissioners to fund what individuals truly need, and aligning the financial incentives on all commissioners to invest in community-based provision.
- One robust plan for commissioning on a whole life-course basis, supporting early intervention and support (from early childhood onwards), expanding the provision of community-based support and care, and reducing the number of inpatients and inpatient provision. That plan should be based on a robust understanding of current and future need, a range of existing best practice guidance, and active engagement with people with learning disabilities and/or autism, their families and providers.

5.2. Many local commissioners (in local councils and clinical commissioning groups) are enthusiastic about making this shift happen, and there is much good practice to draw on. But a great

many local commissioners do not have the three pillars above in place. The most recently published stocktake by the Winterbourne View Joint Improvement Programme[34] found many areas were not pooling budgets, commissioners, providers and families continue to cite disputes over who should fund what as a reason for inappropriate placements, and the growing number of people in inpatient settings suggests that in many areas, what local plans were drawn up did not meet the scale of the challenge. We have heard that common causes include:

- Lack of local leadership, and weak accountability. Where local commissioners have been successful in expanding community-based provision and reducing the need for inpatient beds, active senior leadership backing has often been cited as key to their success. But where that leadership has been lacking, the national organisations do not appear to have been able to hold local commissioners to account, and nor do people with learning disabilities and/or autism or their families.
- Systemic barriers. Local commissioners have pointed to a number of systemic barriers to success, such as inconsistent application of rules around Continuing Health Care (CHC) funding, Ordinary Residence rules, NHS Responsible Commissioner rules and difficulties engaging with specialist, secure (forensic) commissioners.
- Insufficient support, assurance and challenge. Commissioning services for people with such complex needs is a highly-skilled job, but we heard that commissioning capacity has reduced in many areas, and that in some areas that lack of capacity is a significant obstacle to progress. The Concordat has resulted in a wide range of useful support for commissioners, from the Joint Improvement Partnership (JIP) and others. But there needs to be more 'on-the-job' support for, and challenge or assurance of, the drawing up of local commissioning plans to ensure that they are sufficiently robust. Critically, there must be a strong role for people with learning disabilities and/or autism and their families in providing that support and challenge.

5.3. To overcome these barriers, we believe national organisations such as NHS England, departments across Government, other Arms-Length Bodies and the LGA need to play a more robust leadership role – unblocking barriers and devolving funding, setting out a mandatory framework for local commissioners to follow, and providing more support and assurance to local commissioners as they do so.

5.4. NHS England should devolve the budget and responsibility for commissioning services for this group as much as possible from NHS specialised commissioning to Clinical Commissioning Groups (CCGs), so that local commissioners are more clearly incentivised

34 LGA & NHS England, *Winterbourne View Joint Improvement Programme: Stocktake of progress report* (2013)

to ensure there is adequate community-based provision, and admitting an individual to a secure bed is never the 'easy option' for local commissioners. NHS England and its partners at a national level should also remove the systemic barriers that make it harder for local commissioners to invest more in community-based provision and to disinvest in inpatient beds, such as the difficulties local commissioners report having as a result of Ordinary Residence rules, Responsible Commissioner rules and eligibility for Continuing Health Care funding.

5.5. Through a mandatory framework, NHS England should require local NHS commissioners to pool their spending with commissioners of social care and housing services for adults with learning disabilities who present behaviour that challenges, and mandate them to produce a single, outcomes-focused plan for using that spending, covering a period of a number of years. Clearly, the successful engagement of local government is critical here. Whilst NHS England cannot mandate local authorities to commission in a particular way, it should seek to work with others (the LGA, ADASS, DCLG, DH) to ensure that the commissioning framework is fit for purpose from a local government perspective, and that the local authorities are fully engaged as equal partners in the drawing up of joint local plans. The NHS should also make the pooling of budgets dependent on that engagement.

5.6. Local plans should be required to follow a basic mandatory framework, answering questions such as:

- What the **measurable objectives** the plan aims to achieve (e.g. what improvements in health, wellbeing and independence we want to see, what reduction in need for inpatient provision we want to see, or what reduction in use of 'out-of-area' inpatient placements, over what timeframe).
- **How those goals will be achieved** (taking into consideration what we know to be key to success, as set out in existing literature such as the Mansell reports[35] and *Ensuring Quality Services*,[36] and including how the rights of people with learning disabilities and/or autism and their families will be made real, as above, and how the local workforce will be developed, as below).
- How the plan ensures local services take a **whole life-course approach**. Appropriate services need to be available for children, young people and adults, with efforts to prevent the need for inpatient services starting in early childhood, and an effective approach in place to managing transition from children's services or residential education to community-based adult services. We heard throughout our work that more effective support for children and better transition between children's and adults' services will be critical earlier intervention in childhood and improving the transitions between will be critical.

35 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)
36 LGA & NHS England, *Ensuring Quality Services* (2014)

- **Who is responsible** for success, including at senior leadership level, and with a single lead commissioner clearly identified.
- What **analysis of current and future need** has been undertaken.
- **How these plans have been co-produced** with people with learning disabilities and/or autism and their families, providers and clinicians. Local providers should be brought together in a forum to collaborate with one another and with commissioners to ensure comprehensive local services are available.

5.7. The commissioning framework should also describe the kind of approach to commissioning we need to see. For instance, we believe commissioners need to:

- Take a more proactive, long-term approach – planning what kind of services will need to be in place for people from childhood onwards, rather than reacting to crises as they emerge.
- Take a more collaborative approach to engaging with providers. Commissioners need to stimulate the market, encouraging the entry and development of smaller, more innovative providers. They also need to engage with providers more proactively in planning services for individuals and for the population as a whole, giving providers greater opportunities to put forward alternative options. The commissioning framework should make clear that this is both entirely permissible under procurement law and to be actively encouraged.
- Take a more outcomes-based approach, so that payment is increasingly linked to outcomes for people, rather than hours of support provided.

5.8. Alongside the commissioning framework set out above, there needs to be more support and assurance from NHS England, the Department of Health and the LGA, who should build on the work of the Winterbourne View Joint Improvement Partnership and provide more intensive, 'on-the-job', action-focused support to local commissioners, helping them to draw up and implement commissioning plans as above, and to extend the uptake of personal budgets. To ensure that local plans are realistic and robust, NHS England and the LGA should also scrutinise and assure them. This process should also involve scrutiny by panels (at local and national level) of people with learning disabilities and/or autism and their families. Local commissioners that submit plans which are insufficiently ambitious or robust should be given extra support to improve them.

5.9. In pursuing this agenda, NHS England and its national partners should learn from the strengths and weaknesses of the Better Care Fund,[37] which also mandated the pooling of budgets, and

37 The Better Care Fund is a £3.8 billion budget, pooling health and social care funding, to support transformation and integration of health and social care services. More detail can be found at www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/

the drawing up of local joint plans with support and assurance from the centre.

5.10. Alongside the model above, the commissioning framework should include measures to facilitate swift, safe discharge from inpatient settings back into the community, such as a standard contract that includes financial incentives for inpatient providers to focus on discharge planning. Currently, the way in which many inpatient providers are contracted gives them no financial incentive to focus on discharge planning from day one (and indeed they may be financially incentivised to keep as many beds full for as long as possible). That should change, so that contracts incentivise the kind of behaviour we want from inpatient providers – including planning for the earliest possible, safe discharge from the point of admission.

6. Community-based providers should be given a 'right to propose alternatives' to inpatient care

6.1. We heard that a barrier to discharge is often that responsible clinicians in inpatient settings will be concerned that appropriate support is not available in the community, and struggle to see how an appropriate community-based support package (potentially including continued assessment, treatment and safeguarding) could realistically be put into place. That can then lead to decisions that it is too early to discharge, or start planning for discharge. To tackle this, community-based providers considered by local commissioners to be of sufficient quality and reliability, and given permission by individuals or their families, should be given the ability to understand the detailed needs and wishes of people in inpatient settings (through access to information, clinicians or the individual and their family), upon which basis they can put forward a potential package of community-based support for consideration by the individual, their family, the commissioner and the responsible clinician. This should be an opportunity for people who can put together innovative solutions – providers, voluntary organisations, support brokers, advocates – to take the initiative.

Closures

7. The commissioning framework should be accompanied by a by a closure programme of inappropriate institutional inpatient facilities, driven by tougher registration requirements, local closure plans, and leadership by NHS England

7.1. We are clear that there must be closures of inpatient institutions:

- The presumption, in the twenty-first century, ought to be that people with learning disabilities and/or autism live in the community, not in hospitals
- People with learning disabilities and/or autism and their families have been very clear that this is what they want. Some, such as the self-advocacy groups who submitted their views to us via CHANGE, argued that all hospitals for people with learning disabilities and/or autism should be shut. Others believe some

hospitals should remain open, providing a high-quality, locally-integrated service more clearly focused on assessment, treatment and discharge – but they want the number reduced. Some suggested that it is learning disability-specific mental health facilities which should be closed, with universal mental health services making the necessary adjustments to be inclusive of people with learning disabilities alongside others. Whatever the precise way forward, the consensus in favour of significant closures is clear.

- This is also an assumption already signed up to by stakeholders across the system via the Concordat that followed Winterbourne view. The Concordat was clear that currently too many people with learning disabilities and/or autism are admitted to inpatient settings when admission could have been avoided, too many stay too long, and so too many are in inpatient settings at any one time. The corollary is that we have too many inpatient beds, some of which should be closed.

7.2. So we are crystal clear that there must be closures. But we are also clear those closures must be implemented in the right way:

- A guiding principle should be 'above all, do no harm' – closures must be accompanied by more and better community-based support in place, and must be driven by what is best for people with learning disabilities and/or autism and that alone.
- We must not close down one set of institutions only for another to appear. People with learning disabilities and/or autism and their families were clear that small residential care homes and group homes can be 'institutions' in that they can be places where people don't choose who to live with or how to spend their time and don't feel like home. We have also heard fears that some inpatient hospitals could simply 'rebadge' as residential care or nursing homes. We need to ensure that the community services we replace hospitals with are genuinely what people with learning disabilities and/or autism want, and the CQC needs to be vigilant against allowing hospitals simply to go on providing the same institutional care under a different label.
- To say we should close inpatient wards is not the same as saying we do not need all the people who work in them, with the expertise that they have. Whilst care in inpatient settings is of variable quality, in places people are providing assessment, treatment and support to the highest standard. Some of that assessment, treatment and support can and should be provided in the community, in people's own homes. The packages of support people need to live in the community are likely to require input from professionals such as support staff, psychologists, occupational therapists, psychiatrists, nurses, some of whom are likely now to be employed in inpatient providers. The shift in care we are seeking is more likely to require professionals to work in different ways and different settings than to stop being involved altogether. The professionals working in inpatient

settings need to be part of the solution, and part of the remit of the national Academy we propose below must be to help make that happen as part of a managed transition.

7.3. Given the consensus that we currently have more inpatient provision than we should need, we propose that the CQC should act as a market entry regulator and work with local commissioners to determine any future registrations of planned local assessment and treatment or inpatient units. It should announce that after a transitional period, it will significantly raise the quality threshold that inpatient settings will need to meet, including measures such as size of institution and average length of stay taken into account in regulatory judgments (recognising that appropriate length of stay will vary according to need). Any inpatient settings that fail to meet the bar should be considered in breach of the relevant fundamental standards. The approach needs to be ambitious, overt and public, such that it sends a clear message to providers about what the future holds.

7.4. Earlier in this report we proposed a mandatory commissioning framework for commissioners of health and social care services, with local commissioners required to draw up a plan for reducing reliance on inpatient beds, and that plan then scrutinised and assured by national system leaders with the involvement of people with learning disabilities and/or autism and their families. Part of that planning process should include a forecast for the number of inpatient beds each area believes it should have, based on a population needs assessment. This should be developed in partnership with others people with learning disabilities and/or autism and their families. A plan to actively decommission any beds surplus to that requirement, together with the transfer of skilled staff into community services where appropriate, can then follow. These local closure programmes should be implemented in close collaboration with people with learning disabilities and/or autism, their families and providers.

7.5. Finally, NHS England, as a direct commissioner of many inpatient services, should also decommission inpatient services that it currently pays for that are surplus to need. It should seek to start doing this at the earliest opportunity, sending a clear signal to the provider market about the direction of travel.

7.6. NHS England should set out a clear timeline for a closure programme of institutions which do not accord with the model of care that the Government committed to following the Winterbourne View scandal[38]. We have heard differing views on what that timeline should look like. The Housing and Support Allowance suggested to us that the number of people with learning disabilities and/or autism in inpatient settings could be reduced to 1,500 and admissions reduced 75% by 2018. Groups of people with learning disabilities brought together by CHANGE called for an end to admissions

38 Department of Health, *Transforming Care: a national response to Winterbourne View hospital* (2012)

in three years, and all institutions specifically for people with learning disabilities to be closed after that – though some people with learning disabilities also said that they wanted better-quality, smaller and more local inpatient services to remain. Some local areas will be able to achieve change quicker than others. The picture is mixed. NHS England should come to a considered, realistic view on what is possible – but then it should set out a clear timetable not just for reductions in admissions or inpatient numbers (as has been tried unsuccessfully to date), but for closures of institutions.

Building capacity in the community

8. Health Education England, Skills for Care, Skills for Health and partners should develop as a priority a national workforce 'Academy' in this field, building on the work already started by Professors Allen and Hastings and colleagues

8.1. We will only successfully prevent people with learning disabilities and/or autism and challenging behaviour needing to be admitted to inpatient settings, and discharge those currently in hospitals, if we can achieve a major expansion, and major improvement in quality, of community-based support services (including robust preventative and pro-active care that starts before problems manifest, care coordination and brokerage, advocacy, appropriate housing, care and support, multi-disciplinary community learning disability teams, crisis support and respite services). Without that expansion and improvement in quality, people will continue to have crises and be admitted to inpatient institutions, and many people with learning disabilities and/or autism, their families, clinicians and commissioners, will continue to be nervous about discharge from hospital back into the community.

8.2. We heard a consistently strong message that building the skills of the workforce (from care assistants to doctors and nurses to commissioners) should be a major priority here. Critically, this support should be available to family carers too, who should be recognised as fundamental partners in care.

8.3. As a result of the programme of work set in train following the Winterbourne View scandal, we now have a significantly enhanced and growing corpus of best practice guidance on working with people who display challenging behaviour (the Concordat has led, for instance, to a wide range of new or updated guidance for commissioners, social workers, clinicians, healthcare support workers, universal services on reasonable adjustments and more). There are also academics, trainers, providers and commissioners across the country with real expertise in supporting people with challenging behaviour in the community. There is a range of guidance on how local commissioners and providers can embed this good practice through workforce development.

8.4. What is needed now is a concerted programme of action to spread that expertise and codified good practice across the workforce, significantly expanding on the provision already available.

The proposal put together by Professor Richard Hastings and Professor David Allen for an 'Academy' to deliver that[39] is persuasive, particularly in its articulation of the need for a programme of action that:

- has two clear goals: firstly, supporting the system transformation that we hope to see in the immediate future in localities across the country as we build capacity in community services and reduce reliance on inpatient provision, and secondly, supporting the continued long-term development of the workforce in services for people with learning disabilities and/or autism who display challenging behaviour.
- achieves those goals through:
  - a programme of training and development available to stakeholders across the system (local leaders of commissioning agencies and provider organisations, provider staff, clinicians, families and carers, individuals with learning disabilities themselves). This needs to focus both on providers of long-term care and support, but also on the community 'infrastructure' that providers, people with learning disabilities and/or autism and their families need to be able to rely on, particularly to manage crises – community learning disability teams, psychologists and psychiatrists able to assess people where they are living and develop appropriate support plans, and so on.
  - quality kite-marking or accreditation (of training providers and of support providers, whose variable quality we heard is a major issue for commissioners and people with learning disabilities and/or autism and their families) and
  - supporting the continued development of a bank of evidence, best practice, minimum standards, toolkits and guidance.
- brings together and helps coordinate (rather than seeking to replace or replicate) the large number of organisations and individual experts already working to build the skills of the workforce in this area – including many people with learning disabilities and/or autism themselves and their families.

8.5. We believe any such programme of action should include a clear role for people with learning disabilities and/or autism and their families, who should be employed to help deliver it.

8.6. We are also clear that any programme along these lines needs to be action-focused – at least in the immediate future, as much a national taskforce or action programme as an 'academy', closely aligned to the mandatory change programme that we set out above. But whatever the name, we have heard a clear consensus (from people with learning disabilities and/or autism and their families, providers, commissioners, clinicians, academic experts) that there

39 The original proposal is available at https://drive.google.com/file/d/0B_At2T3XSWfTd2VOcTRrOURMZW8/edit?pli=1

is a pressing need for urgent and significant investment in workforce development in this field. We therefore recommend that Health Education England, Skills for Care, and Skills for Health build on the momentum generated by Professor Hastings' and Professor Allen's proposal, working with them and stakeholders across the system (including in the self-advocacy movement and the voluntary sector), to fully scope out the gaps in training and development of staff caring for those with a learning disability and/or autism who display challenging behaviour, and then develop a national academy along these lines to expand and develop existing good practice and to fill the identified gaps.

9. A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient facilities and build capacity in community-based services.

9.1. The conundrum we currently face is that people with learning disabilities and/or autism, their families, clinicians and commissioners are nervous of keeping people out of inpatient settings, or discharging them more quickly, in the absence of stronger community-based services. Providers of community-based services, on the other hand, are nervous of investing in expanding their offer in the absence of greater certainty that those services will be called on by commissioners and clinicians.

9.2. The risk we are asking providers of community-based services to take here is significant: for any one person with learning disabilities who displays behaviour that challenges, a support provider may need to recruit and train a number of support workers. In some cases, where suitable accommodation might not be available, a housing provider might need to make adaptations to existing stock or even invest in new buildings. The local community learning disability team might need to invest in recruiting and training more staff (nurses, psychologists, psychiatrists, GPs, speech and language therapists, occupational therapists) to provide support as and when it is needed. This recruitment, training and occasionally investment in property would need to happen months in advance of a person moving in or starting to receive the support, and the provider(s) being paid for delivering it.

9.3. We can reduce the risk that we are asking providers to take by reforming commissioning and clinical practice, so that providers have greater confidence that if they invest in expanding community services, there will in fact be take-up. Our hope is that our other recommendations will do that. A mandatory framework should shift commissioning practice – particularly by requiring commissioners to engage with providers in drawing up local plans, to pool budgets and thereby make for more flexible revenue streams, and to set clear targets for shifting care out of inpatient settings and into the community. Strengthening the rights of people with learning disabilities and/or autism and their families should make it easier for people who want and can be cared for in the community rather than inpatient settings to avoid admission or speed up discharge.

Our proposed reforms to the commissioning of inpatient settings should do the same. But even with these changes to commissioning practice, we will still be asking providers to take a big risk by investing large sums of money in expanding community provision, without certainty that those services will be called on or adequately commissioned. And we are making this ask of a set of providers, often in the voluntary or public sectors, many of whom do not have significant capital of their own to invest, and who are unable, unused or unwilling to access capital from investors.

9.4. We therefore believe there is a strong case for making such investment capital more easily available, so that community-based services can be expanded more quickly.

9.5. We recommend that the Government should allocate £30 million from LIBOR fines or other sources to a 'Life in the Community' Social Investment Fund – in other words, an investment vehicle with a social mission to improve outcomes for people with learning disabilities and/or autism who display challenging behaviour in the community.

9.6. That investment fund should use its capital to leverage that of other investors, so that the pool of capital ultimately available would be multiples of whatever endowment it received from NHS England or the Department of Health. Research commissioned for this steering group and published alongside this report[40] suggests that public investment of the order of the above could leverage investment from others such that the size of the fund might ultimately reach some £200 million. Over time, funds received from the sale of any public sector inpatient units could also be channelled into this fund. Sitting alongside a mandatory commissioning framework, and a national academy aimed at developing the skills of the workforce across the system, it should catalyse an injection of investment into community-based services during the period of transformation we envisage over the next few years. It should do this by addressing three needs:

a) Above all, a need for working capital to enable a range of providers to scale up community-based services in advance of that support being commissioned and made use of – including services that can help make transitions happen, such as independent advocacy and brokerage.

b) In some local areas and for some individuals, a need for capital to secure suitable housing – a need which may grow if we are to see the kind of shift from inpatient provision to community-based support that we hope to achieve.

c) A need to build up investment-ready partnerships or consortia of local providers, from across the public, private and voluntary sectors. Building successful community services is likely to involve a significant degree of partnership working between a range of individual organisations in one local area, and it is also

40 Resonance, *Winterbourne View and Social Investment* (2014)

likely to require smaller, more innovative providers to be able to engage with commissioners.

9.7. To address these two capital needs, the Government-backed fund we are proposing should start by exploring three potential inter-linked solutions, namely:

a) A 'payment for outcomes' fund, whereby investment would be advanced to community-based services upfront, for example to fund working capital to increase staffing teams and also some specialist property adaptations, and the investors would be repaid their investment by commissioners when and only when a reduction in inpatient provision had been safely achieved because more people were being successfully supported in the community. The research commissioned for this report suggests that seed funding of £10 million from NHS England and/or the Government could result in a £30 million payment for outcomes fund.[41] Clearly, any outcomes-based commissioning would need to be carefully designed to avoid perverse incentives, learning from other outcomes-based commissioning models across public services.

b) A linked social property fund, whereby a fund would acquire properties and refurbish them if necessary, before leasing those properties to housing providers. The research commissioned to support this report suggests that seed funding of £10 million from NHS England and/or the Government could result in a social property fund of up to £200 million.[42] For such a fund to work, it will be essential to ensure that any future welfare reforms do not inadvertently make it uneconomic to build or adapt homes for people with learning disabilities and/or autism by capping housing benefit for this group at a level too low to justify investment in their housing. We are also clear that this fund must be to finance the building or acquisition of homes to suit individual needs – not to build homes that risk becoming a new set of smaller institutions. This will be achieved by ensuring that the fund is focused on its social impact mission from the start, as well as being a viable and scalable investment vehicle.

c) Additionally, a £10 million 'market development fund', building on similar initiatives by the Cabinet Office, which would support the building of local partnerships or consortia and support them to be 'investment-ready', as well as supporting smaller, more innovative providers to expand their services.

9.8. Excerpts from the Resonance report can be found in the appendices, setting out how the 'payment for outcomes' fund and linked social property fund could work in more detail.

41 Resonance, *Winterbourne View and Social Investment* (2014)
42 Resonance, *Winterbourne View and Social Investment* (2014)

Holding people to account

10. **Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.** Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning authority) should be collected and published. Both local commissioners and all relevant national bodies should be held to account for implementing our recommendations above.

    10.1. Local commissioners should be held to account by local people, including those with learning disabilities and/or autism and their families (for instance through learning disability partnership boards or similar). They should also be held to account by NHS England.

    10.2. National bodies should be held to account through existing governance structures that include people with learning disabilities and/or autism (such as the Transforming Care Assurance Board co-chaired by the Minister for Care and Support and Gavin Harding MBE).

APPENDIX 1 MEMBERSHIP OF THE STEERING GROUP

Sir Stephen Bubb (chair)	ACEVO
Jane Cummings	NHS England
Andrea Pope-Smith	ADASS
Andrea Sutcliffe/Alan Rosenbach	CQC
Bob Ricketts	NHS England
Dave Williams	Salford CCG
Dominic Slowie	NHS England
Dr Roger Banks	Independent Psychiatrist
Gavin Harding	Co-Chair, Department of Health Transforming Care Assurance Group
Hazel Watson	NHS England
Jan Tregelles	Mencap
Juliet Beal	NHS England
Karen Flood	National Forum of People with Learning Disabilities
Kate Quail	Mencap
Mark Lever/Mark Milton	National Autistic Society
Robert Longley-Cook	HFT
Sharon Allen/Marie Lovell	Skills for Care
Shaun Clee	NHS Confederation/ 2gether NHS Foundation Trust
Steve James	Avenues Group
Vicki Raphael	National Valuing Families Forum
Vivien Cooper	Challenging Behaviour Foundation

APPENDIX 2 'WE HAVE THE RIGHT' STATEMENT

In June 2014, CHANGE and Lumos organised an event to discuss closing institutions for people with learning disabilities. 100 people with learning disabilities attended, from 35 self-advocacy groups. CHANGE then consulted with this group in drawing up a document – 'We Have the Right' – submitted to the steering group responsible for this report. The text of the document is below, and available at www.changepeople.org/blog-and-news/we-have-the-right-have-your-say-on-institutions-now/.

"People with learning disabilities have the same rights as everyone else. No one should be made to live where they don't want to live, just because they need support.

Yet tens of thousands of people with learning disabilities in Britain do not have this right and they should.

Institutions should be closed and replaced with ways of supporting people with learning disabilities which allow us to live in ordinary homes, in our community, with the people we choose.

Institutions aren't just big buildings. Some small buildings like residential care homes and group homes are really institutions, because they are places where people don't get to choose who to live with and how to spend their time and they don't feel like home. No kind of institution should be seen as acceptable.

Before someone moves into an institution, they and their independent advocates should have the right to challenge that decision and to keep on challenging it.

To challenge decisions, people with learning disabilities need to have more power. We could have more power if we are able to:

- Have high quality easy read information that is quality checked by employed people with learning disabilities.
- Have Access to a personal budget (such as a Direct Payment) or a Personal Health Budget.
- Have trained and properly independent advocates to support us to make decisions and a person who looks after our personal budget money (broker) to support us to spend our money differently.
- Be employed and work in support of other people with learning disabilities as advocates, peer supporters, service planners commissioners and inspectors.

- Support self advocacy organisations to become sustainable, find ways to employ people with learning disabilities and develop peer-to-peer working.
- Have powerful representation from employed people with learning disabilities at every point where decisions are made about us.
- Make the people who have made decisions about us explain why they have made that decision at regular meetings which commissioners and directors have to attend.
- We want to be involved in the development of a clear transition plan supporting people with learning disabilities to move from institutions into community based living.
- That every Joint Strategic Needs Assessment and Local Health and Wellbeing strategy is made to show clearly how it considers the needs of people with learning disabilities, and steps they are taking to ensure people with learning disabilities have greater power.
- Councils and the NHS must be made to stop admitting anyone else with learning disabilities into residential care and nursing homes within the next 3 years.
- Councils and the NHS must be told that all residential care homes and nursing homes must close within 10 years, and people with learning disabilities supported to move into their own home, living with only the people they choose to live with.
- CHANGE and the self-advocacy groups want to come up with a definition of institution."

APPENDIX 3 CHALLENGING BEHAVIOUR NATIONAL STRATEGY GROUP CHARTER

Members of the Challenging Behaviour National Strategy Group[43] believe that better support and services could be provided for children and adults who are perceived as challenging, and have developed a charter which sets out the rights of these individuals and the action that needs to be taken. The text of the Charter is reproduced below and is also available at www.challengingbehaviour.org.uk/strategy-group/charter.html.

Rights and values

1. People will be supported to exercise their human rights (which are the same as everyone else's) to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability.
2. All children who are at risk of presenting behavioural challenges have the right to have their needs identified at an early stage, leading to co-ordinated early intervention and support.
3. All families have the right to be supported to maintain the physical and emotional wellbeing of the family unit.
4. All individuals have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs including their communication needs. This will be individually-tailored, flexible, responsive to changes in individual circumstances and delivered in the most appropriate local situation.
5. People have the right to a healthy life, and be given the appropriate support to achieve this.
6. People have the same rights as everyone else to a family and social life, relationships, housing, education, employment and leisure.
7. People have the right to supports and services that create capable environments. These should be developed on the principles of positive behavioural support and other evidence based approaches. They should also draw from additional specialist input as needed and respond to all the needs of the individual.

43 More information about the Group and who it involves is available at www.challengingbehaviour.org.uk/strategy-group/strategy-group.html

8. People have the right not to be hurt or damaged or humiliated in any way by interventions. Support and services must strive to achieve this.

9. People have the right to receive support and care based on good and up to date evidence.

Action to be taken

1. Children's and adults' services will construct long term collaborative plans across education, social and health services and jointly develop and commission support and services to meet the needs of children and adults with learning disabilities, their families and carers.

2. Local Authorities and the NHS will develop and co-ordinate plans to:

   - Reduce the exposure of young children with learning disabilities to environmental conditions that may lead to behavioural challenges.
   - Promote the resilience of young children with learning disabilities who face such environmental conditions.
   - Provide early intervention, support and services that will meet the individual needs (including communication needs) of young children who are showing early signs of developing behavioural challenges.

3. Active listening to the needs of the family will lead to the provision of appropriate and timely support, information and training.

4. People will be supported to have a good quality of life by individuals with the right values, attitudes, training and experience.

5. The NHS and services will proactively plan to ensure that people receive the same range, quality and standard of healthcare as everyone else, making reasonable adjustments when required. People will have an individualised health action plan and be supported to have access to annual health checks to ensure all health needs are met.

6. People and their family carers will receive support and services that are timely, safe, of good quality, co-ordinated and seamless. They will be proactively involved in the planning, commissioning and monitoring of support and services including both specialist and general services.

7. A person-centred approach that enables and manages the taking of risk will be used to ensure that people have access to family and social life, relationships, housing, education, employment and leisure.

8. Local authorities and the NHS will know how many children and adults live in their area and how many they have placed out of area. On the basis of information from person-centred plans all agencies will plan and deliver local support and services.

9. Services will seek to reduce the use of physical intervention, seclusion, mechanical restraint and the inappropriate or harmful use of medication with the clear aim of eliminating them for each individual.

10. All services and agencies will strive to improve continually, using up to date evidence to provide the best support, care and treatment to deliver positive outcomes for individuals.

APPENDIX 4 SUMMARY OF RECOMMENDED SOCIAL INVESTMENT STRUCTURES FROM *WINTERBOURNE VIEW AND SOCIAL INVESTMENT* (2014)

To provide input to the steering group chaired by Sir Stephen Bubb, Resonance were commissioned by Big Society Capital and the Social Investment Business to produce a report on the potential role for social investment in transforming care for people with learning disabilities and/or autism. Their report, *Winterbourne View and Social Investment*, is available at www.resonance.ltd.uk.

Winterbourne View and Social Investment recommends a hybrid approach which uses two linked investment structures in a complementary way: 1) A 'Payment for Outcomes' Fund to provide working capital funding to providers in order to scale up projects and staffing teams as well as specialist property adaptations, ultimately funded by longer term savings to health budgets, and financed by social investment. 2) A linked Social Property Fund to help providers respond to increased property needs if provision was significantly scaled, providing a more standardized leased housing option across the sector, promoting plurality of providers and localised housing/ support choices for individuals, and acting as a focus and catalyst for action.

Winterbourne View and Social Investment argues that whilst the two structures could, in principle, be developed independently, and one could exist without the other, in practice there are strong reasons to develop the two in a coordinated and complementary way. The report argues that Government seed investment/support is needed to kick-start this, providing leadership, confidence to investors and sector stakeholders and an acceleration of timelines. The report further argues that whilst better commissioning alone might in itself reduce net inflows to in-patient facilities, without this investment impetus, constraints on providers will continue to imply thousands of individuals remaining in this situation for decades to come, and the likelihood of future "Winterbourne View" scenarios recurring.

'Payment for Outcomes' Fund

The purpose of this element of the structure would be to help providers to fund the transitional costs of supporting a resident into their new home (advocacy/brokerage and staff mobilisation) and any required adaptations

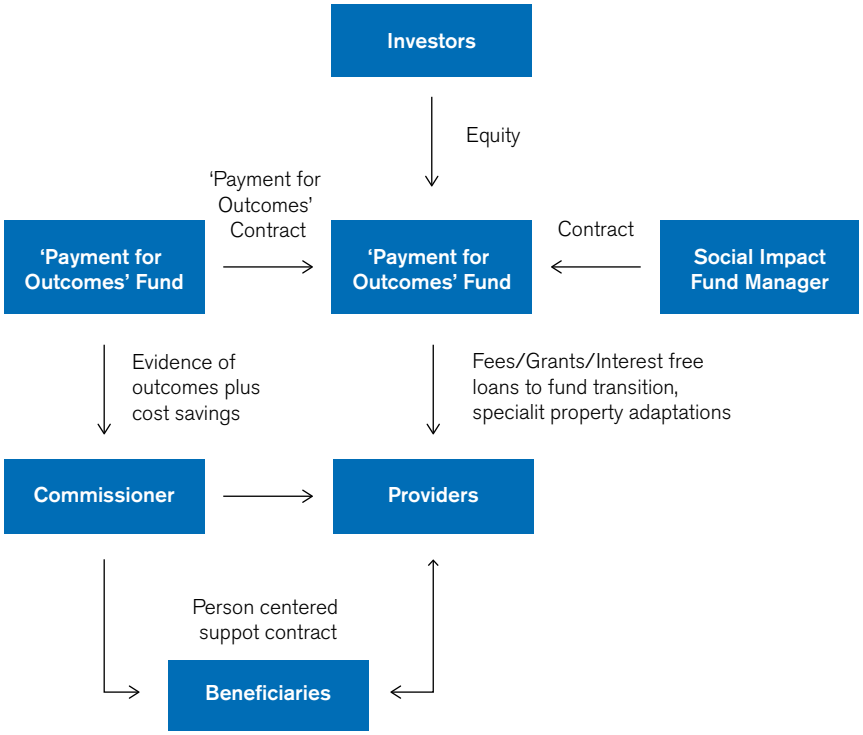
that are above and beyond a standard specification which can be economically provided by a housing provider (including a Social Property Fund) which may be necessary for some tenants but not others. Examples of this could be the conversion of a bedroom to a wetroom, all room air conditioning, or significant strengthening to the fabric of a building.

This funding vehicle (which could take on a number of different legal forms, but is referred to simply below as the Special Purpose Vehicle or "SPV") would have a payment-for-outcomes contract with the NHS England (and other commissioners as they are willing) where payments would be triggered by clear delivery of sustained support and specific positive outcomes for individuals, which would be expected to be at a meaningfully reduced cost in the longer term compared with the inpatient facility.

For example, if the expectation was that, in time, a resident could be supported at a cost of £1500pw in the community, compared with £2500pw in the inpatient facility, then a one-off payment of, say, 50% of this expected saving would be paid to the SPV in the event of the provider achieving the positive 'outcome' for the resident of successfully making this move. In this scenario, assuming a sharing of 50% of the expected saving over a 12 month period, a payment of £26,000 would be paid – an amount which could cover the specialist property adaptations, transitional cost of the provider and a financial return to investors in the 'Payment for Outcomes' Fund. The report notes that at this stage all figures around expected savings are indicative and for illustration purposes only, but the authors point to anecdotal evidence of annual expected savings per individual of anywhere between £50–125k.

The generic structure of a 'Payment for Outcomes' Fund is set out below:

Figure 1: 'Payment for Outcomes' Fund



Appendix 4

Winterbourne View and Social Investment argues that this structure:

- Meets the needs of the sector to help individuals – based on their research, the authors believe that the immediate need is for providers to have the working capital and commissioning clarity to scale up provision from the relatively small numbers who are currently being transferred out of inpatient facilities. A 'Payment for Outcomes' Fund focuses on these two issues directly. It gives providers the data and contracting certainty to plan for scaling up activity, and the capital to do it, rather than simply attempting to respond to shorter term, ad hoc commissioner requests.
- Makes best use of Government support – the main intervention from Government would be to ensure that an attractive 'Payment for Outcomes' contract could be offered. This might involve in the short term some payments which were overlapping (eg if block contracts for inpatient beds could not be immediately unwound) but would ultimately be driving towards savings for Government in this area.
- Fits with reasonable investor requirements – the report argues there is an increasingly developed market of investors who are interested in investing in these structures. For example, there is now an impact investment fund which is dedicated to the purpose of investing into 'Payments for Outcomes' Funds (The Results Fund).
- Can be practically delivered – 'Payments for Outcomes' Funds are still a relatively new investment innovation and can take a considerable time to develop. However, as the costs funded by the 'Payments for Outcomes' Fund would be approximately 8–12% of the property acquisition costs, initially a Fund of just £5–10m would be required to complement the first phase of the linked Social Property Fund discussed further below. This could focus on an initial cohort, and coalition of willing commissioners and providers which could then be further expanded and replicated.

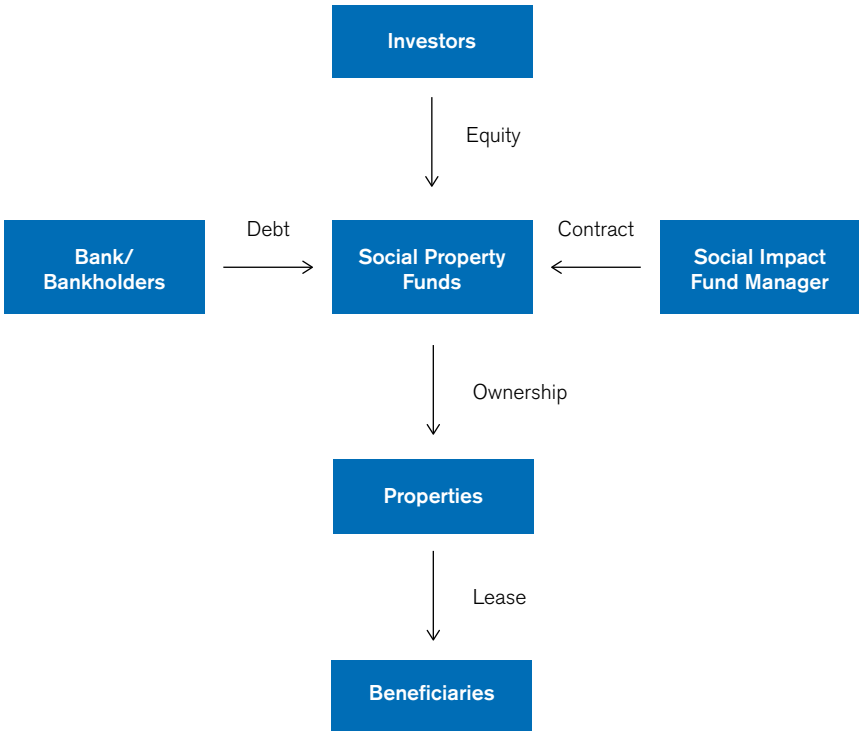
There are a number of more detailed issues which would need to be addressed in the next phase of development of such a structure, which are dealt with in the *Winterbourne View and Social Investment* report.

Social Property Fund

The purpose of this element of the structure would be to give further impetus to the supply of specialized housing, in a scenario where providers were significantly scaling up activity from current levels.

The fund would acquire properties, and cover all acquisition costs and any refurbishment to bring them up to an agreed specification as set out in a Framework Agreement, but not very specialist adaptations necessary for individual tenants, which would be separately covered by the 'Payments for Outcomes' Fund described above. The fund would lease the properties it acquired to an initially small but inclusive group of approved providers with the relationship managed through the Framework Agreement. The financial return to investors would be based on the fund being paid Local Housing Allowance rates (or variations thereon) for rental but would also include capital gain on the property (if any).

Figure 2: Social Property Fund



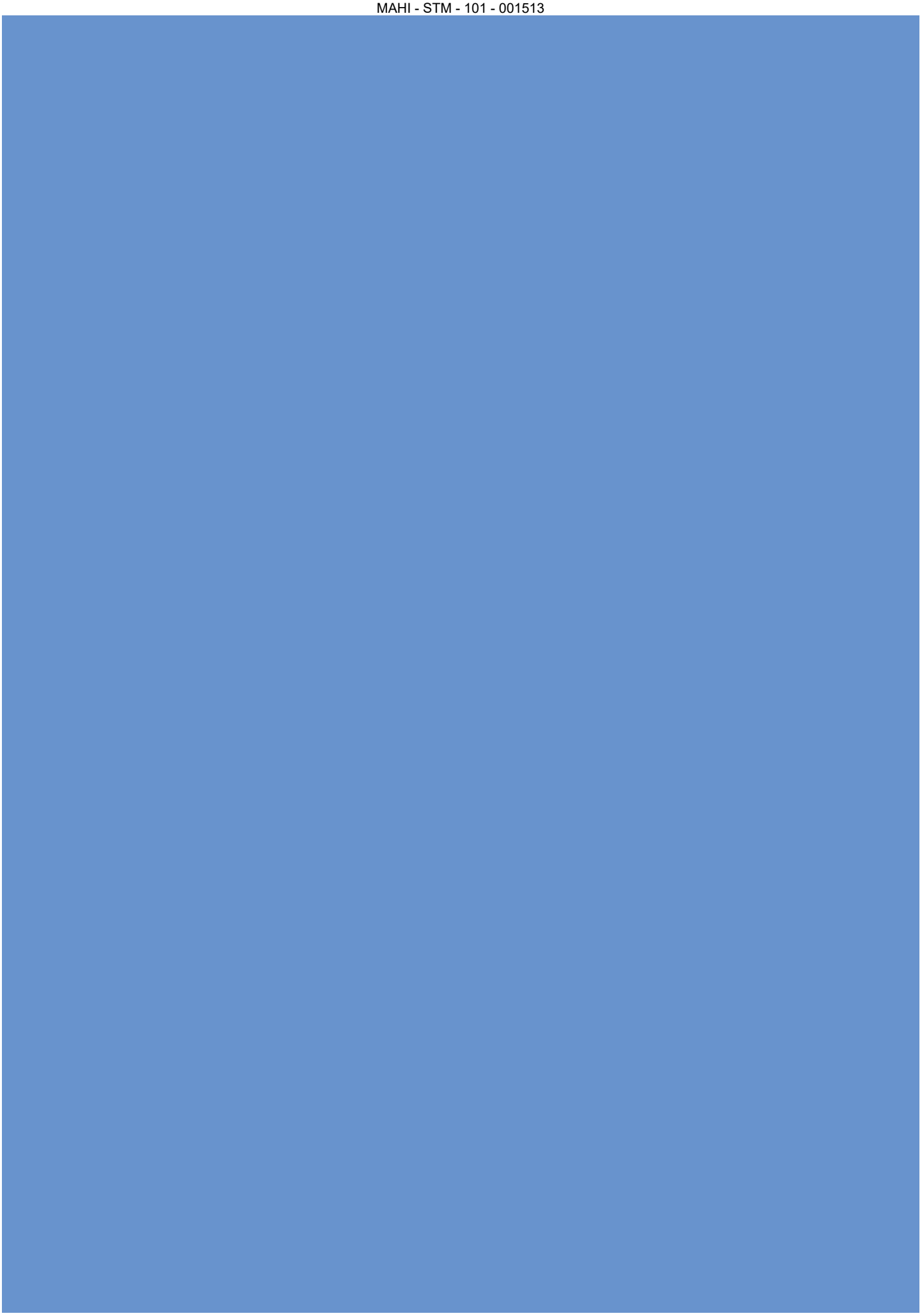
The report authors believe that this structure:

- Meets the needs of the sector to help individuals – the report authors found a general unwillingness or inability from many providers to take on significant levels of debt. Another recurring theme is that complete reliance on a pure private capital model for housing may drive provision models back to the scale and perverse incentives that have arguably helped create the "Winterbourne View problem". It is therefore necessary to think towards a social investment structure which bridges this gap. A property fund makes a clear distinction between the providers of investment capital to fund property assets, the users of those assets, and the providers of support (even if the last two may be the same in many cases). It is also an inherently "open" structure which can provide a diverse range of housing and support providers with access to those assets on appropriate terms.
- Makes best use of Government support – a fund structure should not require government guarantees of the investment vehicle or additional subsidies. It would seek to offer investors a risk adjusted return on their investment as a market based solution to the capital need of this initiative. However, it could be seeded by initial investment from identified Government funding sources which would provide initial impetus and encourage private sector investment.
- Fits with reasonable investor requirements – a property fund is a transparent and recognizable structure for investors. It can take initial "seed" investment from a small number of initial founding investors (including Government) and use this to attract further investment, potentially up to large amounts (£100–300m) which would be very difficult for individual service providers to raise on their own balance sheets.

- Can be practically delivered – there are established models for property funds which can be delivered within reasonable budgets and timing, and which can move from initial smaller scale structures to larger scale structures in due course. By avoiding direct Government guarantees and subsidy, and by dealing with specialist property adaptations through the linked 'Payment for Outcomes Fund', it is also inherently scalable to address large scale capital needs for the sector.

There are a number of more detailed issues which would need to be addressed in the next phase of development of such a structure which are dealt with in the *Winterbourne View and Social Investment* report.





Local Government Association

NHS England

Ensuring quality services

Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges

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Contents

Acknowledgements 4

Foreword 6

Introduction 7

Definitions 9

Core principles 11

1. Positive Behavioural Support 11
2. A whole systems life course approach 11
3. Prevention and early intervention 12
4. Family carer and stakeholder partnerships 13
5. Function based holistic assessment 13
6. Behaviour that challenges is reduced by better meeting needs and increasing quality of life 14
7. Support for communication 14
8. Physical health support 15
9. Mental health support 15
10. Support for additional needs 16
11. Specialist local services 17
12. Safeguarding and advocacy 17
13. Workforce 18
14. Monitoring quality 18

Implementation 20

Resources and further reading 21

Appendix Detailed pathway and policy specifications 24

Individuals 24

Organisations 27

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Chris Bean
Project Lead

"Equality and diversity are at the heart of the NHS strategy. Due regard to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it, has been given throughout the development of the policies and processes cited in this document."

Foreword



The aim of this Core Principles Commissioning Tool, and the project that developed it, is to support commissioners to improve the lives of children, young people, adults and older people with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges through better informed local commissioning. This tool builds on the findings of the Department of Health's Review into events at Winterbourne View Hospital, and restates a model of care which is known to represent best practice.

While it is right that we do not inadvertently create unwarranted dependency on support services for any individual, there is clearly a need to look at an individual's whole life and commission services in a way that is personalised and local. Too often the experience for the individual and their family is multiple services working in isolation, working at cross purposes and avoiding responsibility, not wrapping around in the best interests of the individual. It is also frequently reported that emerging problems were predictable and could-have been prevented had co-ordinated, multiagency pro-active care been provided.

This document is for use by commissioners of education, health and social care (local authorities and clinical commissioning groups) and prescribed specialised services (NHS England). It is imperative that they work together and in partnership with the individual and their family when implementing it. A relentless person-centred focus on outcomes is paramount; all decisions should be based on the best interests of the individual with full recognition that family carers are most often those who know what the 'best interests' of the individual are. We believe the result of using this tool, with integrity; will be improved quality of life for individuals and their carers; reductions in prevalence and incidence of behaviour that challenges; reduction of inappropriate placements; and reduction in inappropriate psychoactive medication, restraint and seclusion. What are we waiting for?

The transformation described within 'Transforming Care: A national response to Winterbourne View Hospital', needs to be considered alongside a wide range of other sector improvement programmes and policies. In particular: the introduction of Education, Health and Care Plans for all under 25-year-olds identified with special educational needs or disabilities (SEND); transition to adult services, which is the focus of the Preparing for Adulthood Programme; personal health budgets which will be available to those in receipt of Continuing Healthcare from October; National Market Development Forum tools and guidance on commissioning best practice and integration of services pioneer sites.

We urge commissioners to make full use of this tool in developing their service specifications, engaging meaningfully and in a coproductive way with local individuals and families, and using the learning to continuously improve local decision making and investment plans. The Winterbourne View Improvement Team and our partners welcome feedback and look forward to hearing about the progress you are making.



Bill Mumford
Programme Director, Winterbourne View Joint Improvement Programme

Introduction

What is this document?

The aim of this Core Principles Commissioning Tool is to support the commissioning of high quality and safe services which meet the needs of children, young people, adults and older people with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges, together with the needs of their families, throughout the life course.

This document describes the core principles that should be present across **all education, health and social care services** being accessed by children, young people, adults and older people with learning disabilities and or / autism who either display or are at risk of displaying behaviour that challenges.

Application of the Core Principles Commissioning Tool should result in:

- improved quality of life for children, young people, adults and older people who have learning disabilities and / or autism and their families through improved services which meet their needs
- reductions in the prevalence and incidence of behaviour that challenges amongst children, young people, adults and older people who have learning disabilities and / or autism
- reductions in the number of individuals placed in more restrictive settings which are inappropriate for their needs (for example, specialist hospitals and assessment and treatment (A&T) units, 52-week school/ college placements or residential care homes), especially those that are out of area. The emphasis should always be on the provision of support in the least restrictive setting possible. Where, in a reduced number of cases, provision such as A&T services are required for a short period of time, the principles within this document will remain essential for supporting those who display behaviours that challenge
- reductions in the inappropriate use of psychoactive medication, restraint, and seclusion to manage behaviour that challenges.

Who is this document for?

This Core Principles Commissioning Tool is primarily for commissioners of education, health and social care (local authorities and clinical commissioning groups) and prescribed specialised health services (NHS England) in England. It has been produced in support of the shared commitment to ensure better life experiences and improved outcomes for this group of individuals, as well as delivering service quality and value for money, as outlined in Transforming care: A national response to Winterbourne View Hospital (Department of Health, 2012). It also supports a number of the provisions (subject to parliamentary approval) in the Children and Families Bill (2013) which aim to transform the system for children and young people with special educational needs and disabilities (SEND), including those who have learning/developmental disabilities.

This Core Principles Commissioning Tool is also of relevance to wider stakeholders (family carers, professionals, self-advocacy groups, family carer forums, researchers and providers) who support children, young people, adults and older people with learning disabilities and or / autism to enable them to advocate for and support high quality service transformations.

How should this document be used?

The 14 core principles in this document provide a foundation for commissioners to use to review services and develop more detailed local plans and specifications for future service delivery. Commissioners should also draw upon other specific and related guidance regarding support for children, young people, adults and older adults with learning disabilities and/or autism. **This is particularly true for those individuals who have autism and do not have a learning disability and for those individuals who have mental health difficulties who may or may not display behaviour that challenges.**

Associated guidance

This guidance should be read in conjunction with the forthcoming Department of Health (DH) guidance on the use of Positive Behaviour Support (PBS) and the minimisation or restrictive practices, and the Skills for Care and Skills for Health guidance on the commissioning of training in the use of PBS and restrictive practices. Both these documents will apply to all adults receiving health and social care services and are not focused on learning disability services. The Department of Health is also reviewing and updating the Mental Health Act Code of Practice, which provides guidance on the use of restrictive practices for individuals covered by the Mental Health Act 1983.

NHS Protect has also produced guidance on managing behaviour that challenges and the National Institute of Clinical Excellence (NICE) is also currently developing guidance regarding support for people who display behaviour that challenges, including children and young people which is due to be published in 2015.

Links and references are listed in the 'Resources and further reading' section at the end of this document. The Department of Health, Skills for Care and Skills for Health guidance which is yet to be published will be available via www.gov.uk later this year.

Definitions

Learning disabilities

As set out in Valuing People (HM Government, 2001, p. 14), individuals with learning disabilities (internationally referred to as individuals with intellectual disabilities) are those who have:

- 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.

Intelligence Quotient (IQ) alone should not be used to determine presence of a learning disability and those who have not received an IQ test or who have been found to score in the borderline range should not be automatically excluded from the scope of this guidance or services that are commissioned.

In early childhood (that is, under five years) it can also be difficult to determine whether or not a child with delays in development has a learning disability. During these years a label of Global Developmental Delay is often used. Children and young people with this diagnosis are therefore also considered within the scope of this guidance.

Autism

As described by the NICE Guidelines, autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities. Individuals with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.

This Core Principles Commissioning Tool recognises that individuals and groups may prefer a variety of other terms, including autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. For clarity and consistency, in this document the term 'autism' is used throughout, in keeping with the use of 'autism' as described in 'Fulfilling and rewarding lives: the strategy for adults with autism in England' (DH, 2010).

Some individuals with autism also have a learning disability but many do not (that is, those with high functioning autism or Asperger's Syndrome). As previously indicated, further guidance needs to be drawn upon in addition to this document to ensure commissioners meet their specific needs.

Life course

'Life course' encompasses all age groups from pregnancy and birth through childhood, adulthood and older-adulthood (to the point of death).

Behaviour that challenges

As set out in Challenging Behaviour: A Unified Approach (Royal College of Psychiatrists, et al, 2007, p.14) challenging behaviour is behaviour "of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion".

Risk factors

Not all children, young people, adults and older people who have learning disabilities and / or autism will display behaviour that challenges. A variety of factors are likely to contribute towards the development, maintenance and escalation of behaviour that challenges, these include (but are not limited to): biological and genetic factors, physical health difficulties, communication difficulties, mental health difficulties, neurological difficulties, quality of support, and exposure to adversities.

Behaviour that challenges:

- is displayed by 10 to 15 per cent of adults who have a learning disability (see Emerson & Einfeld, 2011)
- occurs in many forms (for example, aggression, self-injury, property damage, etc) but is defined by the impact it has on the wellbeing and quality of life of the person who displays it and others who support them
- is generally considered as learned behaviour that serves important functions for the person who displays it (it helps the individual to cope better or exert some control over their immediate environment) and is not a deliberate attempt (including if a phenotype) to upset or harm others
- is not a diagnosis, mental health or physical health condition (though mental and physical health conditions can be contributing factors)
- is influenced by a variety of factors including the individual needs and abilities of the person who displays it, the adversities to which they have been exposed and the behaviour of others who support them
- usually begins in childhood or young adulthood and without effective intervention is highly persistent; around 30 per cent of young children with learning disabilities (aged 0 to three) display behaviour difficulties (Emerson & Enfield, 2011)
- puts individuals who display the behaviour at increased risk of exclusion, physical injury, abuse, and harsh restrictive management approaches such as physical restraint
- is associated with high rates of stress and other emotional difficulties amongst family carers and others who support children, young people, adults and older people with learning disabilities and / or autism.

Core principles

1. Positive Behavioural Support

Positive Behavioural Support (PBS) is built on the strongest evidence base for supporting individuals with behaviour that challenges.

PBS is not a single intervention or therapy. It is a multi-component framework for delivering a range of evidence based supports to increase quality of life and **reduce the occurrence, severity or impact of behaviours that challenge**.

PBS is not a 'one-size fits all approach'. It is underpinned by person-centred values and demands flexibility and tailoring that responds to the individual needs, complexities and circumstances of children, young people, adults and older people with learning disabilities and / or autism, together with their families, throughout the life course. A holistic assessment of need underpins the planning and delivery of appropriate support for each individual.

The core principles for commissioning and specifying services outlined below stem from PBS. They are applied here across the life course and settings that cover generic and specialist education, health and social care services commissioned and/or delivered locally, regionally and nationally for individuals who either display or are at risk of displaying behaviour that challenges; as well as prescribed specialised health services. For a comprehensive account of PBS see the essential reading listed at the end of this document.

2. A whole systems life course approach

Behaviour that challenges can be displayed at multiple points during the life course of individuals with learning disabilities and / or autism. It also occurs in multiple settings and is influenced by multiple factors. Commissioners should therefore ensure that:

- The individual is at the centre of planning and commissioning. Services are flexible and adjust to changes in need over the life course.
- Individuals and their families are aware that they can have a personal budget or personal health budget, including the option of a direct payment. Adults and older people receiving NHS Continuing Healthcare and children and young people receiving Continuing Healthcare will have the right to have a personal health budget from October 2014.
- Local specialist challenging behaviour services for individuals with learning disabilities and / or autism are routinely provided to meet the needs of children, young people, adults and older people.
- Wider services (such as those providing physical health care, housing, dental care or leisure activities) should make reasonable adjustments to ensure smooth access and effective support for children, young people, adults and older adults with learning disabilities and / or autism.
- A wide range of mental health services including those provided by general practitioners (GPs), mainstream mental health and forensic services, and specialist

learning disability services are accessible to individuals with learning disabilities and/or autism of all ages who display or are at risk of displaying behaviours that challenge.

- Particular attention should be paid to times of transition both between and within services which are focused on the needs of children and young people and those which are focused on the needs of adults and older adults. Services focusing on each age group need to work closely, well in advance of a transition to support individuals and families effectively.
- At all ages, education, health and social care services should work in partnership to deliver the kind of consistent and holistic support that is required to meet the needs of individuals with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges together with their families.

3. Prevention and early intervention

Behaviour that challenges often (though not always) begins in childhood or young adulthood. There are a number of risk factors that can be used to predict which individuals with learning disabilities and / or autism are most likely to develop behaviour that challenges both at an early stage and in later life. The early detection of risk factors and systematic assessments of behaviour is the key to prevention of behaviour difficulties and the basis of early intervention. A major aim of PBS is to reduce the likelihood of behaviour that challenges by providing supports at an early stage to proactively address these risk factors. This should include:

- early screening and clear, smooth diagnostic pathways for children and young people suspected of having a learning disability and / or autism
- proactive prevention via the identification of additional risk factors for development of behaviour that challenges across all age groups of people with learning disabilities and / or autism. This should include those with rare genetic syndromes (for example, Cornelia de Lange syndrome or Lesch-Nyhan syndrome) associated with behaviour that challenges; those with significant communication impairments; those with additional mental health, physical health or sensory needs; and those who are exposed to high rates of environmental adversity (for example, poverty, abuse, harsh or inconsistent parenting)
- recognition that children, young people, adults and older people with learning disabilities and / or autism are at increased risk of displaying psychiatric disorders; consequently services should ensure support for behavioural problems includes an assessment of possible psychiatric co-morbidities
- early intervention supports to meet the needs of children and young people with learning disabilities and / or autism together with their families at the point of identification; with further specialist supports provided, when additional risk factors have been identified and / or early forms of behaviour that challenges have been highlighted. Consideration should be given to commissioning parenting support programmes that have been shown to be cost effective in reducing behaviour that challenges (see the Department for Education's parenting programme commissioning toolkit)
- recognition that children, young people, adults and older people with learning disabilities and / or autism who are not currently displaying behaviour that challenges may still be at risk of doing so if adequate supports that prevent this behaviour are not in place, or have been removed following a reduction in behaviour that challenges
- recognition that additional risk factors for development of behaviour that challenges may emerge in later stages, including during

adulthood, which need to be predicted, identified and supported proactively (this should include development of dementia amongst older people with learning disabilities and / or autism)

- provision of environments that are suited to the needs of children, young people, adults and older people with learning disabilities and / or autism (this should include a consideration of how predictable the environment is; levels of stimulation, and the quality and frequency of interactions with other people).

4. Family carer and stakeholder partnerships

Whilst the focus on the rights and needs of the individual is paramount, working in partnership with family carers and other stakeholders (ie siblings, professionals, advocates, service providers) who directly support children, young people, adults and older people with learning disabilities and / or autism is an essential aspect of PBS. This does not mean that family carers should be made responsible for implementing or coordinating all supports and interventions unaided; this should remain a partnership with their key worker. Working in partnership should include:

- supporting family members to be parents, siblings and relatives first and foremost, which means supporting the families of individuals with learning disabilities and / or autism to lead a full family life and to maintain their physical and emotional resilience
- close involvement of family carers and other stakeholders throughout assessment, planning and intervention pathways to support children, young people, adults and older people with behaviour that challenges
- specific training and support programmes that empower family carers and other stakeholders to most effectively support children, young people, adults and older people with learning disabilities and / or autism, particularly in relation to behaviour that challenges.
- support for the emotional wellbeing and resilience of family carers (including parents and siblings) and paid carers in recognition of the high rates of stress and other emotional difficulties found amongst those who support individuals with behaviour that challenges.
- support for children, young people, adults and older people with learning disabilities and / or autism who display behaviour that challenges to access short break and respite services (the difficulties to families arising from supporting a relative with behaviour that challenges should not be under-estimated and providing short break and respite services proactively is therefore essential for families to cope over time and lead a full family life)
- recognising the importance of the key worker role and the skills and expertise required to fulfil it within job descriptions.

5. Function based holistic assessment

Within a PBS framework, interventions to support children, young people, adults and older people who display behaviour that challenges should be preceded by a thorough, holistic assessment facilitated by a suitably trained person or group of people. This is generally referred to as a Functional Assessment, the main features of which should:

- ensure individualisation and tailoring of assessment procedures and arrangements with close involvement of family carers and stakeholders
- follow a systematic and data-driven process
- consider the individual's physical environment and consider how other people behave towards the individual and respond

to behaviour that challenges

- consider the broader context that may influence how and why the individual displays behaviour that challenges (including mental health and physical health factors; communication and sensory needs and relationships and social inclusion
- consideration of underlying biological/ genetic factors (certain rare genetic syndromes have a behavioural phenotype which is associated with specific behaviour that challenges)
- provide an understanding of when and why the individual is displaying behaviour that challenges by helping to identify the function of that behaviour (in other words, how it helps the individual to cope better or exert some control over their immediate environment).

6. Behaviour that challenges is reduced by better meeting needs and increasing quality of life

Supports and interventions for children, young people, adults and older people who display behaviour that challenges should be based on a functional understanding of that behaviour following function based holistic assessment. Within a PBS framework the vast majority of supports should focus on better meeting an individual's needs and increasing their quality of life in a way that reduces the likelihood of behaviour that challenges occurring in the future.

Best practice supports should include:

- provision of an environment appropriate to the individual that is less challenging and ensures helpful support arrangements from others (in other words, how others communicate with and proactively meet the needs of an individual to reduce the likelihood of behaviour that challenges)
- strategies that develop the individual's competencies to ensure that their capacity to influence the world is less restricted; this is likely to include support to develop communication or other skills that can serve the same functions as those that relate to behaviour that challenges
- support to address broader needs identified during assessment that relate to why the individual displays behaviour that challenges, including physical health and mental health, communication and sensory difficulties, and relationships and social inclusion
- support to better address the needs of family carers and other stakeholders when these have been found to influence why the individual displays behaviour that challenges
- a set of (reactive) strategies to safely support an individual and others when it has not been possible to prevent an instance of behaviour that challenges
- active avoidance of restrictive and punitive approaches to managing behaviour that challenges at all times
- clear arrangements to support implementation and on-going monitoring of their effectiveness.

7. Support for communication

A high proportion of children, young people, adults and older people with learning disabilities and / or autism have communication difficulties. Communication impairment and insufficient adjustments from other people to support communication increases the likelihood that individuals with learning disabilities and / or autism will display behaviour that challenges. It is important for commissioners and providers to read and implement the Royal College of Speech and Language Therapists' recently published Five good communication standards, produced to meet Action 12 of the Winterbourne View Concordat. Consistent with a PBS framework, services should support communication needs across the life course by:

- providing ongoing support to individuals with learning disabilities and / or autism to develop functional forms of communication together with support to families and paid carers to adjust their own communication appropriately (these supports should be evidence-based and provided as an early-intervention/preventative measure irrespective of whether behaviour that challenges has developed or is currently being displayed and there should be a detailed description of how best to communicate with individuals)
- ensuring additional communication supports are provided as part of a package of interventions to support those who are either currently displaying or are at increased risk of displaying behaviour that challenges
- developing choice-making abilities and ensuring frequent opportunities to make choices that are effectively supported by others, or demonstrating how they support individuals with communication needs to be involved with decisions about their care and their services
- supporting the development and maintenance of positive social relationships, and creating opportunities, relationships and opportunities that make individuals want to communicate.

8. Physical health support

Children, young people, adults and older people with learning disabilities and / or autism are at increased risk of experiencing physical health difficulties. Whilst behaviour that challenges is not a physical health diagnosis, experiencing difficulties in this area may be associated with why some individuals display behaviour that challenges. As part of the broad framework of supports for children, young people, adults and older people who display or are at risk of displaying behaviour that challenges there should be:

- effective systems to ensure the physical health needs of children, young people, adults and older people with learning disabilities and / or autism are identified and supported effectively through partnership working between GPs, acute services and specialist learning disability teams to ensure that physical health problems detected through annual health checks, screening, physical examinations and investigations are acted on and the outcomes monitored
- support for children, young people, adults and older people with learning disabilities and / or autism to understand and express their needs in relation to their health and wellbeing, and to access health-based information together with support and opportunities to lead healthy lifestyles
- support and training for family carers, paid carers and professionals to recognise how the child, young person, adult or older person with learning disabilities and / or autism that they support reacts to and communicates pain and discomfort from a range of conditions which may or may not be known to them
- support for individuals with learning disabilities and / or autism to communicate when they are experiencing pain, discomfort or other symptoms of physical illness.

9. Mental health support

Children, young people, adults and older people with learning disabilities and / or autism are at increased risk, relative to the general population, of experiencing mental health difficulties. Whilst behaviour that challenges is not a mental health diagnosis, experiencing difficulties in this area may be associated with why some individuals display behaviour that challenges. Mental health difficulties, learning disability, autism, behaviours that challenge, and offending behaviour can coexist and be difficult to distinguish especially with coexisting communication difficulties (JCPMH 2013). As part of the broad framework of supports

for children, young people, adults and older people who display or are at risk of displaying behaviour that challenges there should be:

- effective identification of mental health and other emotional difficulties amongst children, young people, adults and older people with learning disabilities and / or autism and active recognition that symptoms of mental health difficulty, such as depression or psychosis, may be presented differently amongst individuals who have learning disabilities and / or autism compared to those who do not
- appropriate use of evidence-based therapeutic interventions and medication to support children, young people, adults and older people with learning disabilities and / or autism who have been identified as having a mental health difficulty, either in the context of a function-based holistic assessment or at a time when they are not displaying behaviour that challenges
- access to appropriately-trained mental health professionals, who have knowledge, expertise and skills in learning disabilities and autism; mental health professionals should not deny access to services (Child and Adolescent Mental Health Services (CAMHS) and adult/older people's mental health services) on the basis of learning disability and / or autism
- strong partnership working between mainstream mental health services and learning disability services and local autism services to ensure that individuals with learning disability and/or autism have access to the full range of support
- support available in the least restrictive setting possible that is therapeutic and safe for children, young people, adults and older people, and safe for their family members, carers and professionals.

10. Support for additional needs

Children, young people, adults and older people with learning disabilities and / or autism are likely to present with a number of other areas of need that if not adequately supported may increase the likelihood of behaviour that displays as challenging developing. As part of a preventative PBS strategy the following areas should be addressed:

- A high proportion of children, young people, adults and older people with learning disabilities and / or autism experience sleep difficulties. This has a negative impact on their wellbeing and impacts on the wellbeing of family carers. Both of these factors may increase the likelihood of behaviour that challenges. Sleep difficulties should be actively screened for and evidence-based sleep programmes, with medication to support where appropriate, should be implemented routinely and appropriately by services supporting individuals across the life course.
- Young People with learning disabilities and/ or autism may have coexisting Attention Deficit Hyperactivity Disorder (ADHD) that is either undiagnosed or overlooked during transition to adult services. The appropriate treatment and support needs to be made available from childhood into adulthood.
- High numbers of children, young people, adults and older people with learning disabilities and / or autism experience sensory difficulties. This includes sensory impairments (in other words, hearing difficulties and visual difficulties) and increased sensitivity across a number of areas (for example, tactile sensitivity). These should be addressed as part of a package of intervention supports through provision of equipment/devices, communication methods, therapeutic work and appropriate structuring of an individual's environment.
- Children, young people, adults and older

people with learning disabilities and / or autism often require support to engage in stimulating and meaningful activities. When deprived of activity and appropriate levels of stimulation there is an increased likelihood that individuals will display behaviour that challenges. Family carers and paid staff require training and support to help those children, young people, adults and older people they support to live full and active lives in the community. In addition (in line with wider equality and diversity agendas) increased support is required to raise public awareness of the needs of individuals with learning disability and or/autism and their families.

11. Specialist local services

Local specialist services that focus on the needs of individuals with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges need to be routinely available for children, young people, adults, older people and their families. These services should:

- demonstrate a clear PBS pathway and local policy that reflects all principles covered in this document and embodies the highest level of expertise in this approach
- support other services for children, young people, adults and older people with learning disabilities and / or autism and generic services (in other words, non-specialist physical health services) to use the principles outlined in this document.

Further guidance for the design and delivery of these services produced by McGill (2013) is provided as an appendix.

12. Safeguarding and advocacy

The whole system has responsibility to work with families to safeguard the safety and wellbeing of children, young people, adults and older people with learning disabilities and / or autism: those without positive family involvement are likely to require additional support. The provision of independent advocacy at these times is central to safeguarding vulnerable people across the life course and needs to be tailored accordingly to take into consideration mental and physical capacity. At all times commissioners should:

- identify clearly and transparently (both within and across geographical areas) the responsibilities of different parts of the whole system for safeguarding children, young people, adults and older people with learning disabilities and / or autism
- ensure the availability of independent advocates especially for those whose situations are at increased risk (for example, because of limited family involvement or placement far from home)
- have policies and procedures for supporting whistleblowing and other activities that may prevent or lead to the early detection of abuse or inappropriate treatment and should also ensure that providers have clear whistleblowing policies and procedures, and a means of assuring themselves that these are adequate and understood by staff within provider settings
- ensure that a range of stakeholders (family carers, professionals, researchers, partnership boards, and providers) are made aware of the use of specialist services (including residential schools and out of area placements) and the use of restrictive treatment (including physical restraint, seclusion and excessive/inappropriate medication) via transparent data reporting approaches.

13. Workforce

The constitution of the workforce will be partly dependent upon the specific service commissioned. It is likely that a range of different professionals, working together in a multi-disciplinary and multi-agency team/ network will be required to provide the kind of holistic support outlined in this Core Principles Commissioning Tool. Further guidance on the roles of particular professionals is described in the 'Challenging Behaviour Foundation Pamphlets for Commissioners' referenced at the end of this document.

Children, young people, adults and older people with learning disabilities and / or autism need a workforce that know and value how to provide safe high quality services. Those who are providing educational, health or social services should demonstrate they are managing their workforce to achieve this by:

- involving children, young people, adults and older people with learning disabilities and / or autism and their family and carers in the recruitment process, especially interview panels, for all staff
- providing accredited training to keep up to date with best practice and maintain professional development in PBS and other related areas
- involving, wherever appropriate, family and carers in the delivery and review of training sessions/programmes
- supporting staff to value and use competently the best approaches to communication with each individual they support
- ensuring their staff have a good understanding of the symptoms/signs of co-morbid conditions (for example, Mental Health and ADHD) which can be associated with behaviours that challenge
- ensuring all staff receive regular supervision, appraisal and support
- ensuring staff understand the Mental Capacity Act to a level that is applicable to their role and the environment in which they work
- having a clear process for raising and discussing concerns
- actively encouraging innovation and creativity, especially in relation to reasonable adjustments
- supporting the development of a competencies framework to monitor quality of PBS provision.

14. Monitoring quality

Commissioners and providers need to work collaboratively to specify and deliver services that are safe and of a high quality. These should be informed by the key principles and outcomes described in the 'model of care' contained within Transforming care: A national response to Winterbourne View Hospital. The focus of assurance systems should include:

- the experiences of children, young people, adults and older people with learning disabilities and / or autism and their families
- timely and regular review and audit of services and care plans to ensure they are safe, meeting needs and delivering outcomes
- local quality requirements, including initiatives to make marked improvements (eg, Commissioning for Quality and Innovation (CQUIN))
- national quality requirements, (for example, Ofsted and Care Quality Commission)
- early warning and learning from complaints and serious incidents
- involvement of children, young people, adults and older people with learning disabilities and /or autism; and their family and carers as Experts by Experience

- clear understanding of monitoring and reporting arrangements, including through to local Partnership Boards and Health and Wellbeing Boards.

Mechanisms are also required to monitor the quality of commissioning procedures and should form part of the Joint Strategy as per Action 57 of the 'Concordat: Programme of Action' (DH, 2012). This should be assessed by measuring outcomes for individuals with learning disabilities and / or autism and other stakeholders and should include:

- the satisfaction of individuals and families regarding service provision
- positive increases in quality of life for individuals and families
- population level changes in prevalence of behaviour that challenges
- reduced numbers of individuals with learning disabilities and / or autism in residential school/out of area placements.

Implementation

To effectively implement this Core Principles Commissioning Tool commissioners should:

- ensure they comprehend what it is describing; reading it alongside the documents highlighted in 'Resources and further reading' section. The information above, whilst updated in places, does not expand significantly on the 'model of care' published in the 2007 revision of 'The Mansell Report' (this point is made because it is important to remember that the DH's Review found there was a widespread failure to: design, commission and provide community-based services that meet the needs of children, young people, adults and older people with learning disabilities and / or autism who display or are at risk of displaying behaviour that challenges)
- work through the commissioning cycle so that existing specifications are reviewed and revised and/or new ones are developed that are consistent with the model of care and established best practice including personal budgets and personal health budgets; it is important that this is done collaboratively across education, health and social care; and with involvement of providers and partnership boards, parent carer forums, and self-advocacy groups
- consider the full transformation programme set-out in Transforming care: A national response to 'Winterbourne View Hospital'; and the local response to the Stocktake; the findings from reviewing existing specifications should inform local Joint Strategies, which the Concordat requires to be in place by April 2014
- implement this guidance alongside their preparation to implement the provisions (subject to Parliamentary approval) in the Children and Families Bill 2013, in particular the requirements to:
  - provide a 'local offer' of services for children with Special Educational Needs (SEN) and their families
  - replace statements with birth-to-25 education, health and care plans
  - offer families personal budgets (which can include education, health and care)
  - jointly commission services across education, health and care.

It is by following these stages that commissioners can support the realisation of the vision in Transforming care: A national response to Winterbourne View Hospital, which is to ensure all services across England are consistent with established best practice; and deliver good outcomes for all children, young people, adults, older people, and their families.

Resources and further reading

Resources

Children and Families Bill 2013. www.education.gov.uk/a00221161/

Department for Education. ***Parenting programme commissioning toolkit***. www.education.gov.uk/commissioning-toolkit/programme/detail/18

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Royal College of Psychiatrists (2012). ***Enabling people with mild intellectual disability and mental health problems to access healthcare services.*** www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr175.aspx

Foundation for People with Learning Disabilities (2004) ***Green Light for Mental Health***. www.learningdisabilities.org.uk/publications/green-light/

HM Government. (2001). ***Valuing people: a new strategy for learning disability for the 21st century***. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153

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Improving Health and Lives: Learning Disabilities Observatory, Royal College of General Practitioners, Royal College of Psychiatrists (2012). ***Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Groups***. https://www.improvinghealthandlives.org.uk/publications/1213/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups_(CCGs)_-_revised

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Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. (2007). ***Challenging behaviour: a unified approach.*** www.rcpsych.ac.uk/publications/collegereports/cr/cr144.aspx

Royal College of Nursing. (In development). ***Use of restrictive practices in health and adult social care and special schools.*** www.rcn.org.uk/support/consultations/pages/use_of_restrictive_practices_in_health_and_adult_social_care_and_special_schools

Royal College of Speech and Language Therapists. (2013). ***Five good communication standards.*** www.rcslt.org/news/good_comm_standards

Skills for Care. (In development). ***People whose behaviour challenges***. www.skillsforcare.org.uk/Skills/People-whose-behaviour-challenges/People-whose-behaviour-challenges.aspx

The Challenging Behaviour Foundation. (2009/13). ***The challenging behaviour national strategy group charter***. www.challengingbehaviour.org.uk/strategy-group/charter.html

Further reading

Allen, D., McGill, P. et al (2013). Implementing Positive Behavioural Support: Changing Social and Organisational Contexts. ***International Journal of Positive behavioural Support***

Baker, P. (2011). ***Pamphlet for commissioners: services for adults with learning disabilities who display challenging behaviour – well matched and skilled staff***. Kent: The Challenging Behaviour Foundation

Bernard, S., Turk, J. (2009). ***Developing mental health services for children and adolescents with learning disabilities.*** Royal College of Psychiatrists

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Hastings, R.P., Allen, D., Baker, P., Gore, N.J., Hughes, C.J., McGill, P., Noone, S.J., & Toogood, S. (2013). A conceptual framework for understanding why Challenging Behaviours occur in people with developmental disabilities. International Journal of Positive behavioural Support (in press)

Appendix

Detailed Pathway and Policy Specification (McGill, 2013)

Individuals

What needs to happen	Evidence that happening
Behaviour support is based on a holistic assessment (incorporating functional assessment) of the context in which the person's behaviour occurs.	• A copy of a recent (or recently reviewed) assessment report can be provided. • The report provides evidence of assessment of: ◦ history ◦ immediate antecedents and consequences ◦ genetic context ◦ physical health context ◦ mental health context ◦ broader social context ◦ communication and social skills. • The report provides evidence of involvement or attempted involvement in the assessment process of: ◦ the individual ◦ the individual's family, friends and independent advocate ◦ the paid carers supporting the person. • The report provides evidence of the assessment having been conducted in a manner consistent with the Mental Capacity Act. • The report includes a summary which integrates the information gathered into a coherent formulation of the factors influencing the person's behaviour

There is a written, individualised behaviour support plan.	• A written plan can be provided • The written plan is personalised (for example, includes person's name). • The written plan is different to written plans for other individuals. • The written plan is integrated with a wider person-centred plan for the individual. • A named individual has responsibility for implementing, monitoring and reviewing the plan.
The behaviour support plan includes:	
1. a description of the person's challenging behaviour(s)	• The behaviour(s) are operationally defined, observable and measurable.
2. a summary of the most probable reasons underlying the person's challenging behaviour	• The summary is written in everyday language and is consistent with the conclusions of the assessment informing the support plan. • The function(s) of the person's behaviour(s) is/are clearly stated.
3. proactive strategies	• The plan states how to avoid or prevent all of the challenging behaviours identified. • The plan includes one or more, clearly defined strategies for developing the person's ability to communicate or otherwise more effectively influence what happens to them without displaying challenging behaviour. These strategies comprehensively address the identified functions of the behaviour(s).
4. reactive strategies	• The plan specifies how carers should respond to instances of the person's challenging behaviour(s). • The plan includes one or more non-restrictive strategies for responding to instances of the person's challenging behaviour. • Where restrictive strategies (for example, physical intervention, seclusion, prn medication) are included, these are not identified as the first reactive strategy to be used without a clear rationale for this being provided. • Circumstances in which restrictive strategies are recommended are defined unambiguously.

5. monitoring and review arrangements	• The plan specifies expected outcomes (in terms of reductions in challenging behaviour, improvements in quality of life, reductions in restrictive practices) and how these will be measured. • The plan includes a timetable and organisational arrangement for review (for example, through a multidisciplinary meeting in six months).
6. implementation arrangements	• The plan specifies any necessary characteristics for those implementing ("mediators") the strategies described. • The plan specifies how mediators will be trained to reliably and consistently implement strategies. • The plan specifies any additional or changed resources required, such as additional mediators or specific materials.
The plan is implemented, monitored and evaluated.	• Data on the consistency and correctness of implementation shows at least 80 per cent correct implementation. • Data on expected outcomes demonstrates reductions in challenging behaviour and/or improvements in quality of life and/or reductions in restrictive practices leading to review and continuation of the plan; or • Data on expected outcomes demonstrates no change or worsening in challenging behaviour and/or quality of life and/or use of restrictive practices leading to reassessment and redevelopment of behaviour support strategies.

Organisations

What the organisation needs to do	Evidence that this is happening
Provide leadership for, and take ownership of, the implementation of Positive Behaviour Support (PBS)	• Clear, written statement of policy and practice commitment to PBS that is available to all staff and accessible to service users and family members. • At least one member of executive team/ Board has specific responsibility for organisation-wide implementation of PBS. • At least one member of executive team/ Board (probably the same person as in 2) has experience and training in using a PBS approach with individuals.
Develop and maintain an inclusive strategy for organisation-wide PBS	• The strategy includes components relating to: ◦ the primary prevention of challenging behaviour through organisation-wide procedures and methods of working ◦ the secondary prevention of challenging behaviour through the identification and support of at-risk individuals; ◦ the implementation of PBS with individuals who display challenging behaviour of a defined severity. • The strategy is informed by consultation with service users, frontline staff and family members and is reviewed annually.
Provide person-centred supports and services	• Services provided to individuals are clearly related to the needs and aspirations of those individuals and their families/friends/ advocates. • The organisation can provide recent and checkable examples of having changed aspects of its provision in response to requests/complaints by individuals and their families/friends/advocates. • The organisation can provide recent and checkable examples of having changed or audited aspects of its organisational procedures (for example, duty rotas, staff recruitment, quality assurance etc) to adapt them to the needs and aspirations of individuals and their families/friends/ advocates.

Provide acceptable physical environments	• The physical environments where services are provided are within a typical range (for that type of environment) in respect of: ◦ space ◦ aesthetic appearance ◦ noise ◦ state of repair. • Standard adaptations to fittings and fabric have been made to increase environmental safety without disrupting the environment's typical nature. • The organisation can provide recent and checkable examples of adaptations being made to the physical environment to reduce the likelihood of challenging behaviour and/or to increase the safety of the individual or others.
Provide an active support model of care	• All service users routinely participate in personalised, meaningful activities for the majority of their time. • All service users have personalised and predictable routines and timetables. • Staff are skilled in providing personalised levels and kinds of assistance – enhancing participation, preventing challenging behaviour and reducing risk. • The organisation collates information on levels of participation in meaningful activity and uses the information to review and change support arrangements
Provide well-trained and supported staff, deployed in the right places at the right times	• All support staff receive in-house training in PBS which is refreshed at least annually. • All support staff with a leadership role (for example, shift leaders, frontline managers) have completed, or are undergoing, more extensive training in PBS which includes practice-based assignments and independent assessment of performance. • All staff with a role (which may be peripatetic or consultant) in respect of assessing or advising on the use of PBS with individuals have completed, or are undergoing, externally-validated training in PBS which includes both practice- and theory-based assignments with independent assessment of performance at National Qualifications Framework Level 5 or above.

	• All staff involved in the development or implementation of PBS strategies receive supervision from an individual with more extensive PBS training and experience. Staff in consultant roles are supervised by an individual (within or outside the organisation) with a relevant postgraduate qualification, for example, applied behaviour analysis, positive behaviour support, clinical psychology. • The organisation can provide examples of (or equivalent plans for) the flexible deployment of staff to support an individual during a period of crisis.
Have a quality assurance strategy which is driven by data and a desire for organisational development and learning	• A range of data is systematically collated and considered within the organisation on a monthly basis, informing organisational responses in respect of specific individuals or services: ◦ frequency and severity of challenging behaviour ◦ use of restrictive practices (physical intervention, seclusion, prn medication) ◦ injuries sustained as a result of challenging behaviour ◦ safeguarding alerts ◦ extent and variety of service user participation in meaningful activities. • A range of data is systematically collated and considered within the organisation on an annual basis, informing organisational responses in respect of specific services or more widely: ◦ attainment of specific objectives identified in PBS plans for individuals ◦ service user and family carer/friend/ advocate satisfaction ◦ support staff turnover, sickness, stress and morale ◦ changes in the abilities and general health of service users.

Winterbourne View Joint Improvement Programme

This programme is led by the Local Government Association (LGA) and NHS England, and funded by the Department of Health.

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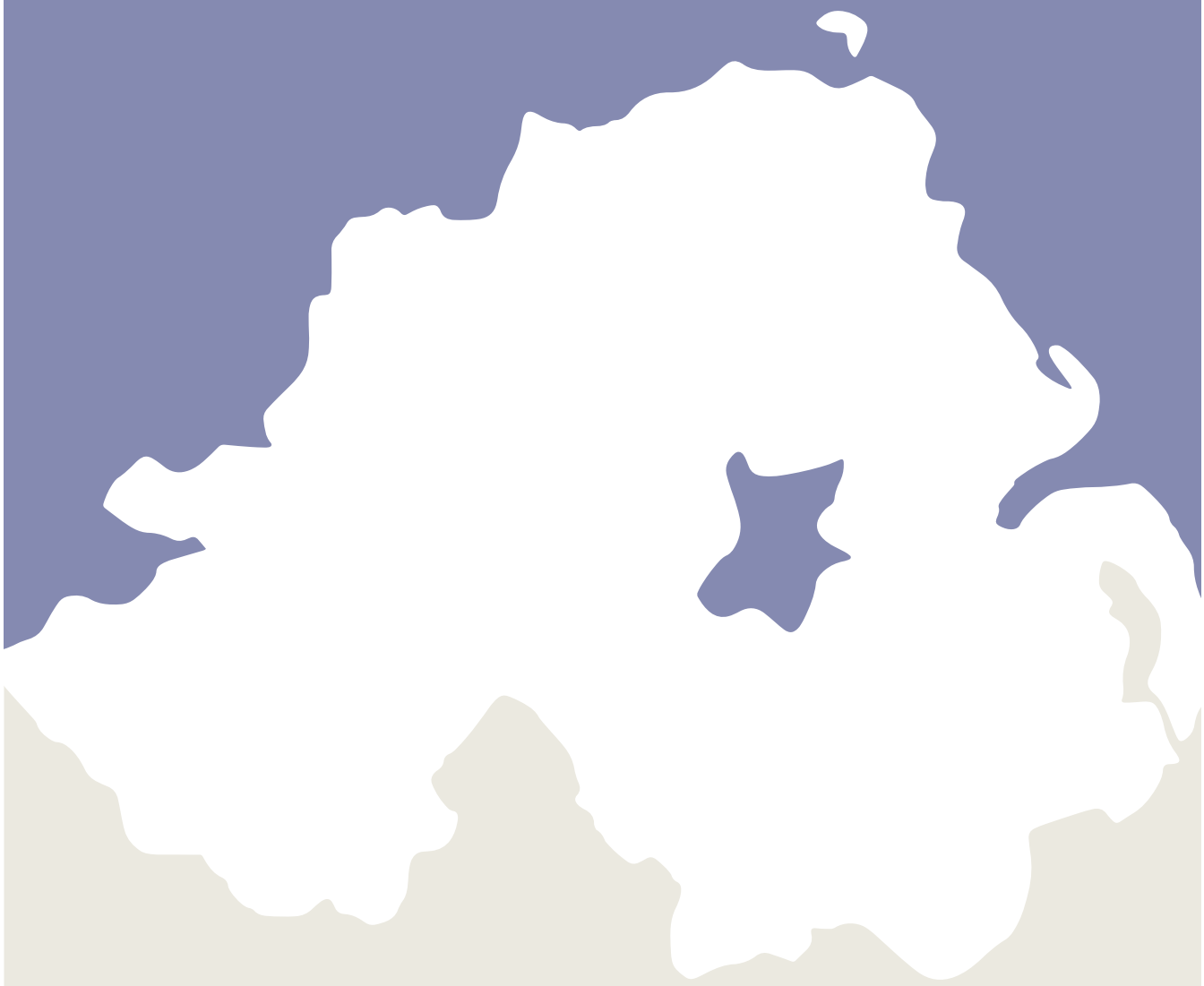
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L14-105

THE RIGHT TIME, THE RIGHT PLACE

An expert examination of the application of health and social care governance arrangements for ensuring the quality of care provision in Northern Ireland

DECEMBER 2014



Review Team | Sir Liam Donaldson | Dr Paul Rutter | Dr Michael Henderson

CONTENTS

1 CONTEXT 3

2 TERMS OF REFERENCE AND WORKING METHODS 5

3 THE CHALLENGES OF DELIVERING HIGH QUALITY, SAFE CARE 7

4 KEY THEMES ESTABLISHED BY THE REVIEW 8

4.1 A system under the microscope 8

4.2 The design of the system hinders high quality, safe care 11

4.3 Insufficient focus on the key ingredients of quality and safety improvement 18

4.4 Extracting full value from incidents and complaints 22

4.5 The benefits and challenges of being open 34

4.6 The voices of patients, clients and families are too muted 37

5 CONCLUSIONS 39

5.1 Relative safety of the Northern Ireland care system 39

5.2 Problems generated by the design of the health and social care system 39

5.3 Focus on quality and safety improvement 40

5.4 The extent to which Serious Adverse Incident reporting improves safety 41

5.5 Openness with patients and families 43

6 RECOMMENDATIONS 44

1 CONTEXT

Throughout the developed world much healthcare is of a very high standard. The range of technologies and drugs available to diagnose and treat illness greatly increased during the second half of the 20th Century, and into the 21st, offering life and hope where patients' prospects were once bleak. As a consequence, the number of people living with disease and needing years or even decades of support from care systems has expanded enormously.

The ageing population of today is a central consideration in a way that was not foreseen when modern healthcare came into being in the aftermath of the Second World War. Today, people are living much longer and developing not just one disease but several that co-exist. In old age, the twin states of multi-morbidity and frailty are creating acute and long-term health and social care needs on an unprecedented scale.

Technology has continued its rapid and beneficial advance, opening up new opportunities for diagnosis and treatment but bringing even greater numbers through the doors of hospitals and health centres. Citizens experience the benefits of an advanced consumer society and when they encounter the health and social care system, they rightly expect it to be commensurate with this. Rising public expectations are a further driver of demand for healthcare. There are other, less predictable sources of pressure on services. For example, a change in the pattern of winter viruses can bring surges in demand that threaten to overwhelm emergency departments. In response to all of this, the size of budgets devoted to health and social care has had to expand dramatically.

At the epicentre of this complex, pressurised, fast-moving environment is the patient. The primary goal of the care provided must always be to make *their* experience, the outcome of *their* condition, *their* treatment, and *their* safety as good as it gets. Health and social care systems around the world struggle to meet this simple ideal. Evaluations repeatedly show that: variation in standards of care within countries is extensive; some of the basics such as cleanliness and infection are too often neglected; evidence-based best practice is adopted slowly and inconsistently; the avoidable risks of care are too high; there are periodic instances of serious failures in standards of care; and, many patients experience disrespect for them and their families, bad communication and poor coordination of care.

The health and social care system in Northern Ireland serves a population of 1.8 million. People live in urban, semi-rural or rural communities. Responsibility for population health and wellbeing, and the provision of health and social care, is devolved to the Northern Ireland Assembly from the United Kingdom government in Westminster. As in other parts of the United Kingdom, the Northern Ireland health service operates based on the founding principles of the National Health Service - the provision of care according to need, free at the point of access and beyond, funded from taxation. However, since the advent of devolved government, England, Scotland, Wales and Northern Ireland have adopted their own strategies for: promoting and protecting health; preventing disease; reducing health inequalities; and, planning and providing health and social care services. The countries have developed different structures and functions within their systems to meet these responsibilities. Thus, they vary in features such as: arrangements for planning and contracting of care; levels of investment in public health, primary and community care versus hospital provision; funding models; incentives; use of the independent sector; managerial structures; and, the role of the headquarters function.

Various agencies, groups and strategies populate the quality and safety landscape of Northern Ireland. Quality 2020 is the flagship

ten-year strategy. Commissioned by the Minister of Health, Social Services and Public Safety in 2011, its vision is to make Northern Ireland an international leader in high quality, safe care. Quality 2020 is sponsored by the Chief Medical Officer and led by the Department of Health, Social Services and Public Safety. It has a steering group, a management group, an implementation team, project teams, and a stakeholder forum. These bring together representatives from across the statutory care bodies and beyond. Separately, a Health and Social Care Safety Forum convenes a similar group of stakeholders.

The Regulation and Quality Improvement Authority (RQIA) is the main regulator in Northern Ireland's care system. Many of the social care providers, and some healthcare providers, are registered with the Regulation and Quality Improvement Authority. However it does not register the Trusts, which provide the bulk of health and social care in Northern Ireland, or general practices. The Trusts' relationship with the regulator therefore has a somewhat softer edge than might be the case if they were formally registered, although an expanded role has been announced recently by the Minister.

Northern Ireland takes a keen interest in the work of quality and safety bodies elsewhere in the United Kingdom, and often implements their guidance and recommendations. The National Institute for Health and Care Excellence (NICE) and the former National Patient Safety Agency have been prominent in this regard.

Technical quality and safety expertise sits not in the Health and Social Care Board, but next door in the Public Health Agency. The Public Health Agency has a statutory role in approving the Health and Social Care Board's commissioning plans. Two executive directors are jointly appointed between the Public Health Agency and the Health and Social Care Board. There are therefore mechanisms through which quality and safety expertise should inform the Board's work. The Quality Safety Experience Group is jointly managed between these two agencies. It meets monthly and its primary focus is learning. It looks at patterns and trends in incidents and initiates thematic reviews.

In short, there is a good degree of activity in the sphere of quality and safety improvement. There are some unusual features of the landscape, which will emerge in some detail in this Review.

The way in which central bodies seek to achieve compliance with their policies and make broader improvement changes is based on a very traditional and quite bureaucratic management model. There is much detailed specification of what to do, how to do it, and then extensive and detailed checking of whether it has been done. This has strengths in enabling the central bodies and the government to demonstrate their accountability and give public assurances, but it can greatly disempower those at the local level. It can cause those managing locally to look up, rather than looking out to the needs of their populations.

The alternative is a style of leadership based on inspiration, motivation and trust that those closer to the front line will make good judgments and innovate if they are encouraged to do so. Perhaps the relationship needs a lighter touch, to liberate freer thinking on how to make services better for the future.

2 TERMS OF REFERENCE AND WORKING METHODS

The Review's formal Terms of Reference are available online[1]. The overall aim of the Review has been to examine the arrangements for assuring and improving the quality and safety of care in Northern Ireland, to assess their strengths and weaknesses, and to make proposals to strengthen them.

The analysis in this report is based on extensive input from, scrutiny of, and discussion with people across the health and social care system in Northern Ireland. Each of the main statutory organisations made formal submissions to the Review (including records of board meetings, policies, and plans). The Review put substantial emphasis on travelling around the system – both literally and figuratively – to see it from as many different angles as possible, and to come to a rounded view.

The Review Team visited the five Health and Social Care Trusts, the Northern Ireland Ambulance Service, the Department of Health, Social Services and Public Safety, the Health and Social Care Board (and its Local Commissioning Groups), the Public Health Agency, the Patient and Client Council, and the Regulation and Quality Improvement Authority. In each, the Review Team met with the executive team (Chief Executive and executive directors) and, in most cases, the Chair of the Board and other non-executive directors. The management team of each organisation gave a series of presentations covering the areas of interest to the Review, and Review Team members asked questions and led discussion.

During their visit to each Health and Social Care Trust and to the ambulance service, Review Team members also led focus groups discussions amongst frontline staff. In each of the five Health and Social Care Trusts, for example, the team met with separate groups of consultants, nurses, junior doctors, and other health and social care professionals. Senior managers were not present for these discussions. Participants were encouraged to speak openly, and generally did so. It was understood that no comments would be attributed to individuals. The focus groups centered on any concerns about quality and patient safety in their organisation and incident reporting, and other highly-related topics. The team also met with two groups of general practitioners.

The Review Team paid particular attention to the experiences of people who have come to harm within the Northern Ireland health and social care system. At each Trust, including the ambulance service, the team reviewed two recent Serious Adverse Incidents in detail, particularly considering the incident itself, the way in which patients and families were kept informed and involved, and the learning derived. The team later returned to two Trusts to review further incidents, this time selected by the Review Team from a list of all serious adverse incidents in the previous year. The Review Team met with people who have come to harm. Most of these meetings were in person; some were by telephone. In addition to people affected directly, the Review Team spoke to their family members and carers. We are particularly grateful to all of these individuals for giving of their time, and for graciously sharing their stories with us, which were often painful.

Finally, the Review Team met with a series of other individuals and groups that form part of the wider health and social care system in Northern Ireland, or have a strong interest in it. These were: the Attorney General, the British Medical Association, the Chest Heart and Stroke Association, the Commissioner for Older People for Northern Ireland, Diabetes UK, the General Medical Council, MacMillan Cancer Support, the Multiple Sclerosis Society, the Northern Ireland Association of Social Workers, the Northern Ireland Human Rights Commissioner, the Northern Ireland Medical & Dental Training Agency, The Honourable Mr Justice O'Hara,

[1] http://www.dhsspsni.gov.uk/tor-080414.pdf

the Ombudsman for Northern Ireland, the Pain Alliance of Northern Ireland, Patients First Northern Ireland, the Royal College of Nursing, and the Voice of Young People in Care. Other patient and client representative groups were invited to meet with the Review Team, or to make written submissions.

To inform one aspect of the Review, the Regulation and Quality Improvement Authority oversaw a look-back exercise, reviewing the handling of all Serious Adverse Incidents in Northern Ireland between 2009 and 2013. Their report was received late in the Review process, but has been considered by the Review Team and reflected in this report.

Between starting and producing its final report, the Review Team has had a relatively short period of time. It has not been possible to undertake research, extensive data analysis, large-scale surveys of opinion, or formal evidence-taking sessions. However, the documents reviewed, the meetings held, the visits made, and the views heard have given a strikingly consistent picture of quality and safety in the Northern Ireland health and social care system. The Review Team is confident that a longer exercise would not have produced very different findings.

3 THE CHALLENGES OF DELIVERING HIGH QUALITY, SAFE CARE

Patients in hospitals and other health and social care services around the world die unnecessarily, and are avoidably injured and disabled. This sad fact has become well known since the turn of the 20th Century. Awareness of it has not been matched, unfortunately, by effective action to tackle it.

There is consistency in the types of harm that occur in high-income countries. In low-income countries, harm is mainly related to lack of infrastructure and facilities, as well as poor access to care. However, in North America, Europe, Australasia, and many parts of Asia and the Middle East, analysis of incident reports and the findings of patient safety research studies shows a different, strikingly consistent pattern. Between 3% and 25% of all hospital admissions result in an adverse incident, about half potentially avoidable. Within any health or social care service, there are many potential threats to the quality and safety of the care provided:

1. Weak infrastructure - the range and distribution of facilities, equipment and staff is inadequate to provide fair and timely access to required care.
2. Poor co-ordination - the components of care necessary to meet the needs of a patient, or group of patients, do not work well together to produce an effective outcome and to be convenient to patients and their families.
3. Low resilience - the defences in place, and the design of processes of care, are insufficient to reliably protect against harm such as that resulting from errors or from faulty and misused equipment.
4. Poor leadership and adverse culture - the organisation or service providing care does not have clear goals and a philosophy of care that it is embedded in the values of the organisation and visible in every operational activity.
5. Competence, attitudes, and behaviour - the practitioners and care-providers working within the service lack the appropriate skills to deal with the patients that they encounter, or they are unprofessional in their outlook and actions, or they do not respect other team members, nor work effectively with them.
6. Sub-optimal service performance - the way that the service is designed, organised and delivered means that it does not deliver processes of care to a consistently high standard so that over time it chronically under-performs often in a way that is not noticed until comparative performance is looked at.
7. Slow adoption of evidence-based practice - the service does not conform to international best practice in particular areas of care or overall.

The amount of each type of harm varies but the overall burden has changed little over the last decade despite the unprecedented priority that has been given to patient safety within these health systems. Little is known about the level and nature of harm in primary care, though more attention is now being given to it.

Although these threats are described in relation to health, they apply also to social care. Many are strongly related to the level of resources that is available to a health and social care system. The extent to which each problem is present varies hugely across the world, within countries, and even between different parts of the same service or area of care provision.

In some ways it is reassuring to believe that the problems of quality and safety of care are somehow universal, and that no country has the answers. This is dangerous thinking. The best services in the world show that even with the all the pressures of large numbers of patients, many with complex needs, excellence can be achieved consistently across all fields of care. The Northern Ireland health and social care service must not be satisfied with 'good enough.' With a clear recognition of the reasons for its current problems in quality and safety of care, and with everyone working together, it could be amongst the best in the world.

4 KEY THEMES ESTABLISHED BY THE REVIEW

The Review established six key themes. Each is set out in some detail below. Exploration of these themes provides the basis for the Review's conclusions (in section 5) and recommendations (section 6).

4.1 A SYSTEM UNDER THE MICROSCOPE

Northern Ireland's health and social care system is subject to a high, perhaps unrivalled, level of media coverage – much of it negative. Over recent years, it has also been the subject of a series of high profile inquiries. All have highlighted numerous failings in the leadership and governance of care. Many have made extensive recommendations and the extent to which these have been implemented has itself been controversial. The pressures of increasing demand for care have meant that access has been more difficult. There has been a focus on over-crowding and delays in emergency departments, the front door of the hospital service. All of this has meant that the last five years has been a period of unprecedented scrutiny of the way that health and social care in Northern Ireland is planned, provided and funded.

4.1.1 A stream of inquiries highlighting service failures

The number of recent major investigations and inquiries into shortfalls in standards of care in health and social care services in Northern Ireland is striking in relation to the size of its population. This does not necessarily mean that such occurrences are commoner than elsewhere in the United Kingdom. It may simply be that the level of public and media scrutiny is higher and the pressure from this triggers a statutory response by government ministers and officials. The end-result is that the profile of the service is more often one of failure rather than success.

In March 2011, Dame Deirdre Hine, a former Chief Medical Officer for Wales, issued the report of her inquiry into deaths from *Clostridium difficile* in hospitals in the Northern Trust area. She had been brought in to investigate 60 deaths that had been attributed to the organism. She found that the true figure was 31 deaths. She found management, organisational, clinical governance and communication failings. She made 12 recommendations. It took 23 months to complete.

In February 2011, the Belfast Trust recalled 117 dental patients following a review of the clinical performance of a senior consultant. An independent inquiry commissioned by the Minister was published in July 2013 and made 45 recommendations. An action plan developed by the Department of Health, Social Services and Public Safety identified 42 key actions including on staffing, training, supervision and clinical governance. In November 2013, the Regulation and Quality Improvement Authority conducted an assessment of implementation of those actions.

In December 2011, an independent report by the Regulation and Quality Improvement Authority examined delays in the reporting of plain X-rays in all Trusts after concerns were expressed about delays in two hospitals. The review found that serious delays had occurred and were caused by three main factors: a shortfall in consultant radiology staffing, a growth in numbers of x-rays to be reported after the introduction of digital imaging and the introduction of a new policy to report on all hospital chest x-rays because of worries about patient safety. The review found that there was little awareness at regional level that a serious backlog in reporting was developing with potential risks to patients due to delayed diagnosis. The review made 14 recommendations.

In May 2012, Doctor Pat Troop, former chief executive officer of the Health Protection Agency in England, issued her final report of the independent investigation into an outbreak of infections in neonatal units due to the organism *Pseudomonas aeruginosa*. Five babies had died in the outbreak and 32 recommendations were made covering technical matters, management, governance, communication, training, and outbreak management.

In April 2012, the Minister asked for special measures to be put in place to oversee the Belfast Trust because of major concerns about serious adverse incidents in the emergency department, recommendations from the Pseudomonas review, reviews of paediatric congenital cardiac surgery and recommendations of the dental inquiry.

In December 2012, the Minister appointed a Turnround and Support Team to go into the Northern Health and Social Care Trust because of concerns about the weakness of governance and quality assurance systems, the paucity of clinical leadership, and uncertainties about the reliability of mortality data. This particular Trust has had five chief executive officers in the last seven years.

In June 2014, the Regulation and Quality Improvement Authority reported on its review of unscheduled care services in the Belfast Trust. The concerns that led to the review included: the declaration of a major incident, 12-hour waiting time breaches, dysfunctional patient flows and gross overcrowding of patient care areas. This triggered a fuller review that looked at matters region-wide. This produced 16 recommendations.

The dominant inquiry in recent times remains the *Independent Inquiry into Hyponatraemia–Related Deaths*. It is examining the deaths of children after being transfused in hospital with a fluid that was subsequently found to carry a significant risk. Concerns had been raised by the parents and others that this risk should have been identified much earlier, that action should have been taken to stop it being used, that there was a cover-up and that systems for monitoring safety were inadequate. It is being chaired by John O'Hara QC and was commissioned in 2003/4 but, because of other legal processes, was not able to hear full evidence until more recently. The report is expected in 2015.

The criticisms in inquiries like these have been largely justified and must be followed by action to improve the situations. Whether establishing formal, often lengthy, and costly inquiries is the right way to drive improvement is very debatable. Certainly doing so as the normative response to failure has important disadvantages. In particular, it often paralyses the organisation under scrutiny as its staff become pre-occupied with preparing evidence and supplying information. The learning is often put on hold - sometimes never to be returned to - until the inquiry is over. The burden of recommendations to be implemented and progress-checked can be overwhelming, so that the implementation becomes a bureaucratic exercise rather than a watershed moment for leadership, culture and the content of practice. It might be better to define a clear threshold for when a full-blown inquiry is initiated.

4.1.2 Intense political and media interest in service provision

Northern Ireland's health and social care system is subject to a high degree of political, as well as media, interest. This is a valid and expected feature of a publicly-funded system. Ironically, though, the way in which this interest becomes manifest often creates results that are counter to the true public interest. There have been many examples of local communities – and therefore their politicians – wanting to keep a local hospital open, contrary to the analysis of service planners. This has created

a situation in which Northern Ireland has more inpatient units than is really justified for the size of population, and the expense of maintaining them impedes provision of other services that would represent better value for money and more appropriately meet the needs of the population. Likewise, political pressure and media interest has prevented the salaries of top managers from being raised too substantially. However, senior executives in the Northern Ireland care system are now paid much less than their counterparts elsewhere in the United Kingdom. The public would be better served if their care system could compete to attract the very best managerial talent. The pressure to keep salaries down may be penny-wise and pound-foolish.

4.2 THE DESIGN OF THE SYSTEM HINDERS HIGH QUALITY, SAFE CARE

When a quality or safety problem arises somewhere within the Northern Ireland care system, the tendency is to point to the individuals or services involved, and to find fault there. As with so many other features identified in this report, this tendency is far from unique to Northern Ireland. But it represents, in the view of the Review Team, too narrow a focus. In reality, the greatest threats to the quality of care that patients receive, and to their safety, come from the way in which the system as a whole is designed and operates.

In short, the services that exist are not the services that the population truly requires. Political and media pressure acts to resist change, despite the fact that change is much needed. It is not clear who is in charge of the system, and the commissioning system is underpowered. All of this compounds the pressures, creating high intensity environments that are stressful for staff and unsafe for patients – particularly out of hours. These effects are explored further below.

The Northern Ireland care system has some elements in common with the other United Kingdom countries, and some that differ. Observers, asked to describe the Northern Ireland system, often point first to the integration of health and social care as its distinguishing feature. It is clear though from the findings of this Review that whilst the integrated design of the system has great advantages, it falls well short of perfection in promoting the highest standards of care and in preventing the dysfunctions in the co-ordination of care that are prevalent elsewhere.

4.2.1 Service configuration creates safety concerns

A striking feature of the provision of care in Northern Ireland is the wide distribution of hospital-type facilities outside the major city, Belfast, some serving relatively small populations by United Kingdom standards. This geographical pattern leads to specialist expertise being too thinly spread, and to the patchy availability of experienced and fully competent staff. It means that it is not possible everywhere to deliver the same quality of service for an acutely ill person at 4 a.m. on a Sunday as at 4 o'clock on a Wednesday afternoon. There is therefore a two-tier service operating in Northern Ireland - in-hours and out-of-hours - that is more pronounced in some places than in others. This is one of the biggest influences on the quality and safety of care. Delivery of services is too often higher risk than it should be in a 21st Century healthcare system because of the pattern of services.

Past analysts and observers have pointed to the current level and siting of provision not being in keeping with maintaining high standards of care. Some populations are just too small to warrant full-blown general hospital facilities yet they are kept in place because of public and political pressure. Amongst those who work within the system, there is deep frustration that the public are not properly informed about the higher risks of smaller hospitals and that the misapprehension that alternative forms of provision are in some way inferior to a hospital. These issues are illuminated by two wry comments made to the Review: "the word 'hospital' should be removed from the Oxford English Dictionary" and " Northern Ireland needs more roads not more hospitals."

Despite its small size, there is less co-operative working across Northern Ireland than might be expected. Silos reign supreme. The Health and Social Care Board runs regional commissioning teams, covering areas such as learning

disability, mental health, prison health and a very broad category of 'hospital and related services'. However, particular scope exists to do more in improving standards in areas of clinical care where there is a strong evidence base for what is effective. In the cases where clinicians have worked together across organisational boundaries, remarkable transformations have occurred. This happened in cardiology where a regionally planned and coordinated service means that more patients with heart attacks get treated early, get less damage to their hearts, and more people live rather than die. The Ambulance Trust is the only one of the six Trusts organised on a regional basis. The Review Team was very struck by how much pressure this important service was under. This is consistent with the headline stories in other parts of the United Kingdom about ambulance services being unable to meet their service standards because of huge surges in demand. All parts of the service are taking the strain – from those in the control centre to those on the road. Yet when the detail of their situations is explored in depth, it is clear again that the problems stem from dysfunctional patient flows and pathways where different parts of the system are not working together.

4.2.2 Adverse consequences for primary and social care

The pressures on hospitals have consequences for primary and community services. There is a constant need for hospitals to discharge patients as soon as they possibly can to free-up beds for new admissions. Generally, this happens when an older person is judged medically fit for discharge. However, this does not necessarily mean that their physical and social functioning has reached a level where they can cope with a return to the community. The Review was told by general practitioners and social care staff that they often have to step in to provide unscheduled support in such circumstances and, because of inadequate communication at the time of discharge, they can be left in the dark about ongoing treatment plans and even be unclear about something as basic as a patient's medication regime. Some general practitioners spoke of spending long, frustrating hours trying to get to speak to a hospital doctor about their patient, without success.

Over the last decade, there has been a major increase in the dependency levels of people being cared for in the community. For example, the use of PEG feeding (directly into the stomach through a tube in the skin) is now commonplace in community settings, whereas it used to be a hospital treatment. As a result, community nursing staff have much more complex caseloads. There is also greater complexity in the other forms of disability, as well as in the treatments that people are receiving and other technologies that are supporting them.

The Review Team was very struck by the experience of one on-call pharmacist whom they talked to. He was responsible for preparing the discharge medication for patients leaving hospital on a particular Bank Holiday weekend. He reported filling a doctor's prescription for 20 different medications for each of four patients. This strongly illustrates several points. Firstly, it is not right that such an excessive amount of medication should be routinely prescribed. It should be rigorously reviewed and adjusted. Secondly, it again shows the complexity and multiple conditions affecting many patients, who move regularly between hospital and community. Thirdly, it highlights the opportunity for a much stronger role for under-appreciated disciplines like pharmacy on the boundary between hospital and population.

The integration of health and social care means that the Review Team's discussions within Trusts necessarily took account of the important role of social care staff, and particularly social workers. They are a vital part of the workforce and although under equal pressure to their

healthcare counterparts, the Review was encouraged to hear about the strong emphasis on professional development in Northern Ireland and the particular expertise in specialist areas such as adult safeguarding.

The knock-on effects of pressures in the hospital system for community services are not restricted to post-discharge matters. Many hospital departments are so pre-occupied with urgent work and the high volume of patients that they do not have time to provide proper responses when patients or their doctors make contact to ask about progress with an outpatient appointment or test results.

4.2.3 High-pressure environments fuel risk to patients and sap morale

The demand from patients who need emergency care, as well as those who require planned investigations and treatments, is extremely high. The pressures on emergency departments and hospital wards are very great. Over-crowded emergency departments and overflowing hospital wards are high-risk environments in which patients are more likely to suffer harm. This is because delays in assessment and treatment occur but also because staff have to make too many important and difficult decisions in a short space of time - what psychologists call cognitive overload. That they will make mistakes and misjudgments is inevitable, and some of them will be in life-and-death areas. Experience in other safety-critical industries, and research, shows that high-pressure, complex, and fast-moving environments are dangerous. If inadequate staff levels are added to the mix, risks escalate further.

The Review met with many groups of health and social care staff, speaking on condition of anonymity. They are overwhelmingly conscientious people who feel deeply for their patients and want to excel in the care that they deliver. Yet, the workloads in some situations are unacceptably high; so too are stress levels. The stress comes not only from the large numbers of cases per se, but much more from the feeling of staff that they are not giving patients the quality of care they were trained to deliver. There is guilt too in knowing that they are forced to compromise their standards to levels that they would not accept for their own families. The phrase "doing just enough" was repeatedly used in the Review's meetings with front-line staff. There are extra pressures for some groups of staff. Doctors in training can find themselves in situations that are beyond their competence and experience. Sometimes they can call on back-up from senior staff, sometimes they have to do their best until the morning or Monday comes. Some nurses can find themselves dealing with an unacceptably large number of patients on a hospital ward at night. They too feel that they are having to lower their professional standards. This assessment is not based on isolated anecdotes but much more widespread and consistent accounts.

4.2.4 Transformation efforts are moving slowly

Transforming Your Care began as a substantial review of health and social care provision in Northern Ireland, commissioned in 2011. The review was led by the then-Chief Executive of the Health and Social Care Board, supported by an independent panel. It was a strong, forward-thinking piece of work.

The whole of the United Kingdom, like most developed countries, has a fundamental problem: the health and social care system that it has is not the health and social care system that it needs. The pattern of ill-health in the population has changed substantially since the systems were founded, and the systems have not changed to keep up. *The Transforming Your Care review* set out a convincing case for change. It described inequalities in health, rising demands, and a workforce under pressure. It particularly established that Northern Ireland has too many acute hospitals

- that elsewhere in the United Kingdom, a population of 1.8 million people would likely be served by four acute hospitals – not the 10 that Northern Ireland had.

Transforming Your Care set out a broad new model of care, which aimed to be tailored to today's needs and person-centered. In practical terms, its most substantial proposal was to move £83 million away from hospitals and give it to primary, community and social care services.

Those interviewed by this Review Team unanimously supported the need for this initiative. The widespread feeling, though, is that *Transforming Your Care* is simply not being implemented.

As a result of weak communication and little action, there is substantial skepticism about *Transforming Your Care*. The Review Team heard it variously referred to as "Transferring Your Care", "Postponing Your Care", and even "Taking Your Chances". One of its central concepts, 'shift left', is viewed particularly warily. Carers see it as a euphemism for dumping work onto them; general practitioners likewise. Those working in the community see their workload increasing, and worry that there is no clarity at all about what the overall care model is supposed to be.

The frustrations of the general practitioner community in Northern Ireland that *Transforming Your Care* has not worked, is not properly planned nor funded, has led them to take matters into their own hands and form federations. General practices themselves are financially contributing to these, in a move to establish community-centered care pathways.

The needs that *Transforming Your Care* sets out to address are becoming ever more pressing. Its implementation needs a major boost in scale and speed, and communication needs particular attention.

4.2.5 An under-powered system of commissioning

At 1.8 million, the population of Northern Ireland is relatively small to justify what is a quite intricately designed health and social care management structure. In addition to the Department of Health, Social Services and Public Safety, there are six Trusts, a Health and Social Care Board with five Local Commissioning Groups, a Public Health Agency, and several other statutory bodies.

A central feature is the split between care providers and commissioners, which increases the complexity of the system and its overhead costs. This began life as the so-called purchaser-provider split, introduced by Margaret Thatcher's government in the late-1980s. In various iterations, it has remained a feature of the NHS ever since. The introduction of a purchaser-provider split was originally intended to create a competitive 'internal market' to drive up quality and so increase value for money. However, the scope for genuine competition has always been very limited. The term 'commissioning' subsequently superseded 'purchasing'. Commissioning involves a wider set of functions – assessing need and planning services accordingly, and the use of financial incentives to intentionally drive the system's development relating to the type of services provided, their quality and their efficiency.

Within the United Kingdom, the English NHS has the most developed commissioning system. NHS England, the national commissioning board, is now separate from the central government Department of Health. It is a pure commissioning organisation, completely free from overseeing the performance of Trusts. Its only relationship with the provider side of the market is through the commissioning process. It devolves the vast majority of funds to local Clinical Commissioning Groups (of general practitioners) that make decisions about the allocation of money against a national

framework of policies and goals. Services are priced under a tariff system. This tariff has become increasingly complex, to facilitate locally agreed variation and to incorporate pay-for-performance elements.

There are several contextual differences between England and Northern Ireland, of which the most obvious is population size. In England, the overhead costs associated with establishing and administering a complex tariff system are essentially divided between 53 million people. With a population one-thirtieth the size, the cost per head of running a similar system in Northern Ireland would be difficult to justify.

The problem for Northern Ireland is that it has gone just partially down the commissioning path. It does not have the benefits of a sophisticated commissioning system, yet has the downside of increased complexity and overhead costs. The worst of both worlds.

Northern Ireland has no service tariffs. The Health and Social Care Board allocates money by a process akin to block contracting. This approach was abolished years ago in England because it was considered old-fashioned, crude and not conducive to achieving value for money. Fully developed tariff systems reimburse providers on a case-by-case basis, with the amount paid dependent on the diagnosis or the procedure undertaken, the complexity of the patient and, in some cases, measures of the quality of care. In Northern Ireland, the funding system is far more basic. Staff the Review Team spoke to believed that it makes no distinction, for example, between a cystoscopy (a simple diagnostic procedure, usually a day case) and a cystectomy (a complex operation), a clear absurdity if true.

Northern Ireland's five Local Commissioning Groups are not like England's Clinical Commissioning Groups. The Local Commissioning Groups have a primary focus on identifying opportunities for local service improvement. They have very few resources and, in effect, are advisers and project managers rather than commissioners. England's Clinical Commissioning Groups, by stark contrast, have a high degree of control over resource allocation.

It is imperative, somewhere in the system, for needs to be assessed, services planned and funds allocated. Whichever part of the system is responsible for this must be sufficiently resourced to do it well – arguably, the Health and Social Care Board is currently not.

The Northern Ireland system would benefit from stronger thought- leadership from within. There is no established health and social care think-tank, and some key disciplines such as health economics are not strongly represented.

Northern Ireland could choose to go down any number of different routes. It could strengthen the current Health and Social Care Board, particularly to create a tariff that includes a strong quality component. Alternatively, it could devolve budgetary responsibility to the five Trusts, making them something akin to Accountable Care Organisations in other countries, responsible for meeting the health and social care needs of their local population. The Trusts would then buy in primary care services, and contract between themselves for tertiary care services.

Recommending a commissioning model is beyond the scope of this Review. It is clear, though, that the Northern Ireland approach to commissioning is not currently working well, and that this is surely affecting the quality of services that are being provided. For that reason, the Review Team must recommend that this issue be addressed.

4.2.6 Who runs the health and social care system in Northern Ireland?

It was instructive for the Review Team to have asked this question of many people. The question elicited a variety of answers, the common feature of which was that no one named a single individual or organisation. Indeed, most reflected their uncertainty with an initial general comment. Typical was a remark like: "The Minister has a high profile."
When pressed to directly answer the question: who runs the service? Their answers included: "The Minister", " The Permanent Secretary in the Department of Health", " The Chief Executive of the Health and Social Care Board", and " The Director of Commissioning of the Health and Social Care Board."

These responses reflect the complexity of the governance arrangements at the top of the health and social care system in Northern Ireland. They show that ambiguity has been created in the minds of people – both clinicians and managers – throughout the system.

The question of who is in charge is both simple and subtle. Whilst overall accountability versus calling the shots versus making things happen are aspects of governance that would have a single leadership locus in many places, this is not the case in Northern Ireland. There is no single person or place in the organisational structure where these things come together in a way that everyone working in the service, the public and the media clearly understand.

The present arrangements have evolved over time but the Review of Public Administration in 2007 led to many of them. Prior to this the Department of Health, Social Services and Public Safety was larger and oversaw four Commissioning Boards and 18 Trusts. There were highly-centralised control mechanisms and the service was subjected to many and frequent circulars and directives. Since then there has been a smaller Department of Health, Social Services and Public Safety that is more focused on providing policy support to the Minister. A single Health and Social Care Board has been created from the previous four. The number of Trusts has been reduced from 18 to six, five organised to provide health and social care services by geographical area and the sixth an ambulance Trust for the whole region. Another important change has been the advent of a fully-devolved administration and the end of direct rule where power was in the hands of civil servants rather than elected local politicians. The lack of clarity about who is in charge is a major problem for Northern's Ireland care system. The difficulty is not that there is no figurehead, but that strategic leadership does not have the visibility of other systems. Without a clear leader, progress is piecemeal and change is hesitant and not driven through at scale – the Review Team was told "there are more pilots than in the RAF".

4.2.7 Clarifying the role of healthcare regulation

Aside from being commissioned by the Department of Health, Social Services and Public Safety to conduct occasional service-specific inspections, the Regulation and Quality Improvement Authority has until now conducted a program of thematic reviews driving more at quality improvement than at regulation.

From 2015, the Minister has decided that the regulator should undertake a rolling programme of unannounced inspections of the quality of services in all acute hospitals in Northern Ireland. The Regulation and Quality Improvement Authority is being directed in this task to examine selected quality indicators in relation to triage, assessment, care, monitoring and discharge. As a result of this change, the regulator will reduce its normal annual programme of thematic reviews.

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These changes give the Regulation and Quality Improvement Authority a much stronger locus in the healthcare side of provision. However, this body has no real tradition of doing this kind of work, unlike its counterparts elsewhere in the United Kingdom. For example, in England, the various health regulators have evolved over a 15-year period with frameworks, methodologies, metrics and inspection regimes. For this reason, the Review is recommending that healthcare regulation in Northern Ireland is re-examined in the round, rather than approaching it piecemeal on an initiative basis.

4.3 INSUFFICIENT FOCUS ON THE KEY INGREDIENTS OF QUALITY AND SAFETY IMPROVEMENT

The recognition that quality and safety should be a priority in the planning and delivery of health and social care arrived late to this sector in developed nations. Until the early 1970s, services operated on the tacit understanding that doctors' and nurses' education, training, professional values and standards of practice ensured that most care was good care. It was not until measurement of quality became more commonplace that it was realised that faith in this ethos had been badly misplaced. A series of scandals blew apart public confidence in the NHS. There were many victims, and it became clear that trust alone was not sufficient. Often, such events depicted cultures in some health and social care organisations in the United Kingdom and other countries that had tolerated poor practice and even sought to actively conceal it.

Organised programmes to assure quality and improve it initially came into healthcare through approaches developed in the industrial sector, notably total quality management and continuous quality improvement. Until 1998, there had never been a framework to progress quality and patient safety in the United Kingdom's NHS. From that time, a comprehensive approach was introduced with: *standards* set by the National Institute for Clinical Excellence and in National Service Frameworks; a programme of *clinical governance* to deliver assurance and improvements at local level backed up by a statutory duty of quality; and, inspection of standards and *clinical governance* arrangements carried out by the Commission for Health Improvement. These roles have changed over time. Some still cover all, or most, of the United Kingdom, whilst others have been taken up differently in the four countries.

Much recent commentary on the NHS in the United Kingdom has focused on whether its leadership is really serious about quality and safety. There is a widespread view within the service that financial performance and productivity are what really matter to managers, despite what might be in the mission statements of their organisations. This came home to roost in the scandalous events at the Mid-Staffordshire NHS Trust in England where the Francis Inquiry heard that concerns about quality were down-played against financial viability in the pressure to gain Foundation Trust status.

A key consideration in quality and safety of healthcare is whether it is embedded in the mainstream at all levels. Up until the late-1990s, it was largely the domain of academics and enthusiasts. Since then, those who are fully committed to its underlying principles and goals have increased in number. However, it is still debatable what proportion of board members, management teams, and clinical leaders are 'card-carrying' quality and safety enthusiasts.

Prominent in international experience are four essential ingredients to improving the quality and safety of care. These are: clinical leadership, cultural change, data linked to goals, and standardisation. In Northern Ireland seeds of each can be found, but none is blossoming. This is substantially holding Northern Ireland's care system back from achieving its full potential.

4.3.1 Clinical leadership

A crucial test of the strength of the quality and safety system is the extent of clinical engagement. This is partly a question of hearts and minds but also a case of knowledge, skills and the philosophy of clinical practice.

The quality and safety of care will only get better if those who deliver the care are not only *involved* in improving it, but are *leading* the improvement effort. In the very best healthcare

systems in the world, clinicians are in the driving seat, supported by skilled managers. Traditionally, doctors, nurses and other health professionals have seen their duty to the patient in front of them. Rightly, this remains the important primary requirement for establishing a culture of good clinical practice. However, this is not enough to enable consistently high standards of care, nor to make care better year-on-year. This requires a paradigm shift in clinical practice, a different mission of practice, so that all healthcare professionals see the essence of their work not just in the care of individual patients but in ensuring that the service for all their patients reaches a consistently high standard and that opportunities for improvement are identified and taken. Accomplishing this is not easy. Clinicians will point out that their workloads are too heavy to make time to reflect on these wider considerations or that they do not have access to reliable data to allow them to compare their service to best practice or that they have not had training in quality and safety improvement.

Clinicians need to step forward to lead. This involves expanding their sense of responsibility beyond the individual patient in front of them to the system as a whole. When clinicians do step forward, they need to be supported. They need to be given responsibility and resources. They need to be given training, because leading improvement is technically and emotionally difficult.

In Northern Ireland, the Review Team met a small number of talented clinicians who have decided to step forward, and who are succeeding in leading positive change. The Review Team met many more clinicians who have tried to engage with 'management' in the past, have been knocked back, and have given up trying. There are many great ideas lying latent in the heads and hearts of clinicians, untapped by the system. The Review Team saw some effort, particularly in the South Eastern Trust, to provide clinicians with the skills that they need to lead improvement projects. Across the system as a whole though, the scale and scope of these is nowhere near what is needed.

4.3.2 Cultural change

Culture determines how individuals and teams behave day to day. It determines how clinicians view and interact with patients; whether they consider harm to be "one of those things", "the cost of doing business", or a feature of healthcare that, with effort, can be banished; whether they react to seeing problems in the system by complaining, or by taking on responsibility for fixing them.

All healthcare systems in the world realise the importance of culture. The difference between the best and the rest is what they do about this. The very best do not hope that culture will change; they put major effort into actively changing it. Their approach is not light-touch or scattergun; they see changing culture as a central management aim.

The Cleveland Clinic in the United States of America, for example, set out to improve patient experience, most of which is determined by how staff behave towards patients. The Clinic's management wanted all staff to better work as a team, and to see their role as being important for patient care – from doctors and nurses, to cleaners, receptionists and electricians. They designated them all 'caregivers'. All 40,000 caregivers attended a series of half-day training sessions, designed to build their practical communication skills and their awareness of self, others and team. They made patient experience scores widely available – ranked by doctor, by hospital, and by department. These efforts have continued for several years. In 2013, the Chief Executive's annual address to all caregivers included a powerful video about empathy. It has since been viewed 1.8 million times on YouTube. In short, the Cleveland Clinic made a major concerted effort to make patient experience important to all who work there.

It has paid off. With staff now more engaged than ever, the Cleveland Clinic has been able to move on to making safety and other elements of quality a crucial part of the culture too.

In Northern Ireland, as in many places, no effort has been made to influence culture on anything like this scale. Many people in the system are able to describe the culture, and many cite it as important. Scattergun efforts are made – a speech here, an awards ceremony there – but shifting culture is hard, and scattergun will not do it. Culture is viewed with a degree of helplessness – but the evidence from elsewhere is that it can be changed, and that doing so is powerful.

4.3.3 Data linked to goals

The importance of data and goals are news to nobody. Yet in Northern Ireland, as in too many other healthcare systems, data systems are weak and proper goals are sorely lacking.

Improving healthcare requires clear and ambitious goals. It requires a statement that preventable harm will be reduced to zero, or that the occurrence of healthcare associated infections will be cut in half within a year. Management guru Jim Collins would call these BHAGs – Big Hairy Audacious Goals. They are goals that are at once exciting and scary. They get people interested and motivated. They are the kind of goals that Northern Ireland should be setting for its care system.

If the goal is the destination, strong data are the sat nav. They show the current position in a form that provides useful information for action. Too often, data show where the system was over the last three months, or what performance has been across large units. They need instead to show the situation in real-time, or as near to it as possible. And they need to show performance at the very local level.

As with culture and leadership, data capability is an area that the best care systems in the world have invested in heavily. They have online dashboards that enable all aspects of the system to be measured, understood, and therefore managed. In comparison, Northern Ireland (and many other places) has a care system that is being managed as if through a blindfold. Investment in information technology is crucial and, if done intelligently, will pay dividends.

4.3.4 Standardisation

Doctors generally dislike standardisation (nurses warm to it more), but it is a crucial part of improving the quality and safety of healthcare.

One healthcare standardisation tool is the World Health Organization's Safe Surgery Checklist. Modelled after the checklists that pilots use throughout every flight, it lists a series of simple actions that should be taken before the patient receives anaesthetic, before the operation starts, and before the patient is moved from the operating theatre. Each item on the list is something blatantly obvious – checking the patient's identity, confirming the type of operation that is planned, and so forth. Without the checklist, each of these things is done most of the time – but not all of the time. The checklist ensures that they are done all of the time – to avoid the occasional instance, as happens, in which nobody properly checks the operation type, and the patient has the wrong operation.

Care bundles are a concept that in recent years have brought higher quality to the areas of care where they have been used well. They help clinicians to reliably give every element of best practice treatment for common conditions such as pneumonia. The evidence is clear: they save lives. Without them, patients get best, safest practice only some of the time and those who do not are the unlucky ones who can suffer greatly as a consequence.

Checklists and care bundles are not widespread in healthcare primarily, because they are counter-cultural. Doctors' training, in particular, emphasises the importance of retaining knowledge, of autonomy, and of variation between patients. All of these go against the idea of standardisation.
The concept of standardisation does not just relate to novel methods like checklists or care bundles. It is also concerned with all patients with a particular disease receiving a consistent process of care based on best practice internationally. The idea that people with conditions like bowel or oesophageal cancer should be receiving different treatment based on clinical preference or where they live is a disgrace. Healthcare should not be a lottery.

The best healthcare systems in the world have a high degree of standardisation. Not for everything – but for the areas of care where the evidence shows that it makes a difference. They have a substantial number of care pathways, checklists, and care bundles. This does not leave the clinicians without a job – far from it. Their judgement is vital in deciding which pathway, checklist or care bundle to use, and in spotting the cases in which a standard approach is not appropriate. They still spend the majority of their time working without reference to any of these things, but use them whenever they are needed.

Northern Ireland has some good examples of work in this area, including the rollout of a National Early Warning System for acutely ill patients, a care bundle for sepsis, an insulin passport, and regional chest drain insertion training. However, the opportunity for standardisation is much greater and needs to be applied at a more fundamental level, which influences the model of practice beyond this series of individual initiatives. There is not yet a critical mass of clinicians clamouring for more standardisation. There are multiple examples of different Trusts approaching the same clinical scenario in different ways, and wanting to retain their autonomy to do so. If Northern Ireland wants to be anything like as good on safety, clinical effectiveness and patient experience as the Cleveland Clinic and other centres of excellence, it needs to be more open to big change.

4.3.5 The recipe for success

There is little doubt that quality and safety are not fully embedded in the planning, design and delivery of services in Northern Ireland. More sleep is lost over budgets than about whether patients are treated with dignity and respect, whether outcomes of care are genuinely world class and whether patients are properly protected from harm when they are being cared for.

Four vital, and often superficially treated, ingredients for quality and safety improvement are: clinical leadership, cultural change, data linked to goals, and standardisation. They are highly inter-linked.

The Northern Ireland care system is not seeing the wood for the trees on these ingredients. The *Quality 2020* strategy cites them (and does set some big goals), but they are not held as central and are therefore somewhat lost. They need to be given far more prominence, because they form the bedrock on which all quality and safety improvement is built.

With focused effort, Northern Ireland could: build a cadre of skilled clinical leaders; develop a culture in which quality improvement is second nature; set big goals; establish the information technology systems required to measure quality locally and in real-time; and standardise processes substantially. If the care system makes these activities central to its quality and safety efforts, improvement will follow and will flourish. Without building this bedrock, no other efforts to improve quality and safety will gain any significant purchase.

4.4 EXTRACTING FULL VALUE FROM INCIDENTS AND COMPLAINTS

Most patient safety programmes have at their core a process to capture and analyse errors and accidents that arise during the provision of care. This is based on the long-established premise that only by learning from things that go wrong can similar events be prevented in the future. To some extent, this draws on the experience of other industries that have successfully reduced accidents and risk year-on-year. This thinking has led to the establishment of incident reporting systems in health services across the world, some operating only at the level of healthcare organisations, some encompassing whole countries and some restricting reports to those within one field of medicine (e.g. surgery).

It is not always appreciated that reporting of incidents (which can be voluntary or mandatory) is only one way of assessing harm in the care of patients. Numerous other approaches have been used, including: prospective observation of care processes; trigger tools involving retrospective case note review; expert case note review; Hospital Standardised Mortality Ratios (and similar metrics); and mining electronic hospital databases.

Alongside Northern Ireland's incident reporting systems runs a complaints system. Globally, surveys have consistently shown that what patients want from a complaints system are: an explanation, an apology, and a reassurance that improvements to the service will be made based on their experience. Other jurisdictions have found that the features of a good complaints system are: satisfactory local resolution of the majority of complaints; speedy response times; excellent communication with patients; good record keeping; apologies made in-person by the senior staff involved not on their behalf; accurate monitoring of the numbers and categories of complaint; effective learning at the local and systemic level.

All these systems have a common primary purpose: to improve the quality of care, and to reduce avoidable harm.

4.4.1 Incident reporting elsewhere

Globally, incident reporting systems vary greatly in: the nature of the data captured, the extent of public release of information, whether reporting is voluntary or mandatory, and the depth of investigation undertaken.

Most reporting systems start by defining in general terms what should be reported. Terminology varies; *adverse event, incident, error, untoward incident* are all in common use internationally. The epithet serious can be applied to any of the terms. The largest national system in the world was established in the NHS in England and Wales as a result of the report *An Organisation with a Memory.* From 2004 until recently, it was run by an independent body, the National Patient Safety Agency, and is called the National Reporting and Learning System. NHS staff are encouraged to make an incident report of any situation in which they believe that a patient's safety was compromised.

In this system, a *"patient safety incident"* is defined as *"any unintended or unexpected incident which could have, or did, lead to harm for one or more patients receiving NHS care."* Reports are first made to a local NHS organisation and then sent in batch returns by the local risk manager to the national level. Staff make a small number of reports electronically directly to the National Reporting and Learning System. The information required covers: demographic and administrative data; the circumstances of occurrence; a categorisation of causation; an assessment of the degree of harm as "no", "low", "moderate", "severe", or "death"; and action taken or planned to investigate or prevent a recurrence. These data are captured in a structured reporting form, but there is also a section of free text where the reporter is asked to describe

what happened and why they think it happened. Data are anonymised to remove the names of patients and staff members.

In just over a decade, covering the NHS in England and Wales, nearly 10 million patient safety incidents have accumulated in this database. Since 2012, it has been mandatory to report all cases of severe harm or death. It remains voluntary to report all other levels of harm.

During the period of its existence, the National Patient Safety Agency in England and Wales issued 77 alerts and many other notices about specific risks, most of which had been identified by analysis of patient safety incident reports. New arrangements for issuing alerts are in place following the abolition of the National Patient Safety Agency.

This system of incident reporting in England and Wales holds a huge amount of data but only a small proportion of it is effectively used. It is currently being reviewed and is unlikely to continue in exactly the same way.

Worldwide, the problems associated with incident reporting are remarkably consistent, whatever system design is adopted. Firstly, under-reporting is the norm, although its degree varies. This seems to depend on the prevailing culture and whether incidents are seen as an opportunity to learn or as a basis for enforcing individual accountability and apportioning blame. It also depends on staff perceptions about the difference their report will make and how easy it is for them to convey the information that they are required to. Reporting rates are much lower in primary care services than in hospitals. Secondly, given the volume of reports made, there is often insufficient time, resource and expertise to carry out the depth of analysis required to fully understand why the incident happened. Thirdly, the balance of activity within reporting systems goes on collecting, storing, and analysing data at the expense of using it for successful learning. Indeed, there are relatively few examples worldwide of major and sustained reductions in error and harm resulting because of lessons learnt from reporting.

4.4.2 Incident reporting in Northern Ireland

Incident reporting began in the Northern Ireland health and social care system in 2004. Two categories of incident were established: *an adverse incident and a serious adverse incident*. The former were reported and investigated locally within each Trust. The latter were documented and investigated locally but also had to be reported to the Department of Health, Social Services and Public Safety. Staff make 80,000 to 90,000 adverse incident reports each year. Over 400 Serious Adverse Incident reports were made in 2013. In the five-year period from 2009, the number of Serious Adverse Incidents related to Emergency Departments rose from 8 to 36.

An adverse incident is defined as:

"Any event or circumstances that could have or did lead to harm, loss or damage to people, property, environment or reputation."

In 2010, major new guidance was issued passing responsibility for managing and further developing the serious adverse incident system to the Health and Social Care Board, where it remains to this day. Further guidance was issued in 2013 with new reporting rules.

To be regarded as a Serious Adverse Incident for reporting purposes, the incident must fall into one of the following categories: the serious injury or unexpected/unexplained death of a service user, staff member or visitor; the death of a child in health or social care; an unexpected serious risk to a service user and/or staff member and/or member of the public; an unexpected or significant threat to service delivery or business continuity; serious

self-harm or assault by a service user, staff member, or member of the public within a healthcare facility; serious self-harm or serious assault by any person in the community who has a mental illness or disorder and is in receipt of mental health and/or learning disability services, or has been within the last twelve months; and, any serious incident of public interest.

Any staff member may report an adverse incident. The reporter is not asked to make a judgment about whether the incident meets the serious adverse incident criteria. A responsible manager makes it based on their reading of the incident and application of the guidelines. Any Serious Adverse Incident must be reported to the Health and Social Care Board within 72 hours. A subset of Serious Adverse Incidents must be simultaneously reported to the Health and Social Care Board and the Regulation and Quality Improvement Authority.

Trusts in Northern Ireland differ slightly in the procedure adopted for encouraging, receiving and investigating incident reports. Generally, all staff are encouraged to make reports as a way of making care safer. They complete an incident report and submit it to the Trust's risk management department so that it can be entered into the risk management database. Increasingly, more reports are being made on-line which cuts out the laborious form-filling which is an undoubted barrier to staff making a report and often leads to paper mountains in the risk management department. Trusts vary in the proportion of incidents that they investigate, the depth of that investigation and the extent to which action is agreed and implemented. Clinical governance committees (or their equivalents), sub-committees of the Trust board or the Board itself usually look at a selection of individual incident reports, at aggregated incident data or at both.

The number of Serious Adverse Incidents varies between Trusts (Figure 1). To some extent this reflects their differing number of patients. However, there is no way of knowing at present whether a higher level of incidents means that the organisation is less safe than others or that it is more safe and that its staff are more conscientious in making reports so that learning can improve patient safety. Whilst data are available on Serious Adverse Incident types, the categories and classifications used do not make it easy to aggregate data in a way that enables systemic weaknesses to be identified. Opportunities are therefore being lost for surveillance of patient safety across Northern Ireland.

The vast majority of Serious Adverse Incidents are reported by the five acute Trusts. Much smaller numbers are reported by the ambulance service and by primary care (Figure 2). The number of incidents reported has increased quite substantially from 2013 to 2014 (Figure 3). In part this is because of improved awareness of the reporting system. In part it is because the reporting criteria were changed – most notably, requiring that all child deaths be reported.

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Figure 1. Serious Adverse Incident reports: by Trust

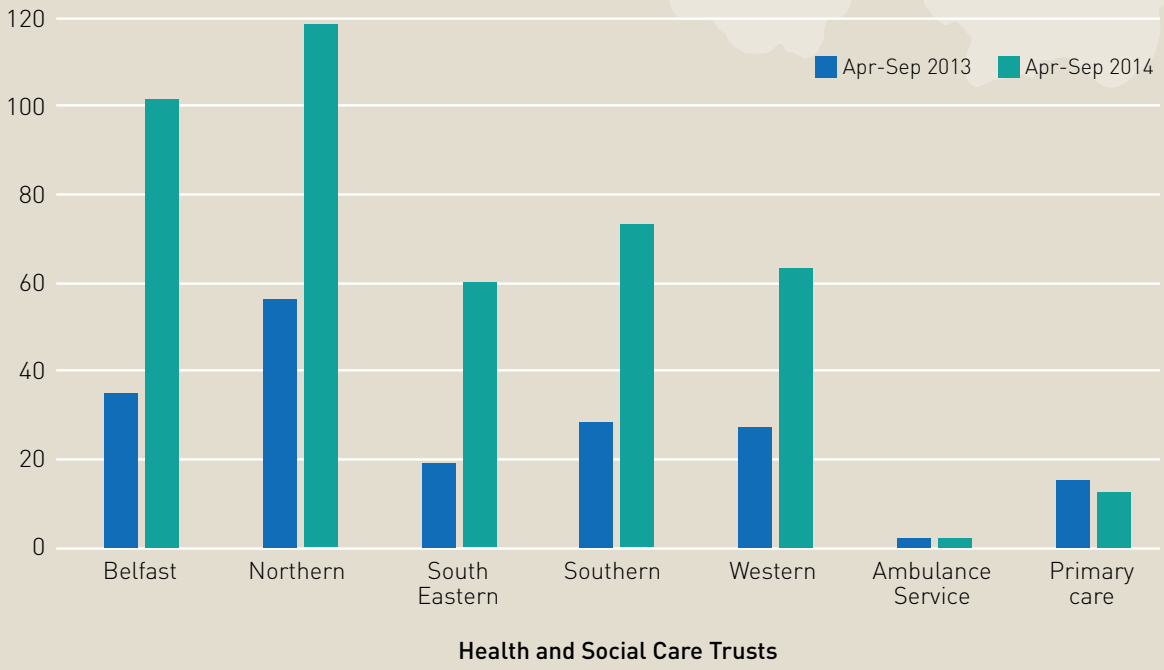
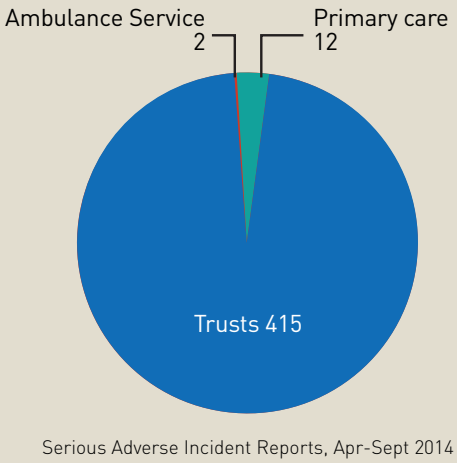
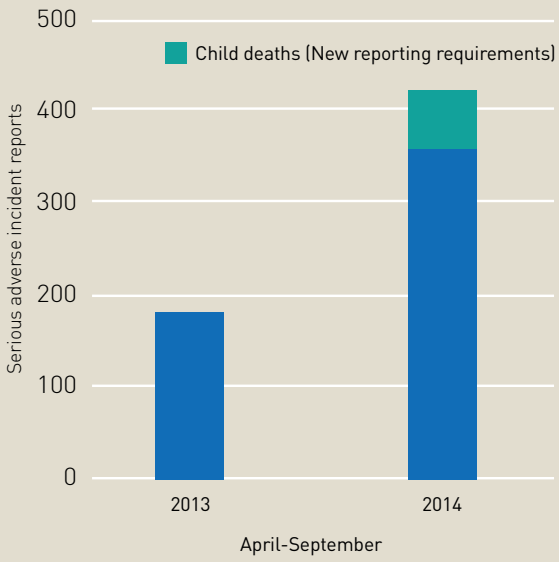


Figure 2. The great majority of Serious Adverse Incident reports are made by the Health & Social Care Trusts



Serious Adverse Incident Reports, Apr-Sept 2014

Figure 3. Serious Adverse Incident reporting increased between 2013 and 2014. Some of the increase was because reporting criteria changed, particularly introducing a requirement to report all child deaths.



All Serious Adverse Incidents are investigated. The type (and therefore intensity) of the investigation should depend on the severity of the incident, its complexity, and the potential to learn from it. Three levels of investigation are stipulated:

- *Level 1* involves a Significant Event Audit – a method of assessing what has happened and why, agreeing follow-up actions, and identifying learning.

- *Level 2* involves a Root Cause Analysis – a more detailed exercise to determine causation and learning, undertaken by a formal investigation team chaired by somebody not involved in the incident.

- *Level 3* involves a full-blown independent investigation.

Most Serious Adverse Incidents start at Level 1 investigation, and may proceed to Level 2 or 3 if the Level 1 investigation suggests that this is necessary or would be useful. A minority start at Level 2 or 3 immediately, bypassing Level 1.

A Designated Review Officer, assigned by the Health and Social Care Board and Public Health Agency, provides independent assurance that an appropriate level of investigation has been chosen, and that it is conducted appropriately.

The process of dealing with Serious Adverse Incidents at the operational level of the service is very involved and highly regulated with little room for flexibility. There are a number of decision-making points at which important judgments must be made by staff on matters such as what level the incident falls into and whether to refer an incident to the coroner.

4.4.3 Frustrations with the incident reporting system

The staff who use the incident reporting system have concerns and frustrations. Firstly, at the policy level, the requirements to report Serious Adverse Incidents places a considerable burden on them to complete forms and meet deadlines, with very little flexibility to deviate from the proscribed procedure. There is an acceptance by staff that it is important to document and investigate Serious Adverse Incidents but the pressure to complete all the steps of the process often means that there is no time to reflect on what can be learned so as to reduce risk for future patients. One of the Serious Adverse Incidents that the Review Team discussed with Trust staff had involved interviews with 34 different people. It was by no means the most complex incident that the Review Team heard about.

There is an almost universal view that the requirement to report and investigate all child deaths in hospital as Serious Adverse Incidents has been a retrograde and damaging policy decision. The consequence of it has been that, if a child dies from a cause such as terminal cancer or a congenital abnormality, a grieving family must be advised that there is to be an investigation. Inevitably, this strongly implies that the service has been at fault. Such an approach is not kind to such families, puts staff in a very difficult position, and diverts attention from the investigation of genuinely avoidable incidents involving the care of children. In a separate aspect of incident policy, many staff working within the mental health field have concerns about the inflexibility of the Serious Adverse Incident scheme as it applies to suicide of their patients. Whilst the time-scales for investigation impose a necessary discipline on the process generally, the range of factors, individuals and agencies that need to be part of the determination of the root causes of the suicide of a mental health patient are very great indeed. The pressure to adhere to statutory deadlines can mean that the work in such cases can sometimes be incomplete and so has limited value in preventing recurrences.

Secondly, at the cultural level, some medical, nursing and social care staff are concerned that, in reporting an adverse incident, they will expose themselves to blame and possible disciplinary action. Junior doctors told the Review Team that making too many reports draws suspicion that they are trouble-makers and that an active interest in patient safety could damage their career prospects. They prefer to make their views on patient safety known through the medical trainee annual survey (Figure 4), where they can remain anonymous.

Figure 4. Percentage of medical trainees reporting concerns about patient safety and the clinical environment

Trust:	Belfast	Northern	South Eastern	Southern	Western
Patient safety	6.5%	6.8%	3.0%	4.7%	3.2%
Clinical environment	2.8%	3.6%	0.8%	1.4%	0.4%
Total	9.3%	10.4%	3.8%	6.0%	3.7%

Source: General Medical Council National Training Survey 2013. Numbers are rounded.

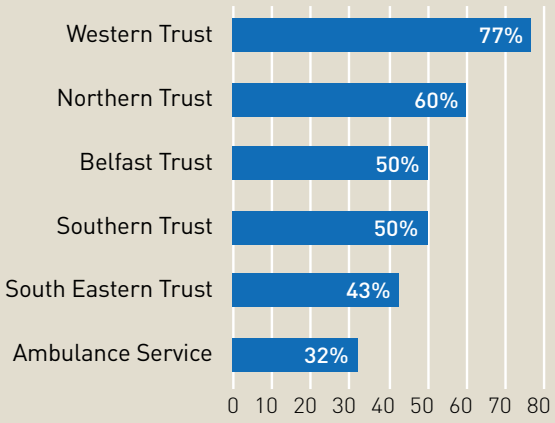
These cultural barriers to reporting and learning are not unique to Northern Ireland. Creating a culture where the normative behavior is learning, not judgment, is very much the responsibility of political leaders, policy-makers, managers and senior clinicians. This does not mean that no-one is ever accountable when something goes wrong but it does mean that a proper regard should be given to the overwhelming evidence that a climate of fear and retribution will cause deaths not prevent them.

Thirdly, at the operational level, staff frustrations with the incident reporting processes range from the very practical, such as not being able to find the form necessary to make the report, to the deeper de-motivating features of the system such as never receiving any feedback or information on the outcome of the report that they had made. Other weaknesses of the process perceived by staff include: having little training in how to investigate properly, reporting an incident then being asked to investigate it yourself, and a tendency for investigations to descend into silos even though there might have been a multi-specialty element to the patient's care.

4.4.4 The complaints system in Northern Ireland

Patients, their carers, and their families can make a complaint about the services received in person, by telephone or in writing. If the complaint concerns the health or social care services delivered by one of the six Trusts in Northern Ireland, a senior officer within the organisation will work with the staff involved in the person's care to investigate and produce a response. A letter from the chief executive officer of the Trust must go to the complainant within 20 working days. However, performance is suboptimal and very variable in this respect (figure 5).

Figure 5. All Trusts are failing to meet the standard 20-day substantive response time for complaints (% meeting standard shown; 2013-14)



The best outcome is for the complaint to be resolved locally to the complainant's complete satisfaction. This is not always possible and if the complainant is not satisfied with the response, the complaint can be re-opened and further investigation can be undertaken or external advice sought. If this still does not resolve the complaint, the complainant can make a submission to the Ombudsman. He will look at whether the process of responding to the complaint was undertaken appropriately. He can also investigate the substance of the complaint but under present legislation, he cannot make these reports public. This bizarre situation means that the public is unaware of where standards have fallen short and what the Ombudsman thinks should be done.

An increasing number of people who have complaints contact The Patient and Client Council asking for help. The Council does not have powers to investigate complaints, only to provide support. Nearly 2000 complainants contacted the Council last year. Many such contacts were from people who had tried to navigate the complaints system alone and had had difficulties. The Patient and Client Council's involvement often helps in facilitating resolution of the complaint, sometimes by arranging meetings of the two sides.

Complaints about primary care are handled somewhat differently. They are raised with the Health and Social Care Board directly. The number of complaints from primary care is lower than might be expected. This may reflect the reluctance of patients to complain about a service that they are totally reliant on.

4.4.5 Involvement of the coroner

Northern Ireland, like elsewhere, is still grappling with a difficult question: what is the appropriate role for the Coroner in the investigation of deaths that may have been caused, at least in part, by patient safety problems? This is not an easy question. It is difficult to create guidance that precisely defines which deaths should be investigated by the coroner and which should not. And Coroner's inquests have major pros and cons.

When somebody dies and their care may have been perceived as poor, some families call for a Coroner's inquest. The positive elements of this are that the Coroner is independent of the health and social care system, has clear legal powers, and is skilled in the investigation of deaths.

On the other hand, conducting an inquest into every Serious Adverse Incident that results in a death would be a resource-intensive undertaking. It also may not result in the most effective learning. Few could honestly say that the courtroom environment does not intimidate them. It is not the easiest place to build a constructive relationship between the clinicians involved in the care of the deceased and the deceased's family. It is not the most conducive environment to open, reflective learning.

In cases of negligence or gross breaches of standards of care, it is very clear that referral to the Coroner is the most appropriate course.

At the other end of the spectrum, in a few cases there is a Serious Adverse Incident at some point during a patient's care and this patient subsequently dies, but the death is entirely unrelated to the incident and so an inquest is really not warranted. In between these two extremes lies a substantial grey area, in which the relative merits of a Coroner's inquest and an internal Serious Adverse Incident investigation are debatable. This is not only the case in Northern Ireland, but across the United Kingdom as a whole (except that Scotland does not have a Coroner).

This is a complex issue. Currently only a subset of the deaths that could be the subject of a Coroner's inquest actually become so. Some are not reported to the coroner's office (largely appropriately, it seems) and some are discussed with the coroner's office but not listed for inquest. In other words, the judgments of clinicians and coroners' officers alike have a substantial bearing on which cases proceed to inquest. The subset of cases that end up in front of a coroner's inquest are also determined as much by family's wishes as by the content of the cases.

To some this may sound shocking but, given the complexity of the issues involved, the status quo is not entirely unreasonable and is in line with practice internationally. But the status quo is certainly not ideal. There is substantial room for improvement, so that the coroner can more optimally contribute to the system's learning.

4.4.6 Redress

The creation of financial, and other new, forms of redress would have to be linked to the handling of complaints, incidents and medical negligence claims in a whole systems manner. This is a highly complex area that was extensively examined in England in the report *Making Amends*. In the end, the central idea of introducing some payments for victims of harm and recipients of poor quality care, as well as potential litigants, was not taken forward. There were sound principles behind the proposals, but there was a leap-in-the-dark element too. Priority was given instead to action to improve the quality and safety of care and to improve responses to complaints. However, one of the other proposals of *Making Amends*, the introduction of a Duty of Candour, is finally being implemented in England. The Review Team considers that priority in Northern Ireland should be given to the areas covered by its recommendations, to making important changes to generate safer higher quality care, rather than embarking on new policies for redress, including financial compensation.

4.4.7 The nature of learning

The whole question of how *learning* takes place in healthcare through the scrutiny and analysis of incident reports or through their investigation has been little debated. Indeed, the term learning itself is very loosely applied in this context. Strictly applied, it would mean acquiring new knowledge from incidents about how harm happens. Yet, the way in which the word learning is repeatedly used in the context of patient safety is more than increasing understanding. It implies that behaviour will change or actions will be taken to prevent future harm. Unfortunately, although there are some exceptions, there is little evidence that major gains in the reduction of harm have been achieved in Northern Ireland or in many other jurisdictions through the so-called learning component of patient safety programmes.

In Northern Ireland, the main formally-identified processes for reducing risk or improving patient safety, aside from action plans derived at Trust level, are:

- the production of learning letters
- the bi-annual Serious Adverse Incident Learning Report
- the circulation of newsletters such as *Learning Matters*
- thematic reviews
- training and learning events

- implementing the recommendations of reviews and inquiries
- disseminating alerts and guidance imported from other parts of the United Kingdom or further afield.

On many, perhaps most, occasions when something goes wrong, the potential for learning from this is very rich indeed. This potential too often goes unrealised. This is a problem not just in Northern Ireland, but in care systems worldwide.

Three features determine the extent to which investigation of an adverse event results in risk being reduced:

- How deep the investigation gets, in understanding the true systemic issues that helped something go wrong
- How systemic the investigation's focus is, in considering where else a similar problem could have occurred beyond the local context in which it did occur
- How strong the corrective actions are in actually, and sustainably, reducing the risk of a repeat

The first of these, depth of investigation, is done reasonably well. A decade ago, harm was often put down to 'human error'. There is now far greater recognition that this is a superficial interpretation – that there are almost always problems within the system which not only allowed that harm to occur but made it more likely. The technique of root cause analysis is widely used in Northern Ireland, and helps to uncover some of the causal elements. Often, though, it does not find the deeper reasons. This is partly because of the time pressures to finish the investigation, partly because not all staff have had the necessary training to do this deeper analysis, and partly because of a lack of human factors expertise in the process. Also, many hospital incidents involve primary care in the chain of possible causation, yet primary care staff play a minor, or no, role in many investigations.

In relation to the systemic view, when a problem occurs, there is too great a tendency to investigate that specific problem, without looking for the broader systemic issues that it highlights. Problems are often addressed in the department where they occur, without asking whether they could have occurred in other departments, for example. Similarly, if a medication incident occurs, there is a tendency to fix the problem for that medication, without looking at whether there is a problem for similar medication or routes of administration.

This narrow, reactive approach fails to make full use of incident reports. In short, it reflects an erroneous assumption that the system as a whole is working fine, and that the problems that allowed the event to occur are specific, local ones. This is not the case. There are systemic problems through the health and social care system. Incidents of harm are distributed largely by chance – by location and by type. Fixing each specific problem is like playing "Whack-A-Mole" – it does not get to the nub of the issues.

The ultimate aim of investigation is to reduce the risk of harm, not simply to understand what went wrong. Corrective action is too often inadequate. There is no automatic link between understanding what went wrong and being able to reduce the risk of it happening again. Indeed, making the leap between investigation and risk reduction is really very challenging.

In Northern Ireland, the action lists that are generated by Serious Adverse Incident investigation commonly feature plans of the following kinds:

- Making staff aware that the incident took place
- Explaining to staff what went wrong
- Circulating a written description of the incident and actions taken to other parts of the health and social care system to share the learning

Such information sharing actions should form part of the plan but they do not amount to systemic measures that will reliably and significantly reduce the risk to patients.

Research and experience outside health care has shown that safety comes down to appreciating that big improvements are not made by telling people to take care but by understanding the conditions that provoke error.

Action plans often also feature some change to current paperwork or introduction of new documentation. This, too, is very reasonable but often has a weak impact on outcomes. It also has the important downside that mounting paperwork reduces the time for patient care and introduces complications of its own.

So what do strong corrective actions look like? Technological solutions have an important role to play. Electronic prescribing systems, patient monitoring systems, and shared care records can address multiple patient safety issues simultaneously (although their implementation and use is not without risk). Policies, rules, and checklists can also be useful, but are easy to implement badly and more difficult to implement well.

As discussed earlier in this Report, one area of high potential is the use of standardisation of procedure. It is underutilised in healthcare worldwide but where it is applied it has brought results. Standardisation of procedure is a mainstay of safety assurance and improvement in other sectors.

In large part, though, healthcare systems worldwide are not yet good at implementing solutions that will truly reduce risk. It is not the case that Northern Ireland is lagging behind – but that Northern Ireland is struggling with this problem alongside other countries.

Identifying the systemic issues and identifying strong corrective actions: each of these is tough; an art and a science in itself; an area in need of intense and rigorous study. Until these issues are tackled head on, in Northern Ireland and elsewhere, the system's learning when things go wrong will fall short.

When something goes wrong, patients and families ask for reassurance that it will not happen again. As it stands, nobody can honestly provide this reassurance. In fact, it is difficult even to say that the risk has been significantly reduced – let alone to zero. This needs to change.

4.4.8 Strengths and weaknesses of Northern Ireland's systems for incident reporting and learning

No system of reporting and analysing patient safety incidents is perfect. In an ideal world, all events and occurrences in a health service that caused harm or had the potential to cause harm would be quickly recognised by alert, knowledgeable front-line staff who would carefully document and communicate their concern. They would be enthusiastic about their involvement in this activity because they would have seen many examples of how such reports improved the safety of care. The resulting investigation would be impartial and multi-disciplinary, involving expertise from relevant clinical specialties but, crucially, also from other non-health disciplines that successfully contribute to accident reduction in other fields of safety. Investigation would be carried out in an atmosphere of trust where blame and retribution were absent, and disciplinary action or criminal sanctions would only be taken in appropriate and rare circumstances. Action resulting from investigation would lead to re-design of processes of care, products, procedures and changes to the working practices and styles of individuals and teams. Such actions would usually lead to measurable and sustained reduction of risk for future patients. Some types of harm would be eliminated entirely.

4

Very few, if any, health services in the world could come anywhere near to this ideal level of performance in capturing and learning from incidents of avoidable harm. This is so for all sorts of reasons ranging from an insufficiency of leaders skilled and passionate enough to engage their whole workforces on a quest to make care safer, through an inability to investigate properly the volume of reports generated, to the weak evidence-base on how to reduce harm.

The system of adverse incident reporting in Northern Ireland operates to highly-specified processes to which providers of health and social care must adhere. The main emphasis is on the Serious Adverse Incidents. The requirements laid down for reporting, documenting and investigating such incidents together with the rules for communicating about them and formulating action plans to prevent recurrence have created an approach that has strengths and weaknesses (Figure 6). In general, the mandatory nature of reporting means that there is likely to be less under-reporting than in many other jurisdictions. However, staff in Trusts must exercise judgment on whether to classify occurrences of harm as Serious Adverse Incidents. Whether they always make the right decision has not been formally evaluated. The Review did not find any evidence of suppression or cover-up of cases of serious harm.

Figure 6. Serious Adverse Incident reporting system in Northern Ireland: Strengths and weaknesses

Dimension	Strengths	Weaknesses
Accountability	Absolute requirement to report and investigate	Creates some fear and defensiveness
Coverage	Relatively high for serious outcomes	Less attention given to incidents with lower harm levels
Timescales	Clear deadlines for investigation and communication	Pressure to meet deadlines leaves little time for reflection
Investigation	Reasonable depth with frequent root cause analysis	Quality variable and little use of human factors expertise
Staff engagement	All appear to understand the importance of reporting	Do not often see the reports translating into safer care
Patient and family involvement	Requirement to communicate reinforced by checklist	Often creates tension and little ongoing engagement
Learning	Specified action plan required in every case	Not clear whether action is effective in reducing future risk

4

Tight time-scales are laid down for the various stages of handling a Serious Adverse Incident. These generally add a necessary discipline to a process that in other places can become protracted or drift off-track. There is a need, though, for some flexibility where an investigation requires more time. This is particularly so in the mental health field where the avoidable factors in a death can be very complex and are only discernible after interviewing very many people.

It is important to recognise that, whilst almost all of the experience and research literature is about patient safety, Northern Ireland has an integrated health and social care system. Social care in the United Kingdom has its own traditions in recognising, investigating and learning from episodes of serious harm involving those who use its services; the fields of child protection and mental health exemplify this. It is not entirely straightforward to integrate incidents in social care into the overall patient safety approach but the essential principles and concepts are little different.

The Northern Ireland health service falls short of the ideal just as do most other parts of the United Kingdom and many other places in the world. In all of these places, including Northern Ireland, patients are dying and suffering injuries and disabilities from poorly designed and executed care on a scale that would be totally unacceptable in any other high-risk industry.

The Northern Ireland approach to incident reporting and learning does not make its services any less safe than most of the rest of the United Kingdom or many other parts of the world. However, this should not be a reason for comfort, nor a cause for satisfaction.

The current requirement for all child deaths to be reported and managed as serious adverse incidents seems to be doing far more harm than good. It is distressing for families, burdensome for staff, and is not producing useful learning.

The ethos of improving safety by learning from incident investigations needs to shift:

- Away from actions that only make a difference in the particular unit where the incident occurred, towards actions that also make a difference across the whole of Northern Ireland
- Away from actions that only target that particular incident, towards actions that also reduce the risk of many related incidents occurring
- Away from weak actions such as informing staff, training staff and updating policies, towards stronger actions of improving systems and processes
- Away from long lists of actions, towards smaller numbers of high-impact actions

Less attention has been given in Northern Ireland to adverse incidents that do not meet the definition of a Serious Adverse Incident. They are reported, analysed and acted upon at Trust level. Only exceptionally are they considered centrally. The numbers are much greater so the logistics of analysing more would be considerable. However, there is much to be learned from situations when something went wrong in a patient's care but they did not die or suffer serious harm.

4.5 THE BENEFITS AND CHALLENGES OF BEING OPEN

The health and social care system aspires to a 'no blame' culture, or a 'just' culture, in which staff can be open without fear of inappropriate reprisal. In reality, this is not the culture that currently exists. This is not primarily the fault of those delivering health and social care.

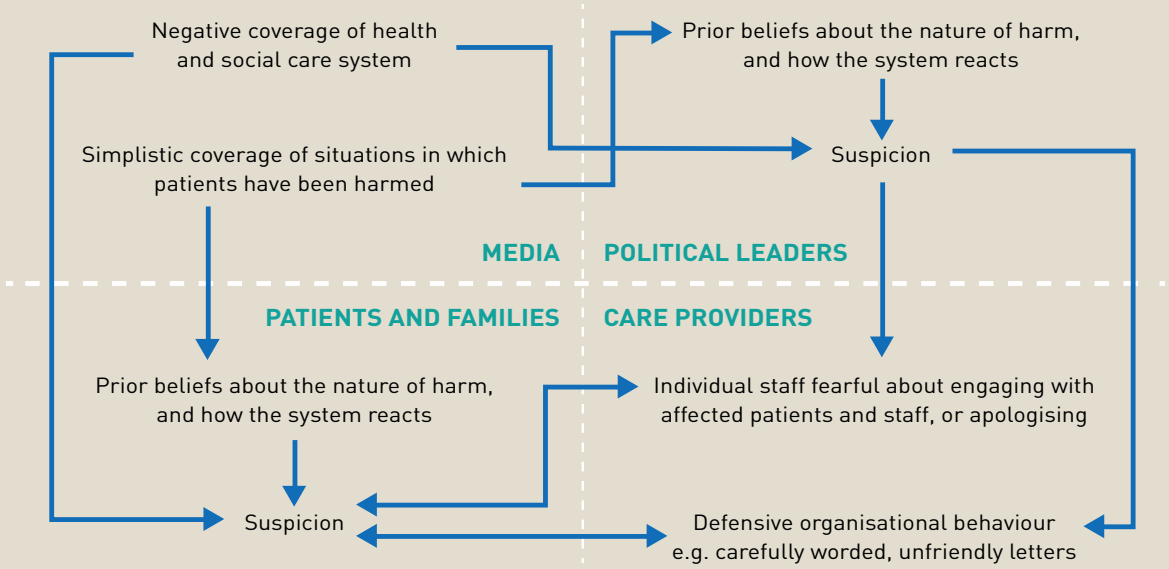
Openness is not something that can simply be demanded. It needs the right conditions in order to flourish. The enemy of openness is fear.

When something goes wrong, many patients' and families' first reaction is to want to know who is to blame. The situation often escalates, with the media coverage and political pressure that the detail of the story generates. In an ideal world, leaders of the system should be able to step in to paint a proper picture of the background to these complex events, and to build public understanding that few are a simple case of incompetence and carelessness. Instead, to remove the heat from the situation, approaches are announced that may not be the most effective way to achieve learning. On top of this, day-by-day the media portrays health and social care in a mainly negative light. There has been one inquiry after another. These are conditions conducive to blame and fear, not to transparency and openness.

Despite these adverse conditions, the Review Team found front-line staff willing to talk about problems, and to be open with families and patients when things go wrong. There is a willingness to be open – but there is blame, and there is fear.

Northern Ireland needs to increase the degree of openness and transparency in talking about harm, and decrease the degree of blame and fear. The responsibility cannot lie solely within the health and social care system. They are complex cycles.

Figure 7. The vicious cycle of suspicion and fear



Openness and transparency, blame and fear: these are multi-dimensional issues that cannot be improved directly by legislation, rules or procedures alone. As this Report has made clear, Northern Ireland is far from unique.

4.5.1 Governance arrangements to promote openness

Promoting openness and avoiding fear is about culture. Responsibility for this sits with many people, within and beyond the health and social care system. Governance may sound like a blunt tool and, used alone, it would be. But alongside other approaches, appropriate governance arrangements can promote openness and dispel fear.

The Serious Adverse Incident process currently requires Trusts to inform affected patients (or families) that their care is the subject of investigation. In general, they are invited to provide input and are provided with a copy of the investigation report. A checklist has been introduced to prompt investigators to take these steps. This is commendable, and represents a basic, but important, degree of openness with patients and families.

The nature of the involvement with patients and families in the aftermath of a Serious Adverse Incident cannot be shaped by a checklist alone. The Review Team heard from each of the Trusts how they handled this aspect of the policy. It is clear that this is a difficult area to get right. Early contact with the family in the event of a death is important but could come at a time when funeral arrangements are being made and perceived as intrusive or insensitive. The bureaucracy of the procedure can create an official feeling that opens up distance in the relationship with the family. It is important that staff in the Trust have the skill, experience and credibility to communicate with a family. It is helpful to have staff who deal with this situation regularly and have good inter-personal and counselling skills. They should be there with the clinical staff who may encounter the situation less frequently. Experience from elsewhere suggests that regular contact with the patient and family is important, not just a couple of one-off meetings with long silences in between. In the best services, the patient and family are fully involved in the process of learning and action-planning. Where this happens, it is empowering for everyone. This is only happening to a limited extent in Northern Ireland currently.

The Serious Adverse Incident process is also overseen by a Designated Review Officer within the Public Health Agency. This is also a welcome feature of the system although there is potential for these officers, or their function, to play a more substantial role.

Every Trust has appropriate arrangements for Serious Adverse Incidents to be discussed within the departments affected. The fact that these conversations are taking place usefully promotes a culture in which talking about harm becomes easier, and openness becomes the norm.

Every Trust also has arrangements for organisation-level oversight of this process. In most, this responsibility sits with a sub-committee of the Trust board. This too is good practice.

When something goes wrong, there is a tendency for the Department of Health, Social Services and Public Safety to deal directly with the Trust's Executive Team, bypassing the board. This happens partly from expediency – because the executive directors are present full-time, and are therefore available to take an urgent phone call from an official concerned about briefing the minister. But it serves to diminish the role of the board, and misses opportunities to build the board's familiarity with these issues and capability in dealing with them.

There is great concern and depth of feeling amongst staff in the system who have attempted to uncover poor standards of

care and been denigrated. Their role as whistleblowers has placed them in an even more isolated position. This unsatisfactory situation needs to be resolved.

4.5.2 Perceptions of openness

The Serious Adverse Incident guidelines include some requirements intended to help openness and transparency. A recent look-back exercise, quality controlled by the Regulation and Quality Improvement Authority, suggests that patients and families are being appropriately informed when a Serious Adverse Incident occurs. This creates a substantially higher degree of openness than is the case in many countries worldwide. In the main, the Trust staff who are leading the investigation are willing to spend time meeting with patients and families.

However, several features of the investigation process too often give patients and families an adverse impression:

- The investigation process is frequently delayed beyond the stipulated timeline, and patients and families experience delays in getting responses to calls and emails. Such delays make people start to wonder, "what is going on?"
- When the investigation process starts, the degree of openness and transparency that the patient and/or family feel they are seeing is highly dependent on the communication skills of the Trust staff that they meet with. Some staff are highly skilled in these potentially difficult meetings; others are not.
- Standard practice is for patients and families to meet with the manager and/or clinician leading the investigation, and not to be asked whom else they would like to meet with. Many, for example, would find it helpful to meet with the staff directly involved in the incident, to put their questions directly, but this is not routinely offered. Such meetings have the potential to be intensely difficult; to be very useful if they go well, but harmful if they go badly.

4.5.3 Duty of candour

In 2003, the head of the Review Team (as Chief Medical Officer for England) issued a consultation paper, *Making Amends*, which set out proposals for reforming the approach to clinical negligence in the NHS. One key recommendation was that a duty of candour should be introduced.

As long ago as 1987 Sir John Donaldson (no relation), who was then Master of the Rolls, said "I personally think that in professional negligence cases, and in particular in medical negligence cases, there is a duty of candour resting on the professional man". There was, at the time of the *Making Amends* report, no binding decision of the courts on whether such a duty exists.

In November 2014, the General Medical Council and the Nursing & Midwifery Council issued a joint consultation document proposing the introduction of a professional duty of candour. Such a duty will give statutory force to the General Medical Council's Code of Good Medical Practice for doctors.

In the concomitant healthcare organisational measures introduced in England, a new "Duty of Candour" scheme will mean that hospitals are required to disclose information about incidents that caused harm to patients, and to provide an apology.

In Northern Ireland, it is already a requirement to disclose to patients if their care has been the subject of a Serious Adverse Incident report. There is no similar requirement for adverse incidents that do not cause the more severe degrees of harm. In promoting a culture of openness, there would be considerable advantages in Northern Ireland taking a lead and introducing an organisational duty of candour to match the duty that doctors and nurses are likely to come under from their professional regulators.

4.6 THE VOICES OF PATIENTS, CLIENTS AND FAMILIES ARE TOO MUTED

The best services in the world today give major priority to involving patients and families across the whole range of their activities, from board-level policy making, to design of care processes, to quality improvement efforts, to evaluation of services, to working on reducing risk to patients as part of patient safety programmes.

At the heart of the traditional approach to assessing whether a service is responsive to its patients and the public are surveys of patient experience and attitudes. This is still a very important part of modern health and social care. In many major centres whose services are highly rated, such surveys are regularly carried out and used to judge performance at the organisational, service and individual practitioner level, as well as, in some cases, being linked to financial incentives. Indeed, in the United States system, observers say that it was not until surveys of patient experience were linked to dollars that it was taken seriously. This is not a prominent feature of the Northern Ireland system, although there is some very good practice, for example the 10,000 Voices initiative, which has so far drawn on the experience of over 6,000 patients and led to new pathways of care in pain management, caring for children in Emergency Departments, and generally focusing on the areas of dignity and respect.

Looked at from first principles, the kind of questions a user, or potential user, of a service could legitimately require an answer to would include:

How quickly will I first be seen, how quickly will I get a diagnosis and how quickly will I receive definitive treatment?

If my condition is potentially life-threatening, will the local service give me the best odds of survival or could I do better elsewhere?

Will each member of staff I encounter be competent and up-to-date in treating my condition and how will I know that they are?

Does the service have a low level of complications for treatment like mine compared to other services?

How likely am I to be harmed by the care that I receive and what measures does the service take to prevent it?

If I am unhappy with a care-provider's response to a complaint about my care, will the substance of it be looked at by people who are genuinely independent?

Which particular service elsewhere in the United Kingdom, and other parts of the world, achieves the best outcome for someone like me with my condition? How close will my outcome be to that gold standard?

Very few of these questions could be answered reliably in Northern Ireland and other parts of the United Kingdom.

There are many potential themes for patient and family engagement in health and social care, for example:

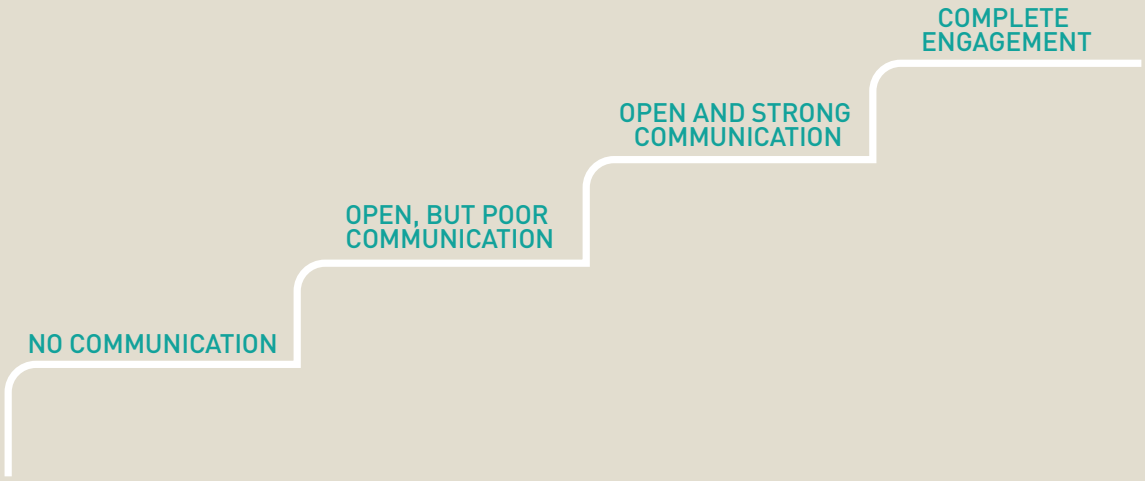
- in shaping and designing services
- in measuring the quality of care
- in setting standards for consultation
- in shared decision-making
- in self-care of chronic diseases
- in preventing harm
- in giving feedback on practitioner performance

Few services do all of these, some only scratch the surface of genuine involvement, others do a few well. Overall, the Northern Ireland care system is engaged in some of these areas but certainly not in an organised and coherent way.

4

The terms of reference of the Review put particlar emphasis on harm. Globally, there is a spectrum in how well health and social care systems interact with patients, clients and families when things go wrong (figure 8). The ideal approach is to engage patients and families completely in the process of learning. They often find this hugely beneficial, because it allows them to play an active part in reducing the risk for future patients. It is also immensely powerful for staff, to hear patients' stories first-hand and to work with them to improve things.

Figure 8. Levels of engagement with patients and families when something goes wrong



Northern Ireland should aim for level three as an absolute minimum, but strive for level four.

The system is too often falling down to level two because:

- Staff who communicate with patients and families during the Serious Adverse Incident investigation process have variable communication skills – some are excellent, but some are less good. Little formal effort has been made to train staff to manage these difficult interactions well.
- Patients and families are often not offered the opportunity to meet with those who they would like to – the staff directly involved in the incident. Instead, they tend to meet with managers, and with clinicians who were not involved.
- There are frequently delays in the process of investigating a Serious Adverse Incident.
- Patients and families are too often sent letters filled with technical jargon and legalese.

When something goes wrong, the harm itself is intensely difficult for patients and families. Poor communication compounds this enormously.

5 CONCLUSIONS

5.1 RELATIVE SAFETY OF THE NORTHERN IRELAND CARE SYSTEM

5.1.1 There is some perception amongst politicians, the press and the public that Northern Ireland's health and social care system:

- Has fundamental safety problems that are not seen elsewhere
- Is less safe than other parts of the United Kingdom, or comparable countries
- Suffers from lack of transparency, a tendency to cover-up, and an adverse culture more broadly.

5.1.2 The Review found no evidence of deep-seated problems of this kind. Northern Ireland is likely to be no more or less safe than any other part of the United Kingdom, or indeed any comparable country globally.

5.1.3 This does not mean that safety can be disregarded, because it is clear from reading the incident reports and accounts of patients' experience that people are being harmed by unsafe care in Northern Ireland, as they are elsewhere. Northern Ireland, like every modern health and social care system, must do all it can to make its patients and clients safer.

5.2 PROBLEMS GENERATED BY THE DESIGN OF THE HEALTH AND SOCIAL CARE SYSTEM

5.2.1 There are longstanding, structural elements of the Northern Ireland care system that fundamentally damage its quality and safety. The present configuration of health facilities serving rural and semi-rural populations in Northern Ireland is not fit for purpose and those who resist change or campaign for the status quo are perpetuating an ossified model of care that acts against the interests of patients and denies many 21st Century standards of care. Many acutely-ill patients in Northern Ireland do not get the same standard of care on a Sunday at 4 am as they would receive on a Wednesday at 4 pm and, therefore, a two-tier service is operating. It may be that local politics means that there is no hope of more modern care for future patients and if so this is a very sad position.

5.2.2 The design of a system to provide comprehensive, high quality, safe, care to a relatively small population like Northern Ireland's needs much more careful thought. This applies to almost all aspects of design including: the role of commissioning, the structuring of provision, the relationship between primary, secondary and social care, the distribution of facilities geographically, the funding flows, the place of regulation, the monitoring of performance, and the use of incentives. Nowhere is the old adage: "I would not start from here" truer than in the Northern Ireland care system today.

5.2.3 There is widespread uncertainty about who is in overall charge of the system in Northern Ireland. In statutory terms, the Permanent Secretary in the Department of Health, Social Services and Public Safety is chief executive of the health and social care system but how this role is delivered from a policy-making position is not widely understood or visible enough.

5.2.4 In the specific domain of quality and safety itself, whilst it is reflected in the goals and activities of boards and senior management teams in Northern Ireland, it is not yet fully embedded with the commitment and purpose to make a real difference. The Review was most impressed with the work of the South Eastern Trust in this regard. The Review Team could not assess each Trust in depth, but its judgment on the South Eastern Trust is backed up, for example, by the national survey of trainee doctors.

5.3 FOCUS ON QUALITY AND SAFETY IMPROVEMENT

5.3.1 *Quality 2020* is a ten-year strategy with a bold vision – that the health and social care system should "be recognised internationally, but especially by the people of Northern Ireland, as a leader for excellence in health and social care". Three years on, there is good evidence of the strategy being implemented. An influential steering group oversees the work.

5.3.2 The Review Team judged that *Quality 2020* represents a strong set of objectives, and that there is clear evidence of extensive work and of some successes in implementation. However, this does not amount to quality and safety improvement being given the primacy of focus that it needs, and Northern Ireland is not seeing the wood for the trees about the need to establish crucial aspects of quality and safety improvement which are not well represented at present: clinical leadership, cultural change, data linked to goals, and standardisation.

5.4 THE EXTENT TO WHICH SERIOUS ADVERSE INCIDENT REPORTING IMPROVES SAFETY

5.4.1 The system of Serious Adverse Incident reporting in Northern Ireland has been an important way to ensure that the most severe forms of harm that are inadvertently caused by care processes are recognised and investigated.

5.4.2 The Serious Adverse Incident process fulfils five main purposes:

- a public accountability function
- a response to the patients and families involved
- a communications alert route
- a barometer of risk within health and social care
- a foundation for learning and improvement

5.4.3 The kinds of incidents reported into this system appear little different to other parts of the United Kingdom and are similar to many other parts of Europe, North America and Australasia. Many harmful events are potentially avoidable and the human cost to patients and families in Northern Ireland is of grave concern, as it is in other jurisdictions.

5.4.4 Good practice elsewhere in the world suggests that patients who suffer harm and their families should be fully informed about what has happened, how it happened and what will be done to prevent another similar occurrence. More than this, they should be fully engaged in working with the organisation to make change. Patient and family engagement is a good and established feature of Serious Adverse Incident reporting in Northern Ireland but it often falls short of this fully engaged scenario. The extent to which it is valued and trusted by patients and families appears to vary, depending on the staff communicating with them.

5.4.5 The design for the specification, and recording, of information on each Serious Adverse Incident is sub-optimal particularly in gathering appropriate information on causation; this hinders aggregation of data to monitor trends and assess the impact of interventions.

5.4.6 The process for investigating Serious Adverse Incidents is clearly set out and involves root cause analysis-type methods. In many cases, it lacks sufficient depth in key areas such as human factors analysis. The degree of oversight by supervisory officials (the Designated Review Officers) is variable in extent and timeliness. Local health and social care staff generally approach the task of investigation conscientiously but many lack the training and experience to reach a standard of international best practice in unequivocally identifying the cause and specifying the actionable learning. They get little expert help and guidance in undertaking this activity.

5.4.7 The most important test of the capability of a patient safety incident reporting system is its effectiveness in reducing future harm of the kind that is being reported to it. Unfortunately, there are few places around the world where there is a powerful flow of learning that moves from identifying instances of avoidable harm, through understanding why they did or could happen, to successful elimination of the risk for future patients. Northern Ireland is no exception to this regrettable state of affairs.

5.4.8 There are two main levels of learning from Serious Adverse Incidents in Northern Ireland. The first is local. The lack of a consistently high standard of investigation and action-planning are barriers to effective risk-reduction within health and social care organisations. Another barrier is the limited degree to which front-line staff are involved in discussing and seeking solutions to things that have gone wrong. Experience elsewhere suggests that this practical and intellectual engagement,

if well-led, often sparks great interest and commitment to patient safety amongst front-line staff. This is not really happening in Northern Ireland at present, for a number of reasons. Firstly, staff do not have the time and space to do it and the leadership of Trusts is not consistently creating and facilitating such opportunities. The Regulation and Quality Improvement Authority has established training in Root Cause Analysis for front-line staff, and this will help. Secondly, the specified rules of the Serious Adverse Incident system mean that Trusts are under a great deal of pressure to meet the time-scales laid down and are often dealing with many such cases simultaneously. As a result, the activity is too often slipping into an incident management role or worse a necessary chore that 'feeds the beast'.

5.4.9 The second level of learning is across the Northern Ireland health and social care system as a whole. The main role is played by the Health and Social Care Board working with the Public Health Agency (and the Regulation and Quality Improvement Authority where appropriate). These bodies have established a multi-disciplinary Quality Safety and Experience Group that undertakes much of the work in assessing patterns, trends and concerns arising from the analysis of locally-generated Serious Adverse Incidents and deciding what action needs to be taken on a Northern Ireland-wide basis. It does so by issuing learning letters, reports, guidance, newsletters and other specified action that the service needs to take. This is a valuable function from which considerable action aimed at improvement has flowed. Experience of improving patient safety elsewhere has shown that specifying action on a particular safety problem is not the same thing as implementing the change required. The latter is often much more difficult and depends on factors such as the systems, culture, attitudes, local priorities and leadership in the organisation receiving the action note. In the Northern Ireland care system more skill needs to be added to the implementation process. This is closely linked to the difficulties that arise when local services feel overloaded with central guidance and requirements for action. They only have enough management and clinical leadership capacity to implement a small number of changes at a time.

5.4.10 General practitioners, and others in primary care, report their Serious Adverse Incidents directly to the Health and Social Care Board, not through any of the Trusts. Levels of reporting of patient safety incidents in primary care services around the world are very low and much less is known about the kinds of harm that arise in this setting compared to hospitals. It is not surprising that the same is so in Northern Ireland. Another aspect of the primary care dimension is that many of the incidents that the Review discussed with the Trusts in Northern Ireland had a primary care element in the key areas of the care processes that had failed, yet general practitioners seemed to be less frequently involved in the investigation and planning of remedial action.

5.4.11 There are two particular aspects of the criteria for Serious Adverse Incident reporting in Northern Ireland that are not working in the best interests of a successful system. Firstly, the requirement that every death of a child in receipt of health and social care should automatically become a Serious Adverse Incident is causing major problems. A proportion of such deaths every month are due to natural causes. Some of the conditions concerned - for example, terminal cancer and serious congenital abnormalities - are particularly harrowing for the parents. After the death of a child, in such circumstances, for a family to be told that their child's death has been categorised as a Serious Adverse Incident carries the clear implication that the quality or safety of care was poor and at fault or even that the death could have been avoided. This can be enormously distressing for families and

is grueling for staff. It is cruel, unnecessary and liable to undermine public confidence in children's services.

5.4.12 Secondly, using the same time-scales for investigating Serious Adverse Incidents in mental health as in in other fields of care is also causing major problems. The complexity of many mental health cases, the long past history of many such patients and clients, and the number of people and organisations who may be able to contribute relevant information to the investigation mean that a longer period is necessarily required to get to the truth than is currently permitted.

5.4.13 Overall, the system of Serious Adverse Incident reporting in Northern Ireland, in comparison to best practice, scores highly on securing accountability, reasonably highly on the level of reporting, does moderately well on meaningful engagement with patients and families, and is weak in producing effective, sustained reduction in risk. Also, the climate of accountability and intense political and media scrutiny does not sit easily with what best practice has repeatedly shown is the key to making care safer: a climate of learning not judgment.

5.4.14 The Review concluded that front-line clinical staff are insufficiently supported to fulfill the role of assessing and improving the quality and safety of the care that they and their teams provide. The lack of time, the paucity of reliable, well-presented data, the absence of in-service training in quality improvement methods, and the patchiness of clinical leadership are all major barriers to achieving this vital shift to mass clinical engagement.

5.5 OPENNESS WITH PATIENTS AND FAMILIES

5.5.1 The Serious Adverse Incident investigation system contains, in the view of the Review Team, sufficient checks and balances to ensure that affected patients and families are informed that something went wrong, except in exceptional circumstances.

5.5.2 Such mechanisms are part of good governance, but alone are insufficient. It will be culture – not accountability – that increases the reporting of harm, and staff's comfort in talking openly about harm.

5.5.3 Those conducting investigations are committed to rigorous investigation, and to being open with patients and families about what is found. But whilst some communicate well in person and in writing, others are less strong. This can come across to families as a lack of openness.

5.5.4 High-profile inquiries and negative media coverage have led some to believe that there is widespread cover-up of harm in the health and social care system. This is simply inconsistent with what the Review Team observed, which was a system trying, as many others in the world are, to get to grips with the difficult problem of patient safety.

5.5.5 Fear and suspicion powerfully inhibit openness. The health and social care system needs to rise to the challenge of tackling these threats head on. Perception is important – even simple delays and communication weaknesses can fuel suspicion. And if staff hear more from the media than direct from their leaders, this does not dispel fear.

6 RECOMMENDATIONS

Recommendation 1: Coming together for world-class care

A proportion of poor quality, unsafe care occurs because local hospital facilities in some parts of Northern Ireland cannot provide the level and standard of care required to meet patients' needs 24 hours a day, 7 days a week. Proposals to close local hospitals tend to be met with public outrage, but this would be turned on its head if it were properly explained that people were trading a degree of geographical inconvenience against life and death. Finding a solution should be above political self-interest.

We recommend that all political parties and the public accept in advance the recommendations of an impartial international panel of experts who should be commissioned to deliver to the Northern Ireland population the configuration of health and social care services commensurate with ensuring world-class standards of care.

Recommendation 2: Strengthened commissioning

The provision of health and social care in Northern Ireland is planned and funded through a process of commissioning that is currently tightly centrally-controlled and based on a crude method of resource allocation. This seems to have evolved without proper thought as to what would be most effective and efficient for a population as small as Northern Ireland's. Although commissioning may seem like a behind-the-scenes management black box that the public do not need to know about, quality of the commissioning process is a major determinant of the quality of care that people ultimately receive.

We recommend that the commissioning system in Northern Ireland should be re-designed to make it simpler and more capable of reshaping services for the future. A choice must be made to adopt a more sophisticated tariff system, or to change the funding flow model altogether.

Recommendation 3: Transforming Your Care – action not words

The demands on hospital services in Northern Ireland are excessive and not sustainable. This is a phenomenon that is occurring in other parts of the United Kingdom. Although triggered by multiple factors, much of it has to do with the increasing levels of frailty and multiple chronic diseases amongst older people together with too many people using the hospital emergency department as their first port of call for minor illness. High-pressure hospital environments are dangerous to patients and highly stressful for staff. The policy document Transforming Your Care contains many of the right ideas for developing high quality alternatives to hospital care but few believe it will ever be implemented or that the necessary funding will flow to it. Damaging cynicism is becoming widespread.

We recommend that a new costed, timetabled implementation plan for *Transforming Your Care* should be produced quickly. We further recommend that two projects with the potential to reduce the demand on hospital beds should be launched immediately: the first, to create a greatly expanded role for pharmacists; the second, to expand the role of paramedics in pre-hospital care. Good work has already taken place in these areas and more is planned, but both offer substantial untapped potential, particularly if front-line creativity can be harnessed. We hope that the initiatives would have high-level leadership to ensure that all elements of the system play their part.

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Recommendation 4: Self-management of chronic disease

Many people in Northern Ireland are spending years of their lives with one or more chronic diseases. How these are managed determines how long they will live, whether they will continue to work, what disabling complications they will develop, and the quality of their life. Too many such people are passive recipients of care. They are defined by their illness and not as people. Priority tends to go to some diseases, like cancer and diabetes, and not to others where provision remains inadequate and fragmented. Quality of care, outcome and patient experience vary greatly. Initiatives elsewhere show that if people are given the skills to manage their own condition they are empowered, feel in control and make much more effective use of services.

We recommend that a programme should be established to give people with long-term illnesses the skills to manage their own conditions. The programme should be properly organised with a small full-time coordinating staff. It should develop metrics to ensure that quality, outcomes and experience are properly monitored. It should be piloted in one disease area to begin with. It should be overseen by the Long Term Conditions Alliance.

Recommendation 5: Better regulation

The regulation of care is a very important part of assuring standards, quality and safety in many other jurisdictions. For example, the Care Quality Commission has a very prominent role in the inspection and registration of healthcare providers in England. In the USA, the Joint Commission's role in accreditation means that no hospital wants to fall below the standards set or it will lose reputation and patients. The Review Team was puzzled that the regulator in Northern Ireland, the Regulation and Quality Improvement Authority, was not mentioned spontaneously in most of the discussions with other groups and organisations. The Authority has a greater role in social care than in health care. It does not register, or really regulate, the Trusts that provide the majority of healthcare and a lot of social care. This light-touch role seems very out of keeping with the positioning of health regulators elsewhere that play a much wider role and help support public accountability. The Minister for Health, Social Services and Patient Safety has already asked that the regulator start unannounced inspections of acute hospitals from 2015, but these plans are relatively limited in extent.

We recommend that the regulatory function is more fully developed on the healthcare side of services in Northern Ireland. Routine inspections, some unannounced, should take place focusing on the areas of patient safety, clinical effectiveness, patient experience, clinical governance arrangements, and leadership. We suggest that extending the role of the Regulation and Quality Improvement Authority is tested against the option of outsourcing this function (for example, to Healthcare Improvement Scotland, the Scottish regulator). The latter option would take account of the relatively small size of Northern Ireland and bring in good opportunities for benchmarking. We further recommend that the Regulation and Quality Improvement Authority should review the current policy on whistleblowing and provide advice to the Minister.

6

Recommendation 6: Making incident reports really count

The system of incident reporting within health and social care in Northern Ireland is an important element of the framework for assuring and improving the safety of care of patients and clients. The way in which it works is falling well below its potential for the many reasons explained in this report. Most importantly, the scale of successful reduction of risk flowing from analysis and investigation of incidents is too small.

We recommend that the system of Serious Adverse Incident and Adverse Incident reporting should be retained with the following modifications:

- **deaths of children from natural causes should not be classified as Serious Adverse Incidents;**
- **there should be consultation with those working in the mental health field to make sensible changes to the rules and time-scales for investigating incidents involving the care of mental health patients;**
- **a clear policy and some re-shaping of the system of Adverse Incident reporting should be introduced so that the lessons emanating from cases of less serious harm can be used for systemic strengthening (the Review Team strongly warns against uncritical adoption of the National Reporting and Learning System for England and Wales that has serious weaknesses);**
- **a duty of candour should be introduced in Northern Ireland consistent with similar action in other parts of the United Kingdom;**
- **a limited list of Never Events should be created**
- **a portal for patients to make incident reports should be created and publicised**
- **other proposed modifications and developments should be considered in the context of Recommendation 7.**

Recommendation 7: A beacon of excellence in patient safety

There is currently a complex interweaving of responsibilities for patient safety amongst the central bodies responsible for the health and social care system in Northern Ireland. The Department of Health, Social Services and Public Safety, the Health and Social Care Board, and the Regulation and Quality Improvement Authority all play a part in: receiving Serious Adverse Incident Reports, analysing them, over-riding local judgments on designation of incidents, requiring and overseeing investigation, auditing action, summarising learning, monitoring progress, issuing alerts, summoning-in outside experts, establishing inquiries, checking-up on implementation of inquiry reports, declaring priorities for action, and various other functions. The respective roles of the Health and Social Care Board and the Public Health Agency are clearly specified in legal regulations but seem very odd to the outsider. The Health and Social Care Board has no full-time officers of its own who lead on quality and safety and no in-house medical or nursing director. These functions are grafted on from the Public Health Agency. The individuals concerned have done some excellent work on quality and patient safety and carry out their roles very conscientiously. However, symbolically, and on grounds of organisational coherence, it appears strange that the main body responsible for planning and securing care does not hold these functions in the heart of its business. The Department of Health, Social Services and Public Safety's role on paper is limited to policy-making but, in practice, steps in regularly on various aspects of quality and safety. The Review Team thought long and hard before making a recommendation in this area. In the end, we believe action is imperative for two reasons: firstly, the present central arrangements are byzantine and confusing; secondly, the overwhelming need is for development of the present system to make it much more successful in bringing about improvement. Currently, almost all the activities

(including those listed above) are orientated to performance management not development. There is a big space for a creative, positive and enhancing role.

We recommend the establishment of a Northern Ireland Institute for Patient Safety, whose functions would include:

- **carrying out analyses of reported incidents, in aggregate, to identify systemic weaknesses and scope for improvement;**
- **improving the reporting process to address under-reporting and introducing modern technology to make it easier for staff to report, and to facilitate analysis;**
- **instigating periodic audits of Serious Adverse Incidents to ensure that all appropriate cases are being referred to the Coroner;**
- **facilitating the investigation of Serious Adverse Incidents to enhance understanding of their causation;**
- **bringing wider scientific disciplines such as human factors, design and technology into the formulation of solutions to problems identified through analysis of incidents;**
- **developing valid metrics to monitor progress and compare performance in patient safety;**
- **analysing adverse incidents on a sampling basis to enhance learning from less severe events;**
- **giving front-line staff skills in recognising sources of unsafe care and the improvement tools to reduce risks;**
- **fully engaging with patients and families to involve them as champions in the Northern Ireland patient safety program, including curating a library of patient stories for use in educational and staff induction programmes;**
- **creating a cadre of leaders in patient safety across the whole health and social care system;**
- **initiating a major programme to build safety resilience into the health and social care system.**

Recommendation 8: System-wide data and goals

The Northern Ireland Health and Social Care system has no consistent method for the regular assessment of its performance on quality and safety at regional-level, Trust-level, clinical service-level, and individual doctor-level. This is in contrast to the best systems in the world. The Review Team is familiar with the Cleveland Clinic. That service operates by managing and rewarding performance based on clinically-relevant metrics covering areas of safety, quality and patient experience. This is strongly linked to standard pathways of care where outcome is variable or where there are high risks in a process.

We recommend the establishment of a small number of systems metrics that can be aggregated and disaggregated from the regional level down to individual service level for the Northern Ireland health and social care system. The measures should be those used in validated programmes in North America (where there is a much longer tradition of doing this) so that regular benchmarking can take place. We further recommend that a clinical leadership academy is established in Northern Ireland and that all clinical staff pass through it.

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Recommendation 9:
Moving to the forefront of new technology

The potential for information and digital technology to revolutionise healthcare is enormous. Its impact on some of the long-standing quality and safety problems of health systems around the world is already becoming evident in leading edge organisations. These developments include: the electronic medical record, electronic prescribing systems for medication, automated monitoring of acutely-ill patients, robotic surgery, smartphone applications to manage workload in hospitals at night, near-patient diagnostics in primary care, simulation training, incident reporting and analysis on mobile devices, extraction of real-time information to assess and monitor service performance, advanced telemedicine, and even smart kitchens and talking walls in dwellings adapted for people with dementia. There is no organised approach to seeking out and making maximum use of technology in the Northern Ireland care system. It could make a big difference in resolving some of the problems described in this report. There is evidence of individual Trusts making their own way forward on some technological fronts, but this uncoordinated development is inappropriate - the size of Northern Ireland is such that there should be one clear, unified approach.

We recommend that a small Technology Hub is established to identify the best technological innovations that are enhancing the quality and safety of care around the world and to make proposals for adoption in Northern Ireland. It is important that this idea is developed carefully. The Technology Hub should not deal primarily with hardware and software companies that are selling products. The emphasis should be on identifying technologies that are in established use, delivering proven benefits, and are highly valued by management and clinical staff in the organisations concerned. They should be replicable at Northern Ireland-scale. The overall aim of this recommendation is to put the Northern Ireland health and social care system in a position where it has the best technology and innovation from all corners of the world and is recognised as the most advanced in Europe.

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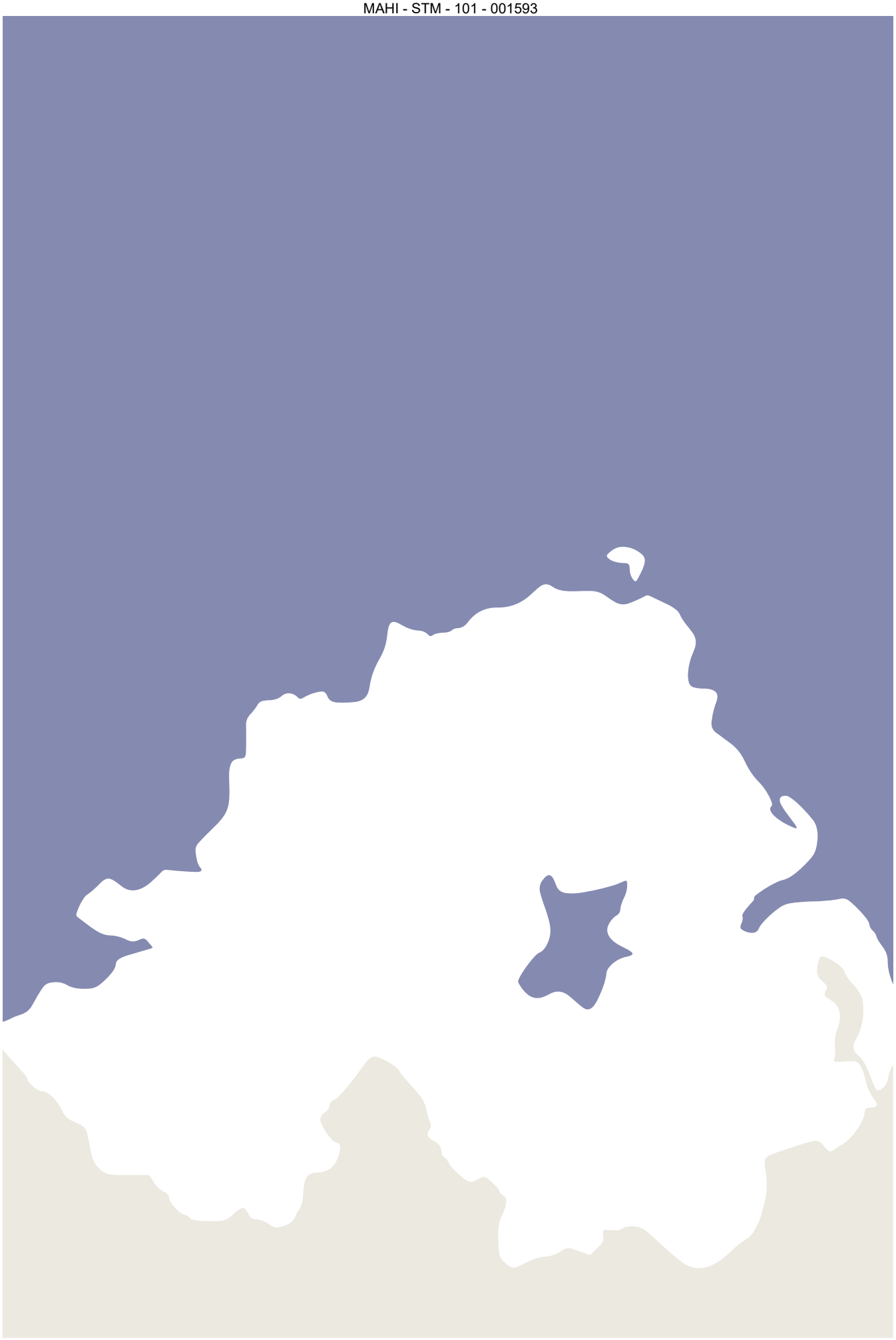
Recommendation 10: A much stronger patient voice

In the last decade, policy-makers in health and social care systems around the world have given increasing emphasis to the role of patients and family members in the wider aspects of planning and delivering services. External reviews – such as the Berwick Report in England - have expressed concern that patients and families are not empowered in the system. Various approaches have been taken worldwide to address concerns like these. Sometimes this has been through system features such as choice and personally-held budgets, sometimes through greater engagement in fields like incident investigation, sometimes through user experience surveys and focus groups, and sometimes through direct involvement in the governance structures of institutions. In the USA, patient experience data now forms part of the way that hospitals are paid and in some it determines part of the remuneration of individuals. This change catalysed the centrality of patients to the healthcare system in swathes of North America. Observers say that the big difference was when dollars were linked to the voice of patients. Northern Ireland has done some good work in the field of patient engagement, in particular the requirement to involve patients and families in Serious Adverse Incident investigation, the 10,000 voices initiative, in the field of mental health and in many aspects of social care. Looked at in the round, though patients and families have a much weaker voice in shaping the delivery and improvement of care than is the case in the best healthcare systems of the world.

We recommend a number of measures to strengthen the patient voice:

- **more independence should be introduced into the complaints process; whilst all efforts should be made to resolve a complaint locally, patients or their families should be able to refer their complaint to an independent service. This would look again at the substance of the complaint, and use its good offices to bring the parties together to seek resolution. The Ombudsman would be the third stage and it is hoped that changes to legislation would allow his reports to be made public;**
- **the board of the Patients and Client Council should be reconstituted to include a higher proportion of current or former patients or clients of the Northern Ireland health and social care system;**
- **the Patients and Client Council should have a revised constitution making it more independent;**
- **the organisations representing patients and clients with chronic diseases in Northern Ireland should be given a more powerful and formal role within the commissioning process, the precise mechanism to be determined by the Department of Health, Social Services and Public Safety;**
- **one of the validated patient experience surveys used by the Centers for Medicare and Medicaid Services in the USA (with minor modification to the Northern Ireland context) to rate hospitals and allocate resources should be carried out annually in Northern Ireland; the resulting data should be used to improve services, and assess progress. Finally and importantly, the survey results should be used in the funding formula for resource allocation to organisations and as part of the remuneration of staff (the mechanisms to be devised and piloted by the Department of Health, Social Services, and Public Safety).**

In implementing the above recommendations, the leaders of the Northern Ireland health and social care system should be clear in their ambition, which is in our view realistic, of making Northern Ireland a world leader in the quality and safety of its care. Northern Ireland is the right place for such a transformation, and now is the right time.



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SERVICE FRAMEWORK FOR LEARNING DISABILITY

Working for a Healthier People

INVESTOR IN PEOPLE

TABLE OF CONTENTS

		Page No
	Foreword	2
	Summary of Standards	3
	A Note on Terminology	22
Section 1	Introduction to Service Frameworks	23
Section 2	Service Framework For Learning Disability	30
Section 3	Why Develop a Service Framework for Learning Disability?	37
Section 4	Standards: Safeguarding and Communication and Involvement in the Planning and Delivery of Services	41
Section 5	Standards: Children and Young People	67
Section 6	Standards: Entering Adulthood	78
Section 7	Standards: Inclusion in Community Life	85
Section 8	Standards: Meeting General Physical and Mental Health Needs	93
Section 9	Standards: Meeting Complex Physical and Mental Health Needs	112
Section 10	Standards: At Home in The Community	119
Section 11	Standards: Ageing Well	129
Section 12	Standards: Palliative and End of Life Care	136
Annex A	Glossary of Terms Used	143
Annex B	Membership of Project Board & Project Team	147
Annex C	Membership of Working Groups	149
Annex D	Equal Lives Review (2005) Core Values	153
Annex E	Bamford Review of Mental Health & Learning Disability Reports	154
Annex F	Abbreviations	155

Foreword

As Minister for Health I am determined to protect and improve the quality of health and social care services and ensure that these are safe, effective and focussed on the patient. Driving up the quality of services and outcomes for people will be my underlying priority. I am committed to working, not only to improve health but to tackle inequalities in health.

I am particularly pleased, therefore, to launch the Service Framework for Learning Disability for implementation. This Framework aims to improve the health and wellbeing of people with a learning disability, their carers and families, by promoting social inclusion, reducing inequalities in health and social wellbeing and improving the quality of health and social care services, especially supporting those most vulnerable in our society.

Service Frameworks aim to set out clear standards of health and social care that are both evidence based and measurable. They set out the standard of care that service users and their carers can expect, and are also to be used by health and social care organisations to drive performance improvement through the commissioning process. The Service Framework for Learning Disability is one of five Frameworks to be issued for implementation to date and, that focus on the most significant causes of ill health and disability in Northern Ireland, namely: cardiovascular disease, respiratory disease, cancer, mental health and learning disability. Two further Frameworks, for children and young people and older people are currently at various stages of development.

This latest Framework has been developed actively involving a wide range of people across all aspects of health and social care including, patients, clients and carers, all of whose support has been invaluable. I would like to convey my sincere thanks, to you all, for your immensely important contribution.

Edwin Poots MLA
Minister for Health, Social Services and Public Safety

SERVICE FRAMEWORK FOR LEARNING DISABILITY

Summary of Standards

Safeguarding and Communication and Involvement in the Planning and Delivery of Services

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 1 (Generic): All HSC staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.	1. All HSC organisations and organisations providing services on behalf of the HSC have a **Safeguarding Policy** in place, which is effectively aligned with other organisational policies (e.g. recruitment, governance, complaints, SAIs, training, supervision, etc.) The Safeguarding Policy is supported by robust procedures and guidelines.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.
	2. All HSC organisations and organisations providing services on behalf of the HSC have **Safeguarding Plans** in place.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.
	3. All HSC organisations and organisations providing services on behalf of the HSC have **safeguarding champions** in place in order to promote awareness of safeguarding issues in their workplace.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 2: People with a learning disability should as a matter of course make choices or decisions about their individual health and social care needs. This needs to be balanced with the individual's ability to make such decisions and then the views of their family, carers and advocates should be taken into account in the planning and delivery of services, unless there are explicit and valid reasons to the contrary agreed with the person.	1. Evidence that people with a learning disability their family and carers have been involved in making choices or decisions about their individual health and social care needs.	Establish baseline March 2015. Performance levels to be determined once baseline established. March 2016.
Standard 3 (Generic): All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.	1. Percentage of job descriptions containing PPI as responsibility March 2015: senior and middle management March 2016: designated PPI leads at all levels of HSC organisations March 2017: all new job descriptions 2. Percentage of patients and clients expressing satisfaction	Establish baseline and set target March 2014. Monitor progress March 2015. 100% in all new job descriptions March 2016. Establish baseline and set target March 2014. Report percentage increase of patient and client satisfaction March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 3 (Generic): (continued)		Report percentage increase of patient and client satisfaction March 2016.
	3. Percentage of staff who have gained PPI training (details to be agreed for 2015/2016)	Conduct training needs assessment for PPI, commission design of PPI training programme March 2014. Establish baseline and set target March 2015. Monitor percentage of staff trained at different levels in PPI March 2016.
Standard 4: Adults with a learning disability should be helped by HSC professionals to develop their capacity to give or refuse informed consent.	1. Develop and agree a regional training plan that ensures that relevant HSC staff are trained in consent and capacity issues. 2. Evidence that robust processes are in place where capacity has been judged to be an issue within HSC services or services commissioned by HSC	All HSC organisations March 2016. Development and implementation of SAAT March 2015. Performance level to be determined based on outcomes of SAAT March 2016.
Standard 5 (Generic): All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.	1. Percentage of patients and clients expressing satisfaction with communication	Establish baseline March 2014. Report percentage increase of patient and client satisfaction with communications March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 5 (Generic): (continued)		Report percentage increase of patient and client satisfaction with communication March 2016.
Standard 6: People with a learning disability should expect effective communication with them by HSC organisations as an essential and universal component of the planning and delivery of health and social care	1. Percentage of people with a learning disability who do not use speech as their main form of communication who have been supported to establish a functional communication system. 2. Develop and agree a regional training plan for staff in both HSC and services commissioned by HSC to raise awareness of communication difficulties and how they may be addressed.	Develop and implement SAAT March 2015. Performance levels to be determined based on outcomes of SAAT March 2016. Regional Training Plan in place. March 2015. Training is delivered in accordance with Regional Training Plan. March 2016.
Standard 7: People with a learning disability should receive information about services and issues that affect their health and social wellbeing in a way that is meaningful to them and their family.	1. All HSC organisations should provide evidence that they are making information accessible to people with a learning disability. 2. Each person with a learning disability can access a named person who can signpost them to relevant services.	Development and implementation of SAAT March 2015. Performance levels to be determined once baseline established March 2016. Establish baseline of information provided March 2016. Performance levels to be determined once baseline established.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 8: People with a learning disability, or their carer, should be able to access self directed support in order to give them more control and choice over the type of care and support they receive.	1 Evidence of provision of accessible information on Direct Payments within HSC organisations.	Develop and implement SAAT March 2015. Establish performance levels based on outcomes from SAAT March 2016.
	2 Percentage of requests for Direct Payments from people with a learning disability that were approved.	Develop and implement SAAT March 2015. Establish performance levels based on outcomes from SAAT March 2016.
	3 Number of adults with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 2.25%).	Performance levels to be determined based on available resources and included in final Framework.
	4 Number of children with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 3.50%).	Performance levels to be determined based on available resources and included in final Framework.
	5 The HSC Board and Trusts have plans in place to extend the range and scope of self directed support including how they will develop skills and expertise in relevant staff.	HSC Board and all Trusts March 2017.
Standard 9 (Generic): Service users and their carers should have access to independent advocacy as required.	1. To be determined	To be determined.

Children and Young People

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 10: From the point at which concerns are raised that a child or young person may have a learning disability, there is an action plan in place to determine the nature and impact of the learning disability	1. Percentage of parents who express satisfaction with the assessment process and how the outcomes were conveyed.	Establish baseline of information provided March 2016. Performance levels to be determined once baseline established March 2017.
Standard 11: Children and young people should receive child-centred and co-ordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability.	1 Percentage of children and young people with a learning disability and carers who have been offered an annual assessment either under the Family Health Needs Assessment or UNOCINI Assessments. 2 Percentage of children and young people who have an agreed care plan detailing a pathway to receiving appropriate care and support	Establish baseline March 2016. Performance levels to be determined once baseline established March 2017. Establish baseline March 2016. Performance levels to be determined once baseline established March 2017.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 12: HSC services should respond to the needs of children and young people who have a learning disability and complex physical health needs in a manner that is personalised, developmentally appropriate and which supports access to appropriate care.	1 Percentage of parents whose child has a learning disability and complex physical health needs who have an identified key worker with co-ordinating responsibility.	Scope requirements and produce audit plan March 2015. Audit 50% of information available March 2016. 100% March 2017.
	2 Percentage of children and young people with complex physical health needs who have effective transition arrangements in place between hospital and community.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcomes March 2016. Fast Track arrangements for access to hospital/community services to be audited following establishment of baseline.
	3 Percentage of children with a learning disability and complex physical health needs who have received a multi-professional assessment as per regional integrated care pathway.	90% March 2015. 95% March 2016. 98% March 2017.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 13: Any child or young person who cannot live at home permanently should have their placement/ accommodation needs addressed in a way that takes full account of their learning disability.	1 Percentage of looked after children or young people with a learning disability who cannot live with their families who have a Permanency Plan.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

Entering Adulthood

Standard 14: Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18th birthday.	1. Percentage of young people who express satisfaction that their transition plan has been implemented within 2 years of leaving school. 2. Evidence of transfer to DES, where appropriate, for health checks for children on transition to adult services.	Develop and implement SAAT March 2016. Performance levels to be determined based on SAAT outcomes March 2017. 90% March 2015. 95% March 2016. 98% March 2017.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 15: People with a learning disability should be supported to have meaningful relationships, which may include marriage and individual, unique, sexual expression within the law, balancing their rights with responsibilities.	1. Regional guidelines on sexuality and personal relationships are developed to ensure a consistent approach. 2. Trusts to facilitate appropriate training for staff. 3. Trusts to facilitate appropriate training for service users and family carers. 4. Increase in the number of people with a learning disability accessing sexual health and reproductive healthcare services.	HSC Board policy developed and agreed March 2015. 40% March 2016. 80% March 2017. Level to be established pending development of regional policy March 2017. Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.

Inclusion in Community Life

Standard 16: Adults with a learning disability should be able to access support in order that they can achieve and maintain employment opportunities in productive work.	1. Percentage of school leavers with a learning disability who access work placements or employment within one year of leaving school (as percentage of total learning disabled school leaving population). 2. Percentage of adults with a learning disability who receive HSC support to help them secure employment (as a measure of those who request support).	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 17: All adults with a severe or profound learning disability should be able to access a range of meaningful day opportunities appropriate to their needs.	1. Percentage of adults with a severe or profound learning disability who have meaningful day opportunities in mainstream community settings, outside of their building based service. 2. Percentage of adults with a severe or profound learning disability receiving support in a building based service, who express satisfaction with the opportunity to experience day opportunities.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016. Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
Standard 18: All parents with a learning disability should be supported to carry out their parenting role effectively.	1. Develop and agree a regional protocol between children's and adult services for joint working and care pathways. 2. Percentage of parents with a learning disability who have a multi-professional/agency competence based assessment. 3. Percentage of parents with a learning disability involved in child protection or judicial processes who have received locally based skills training. 4. Percentage of parents with a learning disability involved in child protection or judicial processes who have access to the services of an independent advocate.	HSC Board in collaboration with all Trusts March 2015. Establish baseline March 2016. Performance levels to be determined once baseline established March 2017. 85% March 2015. 90% March 2016. 95% March 2017. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

Meeting General Physical and Mental Health Needs

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 19: All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.	1. All acute hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan. 2. Percentage of GPs who have a system for identifying people with a learning disability on their register. 3. Each GP practice has a designated link professional within local learning disability services. 4. Evidence of reasonable adjustments by health service providers.	All HSC Trusts establish baseline March 2015. Performance levels to be determined once baseline established March 2016. Baseline as per learning disability DES March 2015. Performance levels to be determined once baseline established March 2016. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 20 (Generic): All HSC staff, as appropriate, should advise people who smoke of the risks associated with smoking and signpost them to well-developed specialist smoking cessation services.	1. Number of people who are accessing Stop Smoking Services 2. Proportion of the smoking population who are accessing Stop Smoking Services. 3. Number of people using stop smoking services who have quit at 4 weeks and 52 weeks.	Baseline 2011/12 = 39204. - 4 % year on year increase March 2014 – March 2016. Baseline 2011/12 =10.8%. NICE guidance and the ten year tobacco strategy call for a target of over 5% of the smoking population to be reached, hence target to maintain at >/= 5% March 2014 – March 2016. Baseline 2011/12 = 20,299 for those quit at 4 weeks and 5,889 for those quit at 52 weeks. Target 4% increase in respective numbers year on year March 2014 – March 2016.
Standard 21: All people with a learning disability should be supported to achieve optimum physical and mental health.	1. The PHA and each HSC Trust has a health improvement strategy for people with a learning disability (children and adults) to address all relevant physical and mental health promotion and improvement needs. 2. Percentage of adults with a learning disability who have an annual health check. 3. Percentage of adults with a learning disability, who have an up to date and active Health Action Plan (HAP) following the annual health check.	All Trusts have in place a health improvement strategy for people with a learning disability March 2015. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 21:(continued)	4. Percentage of people with a learning disability who have been examined by a dentist in the past year.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	5. Percentage of females with a learning disability who access cervical and breast screening services.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	6. Percentage of people with a learning disability who have a sight test with an optometrist in the past year.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
Standard 22: All people with a learning disability who experience mental ill health should be able to access appropriate support.	1. A regional protocol is developed to ensure that people with a learning disability can access mainstream mental health services.	Protocol in place March 2015.
	2. Percentage of people with a learning disability and mental health needs who access mainstream mental health services e.g. psychological and talking therapies where indicated in their treatment plan.	Establish baseline March 2016. Performance levels to be determined once baseline established March 2017.
	3. Percentage of Health Action Plans and health checks which include mental health assessment and mental health promotion.	Establish baseline. March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 23 (Generic): All HSC staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.	1. Percentage of people eating the recommended 5 portions of fruit or vegetables each day.	Baseline for 2011/12 = 32% overall, 26% for males and 36% for females. Target: maintain or at best increase percentage by 1% year on year March 2014 – March 2016.
Standard 24 (Generic): All HSC staff, as appropriate, should provide support and advice on recommended levels of physical activity.	1. Percentage of people meeting the recommended level of physical activity per week.	New physical activity guidelines were launched in 2011 and as such a new suite of questions to establish the percentage of people meeting the recommended level of physical activity per week has been integrated within the 2012/13 Northern Ireland Health Survey. It is anticipated these new baseline results will be available in Nov / Dec 2013 March 2014. Performance level to be agreed thereafter.
Standard 25 (Generic): All HSC staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.	1. Percentage of people who receive screening in primary care settings in relation to their alcohol consumption.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.

Meeting Complex Physical and Mental Health Needs

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 26: All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services, as appropriate, based on assessed need.	1. Percentage of individuals with significant challenging behaviours who have a Behaviour Support Plan including advance directives in place that detail actions to be undertaken in the event of their challenging behaviours escalating.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcome March 2016.
	2. Where challenging behaviours present a significant risk to the individual or others or a risk of breakdown in accommodation arrangements, a specialist assessment has been completed within 24 hours.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcome March 2016.
	3. Where challenging behaviours present a significant risk to the individual, a Management Plan has been developed and implemented within 48 hours.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcome March 2016.
	4. Evidence that HSC has engaged with other relevant delivery partners in developing and implementing consistent approaches in individual cases.	All HSC Trusts March 2016.
	5. Percentage of people labelled as challenging who are not living in a congregate setting described as a challenging behaviour or specialist assessment/treatment service.	Develop and implement SAAT March 2017. Performance level to be determined based on SAAT outcomes.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 27: All people with a learning disability who come into contact with the Criminal Justice System should be able to access appropriate support.	1. Evidence that the HSC has engaged and developed local protocols with relevant delivery partners to achieve consistent and co-ordinated approaches to working with people with a learning disability who have offended or are at risk of offending.	Protocols in place March 2015.

At Home in the Community

Standard 28: HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed.	1. Percentage of support plans that take account of people's aspirations in relation to future accommodation needs, including independent living.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	2. Percentage of adults who are living with a single carer or where there are 2 carers and the primary carer is aged over 65 who have a futures plan in place.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	3. Percentage of people in receipt of public funding living in households of 5 people or less with a learning disability.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	4. Percentage of people leaving learning disability hospital within one week after treatment has been completed.	95% March 2015 97% March 2016 100% March 2017.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 29 (Generic): All HSC staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed**.**	1. Number of front line staff in a range of settings participating in Carer Awareness Training Programmes 2. The number of carers who are offered Carers Assessments 3. The percentage of carers who participate in Carers Assessments	20% March 2015. 50% March 2016. Improvement targets set by HSC Board in conjunction with Carers Strategy. Implementation Group. Reviewed annually. Improvement targets set by HSC Board in conjunction with Carers Strategy. Implementation Group. Reviewed annually.
Standard 30: All family carers should be offered the opportunity to have their needs assessed and reviewed annually.	1. Percentage of carers who express satisfaction at their annual review that their needs as identified in the carers' assessment have been met.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

Ageing Well

Standard 31: All people with a learning disability should have the impact of ageing taken into account in having their future needs assessed and proactively managed.	1. Percentage of people whose care plan has been reviewed taking account of issues associated with ageing. 2. Percentage of carers aged 65 years and over receiving domiciliary or short break support services.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016. Develop and implement SAAT March 2015 Performance levels to be determined based on SAAT outcomes March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 32: All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.	1. Percentage of people with a learning disability and dementia who can access appropriate dementia services as required. 2. Percentage of people with a learning disability and dementia who have received additional supports following a dementia diagnosis. 3. Percentage of HSC professionals and other support providers who have received awareness training on the needs of people with a learning disability and dementia.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016. Develop and implement SAAT March 2016. Performance levels to be determined based on SAAT outcomes March 2017. Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

Palliative and End of Life Care

Standard 33 (Generic): All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care	1. Percentage of the population that is enabled to die in their preferred place of care. 2. Percentage of population with an understanding of advance care planning	Establish baseline March 2014. Performance levels to be determined once baseline established March 2015. Establish baseline March 2014. Performance levels to be determined once baseline established March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 34: All people with a learning disability being assessed for supportive and palliative care should have their learning disability taken into account in consultation with them, their carers and learning disability services when appropriate.	1. Palliative care services have mechanisms to identify whether people have a learning disability. 2. Evidence of specific actions in service delivery that make reasonable adjustment for their learning disability.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016. Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.

A NOTE ON TERMINOLOGY

The following terms will be used throughout this document:

> ‘carer’ will be used to describe a family member including children and young people or informal carers
>
> ‘HSC organisation’ will be used to describe a variety of health and social care providers, such as, the HSC Board, HSC Trusts and the Public Health Agency.
>
> ‘service user’ will be used to describe those who use learning disability services

A glossary of terms used is provided in Annex A

SECTION 1: INTRODUCTION TO SERVICE FRAMEWORKS

Background

The overall aim of the Department of Health, Social Services and Public Safety (DHSSPS) (the Department) is to improve the health and social wellbeing of the people of Northern Ireland (NI).

In support of this the Department is developing a range of Service Frameworks, which set out explicit standards for health and social care that are evidence based and capable of being measured.

The first round of Service Frameworks focuses on the most significant causes for ill health and disability - cardiovascular health and wellbeing; respiratory health and wellbeing; cancer prevention, treatment and care; mental health and wellbeing; and learning disability. Work has also commenced to develop Service Frameworks for children and young people and older people.

Service Frameworks have been identified as a major strand of the reform of health and social care services and provide an opportunity to:

- strengthen the integration of health and social care services;
- enhance health and social wellbeing, to include identification of those at risk, and prevent/ protect individuals and local populations from harm and /or disease;
- promote evidence-informed practice;
- focus on safe and effective care; and
- enhance multi-disciplinary and inter-sectoral working.

Aim of Service Frameworks

Service Frameworks will set out the standards of care that service users, their carers and wider family can expect to receive in order to help people to:

- prevent disease or harm;
- manage their own health and wellbeing including understanding how lifestyle affects health and wellbeing including the causes of ill health

and its effective management;

- be aware of what types of treatment and care are available within health and social care; and
- be clear about the standards of treatment and care they can expect to receive.

All Service Frameworks incorporate a specific set of standards that are identified as Generic[1]. These, essentially, are intended to apply to all the population, or all HSC professionals or all service users, regardless of their health condition or social grouping. These include:

- safeguarding (Generic Standard 1);
- involvement (Generic Standard 3);
- communication (Generic Standard 5);
- independent advocacy (Generic Standard 9);
- smoking prevention & cessation (Generic Standard 20);
- healthy eating (Generic Standard 23);
- physical activity (Generic Standard 24);
- alcohol (Generic Standard 25);
- carers (Generic Standard 29); and
- palliative care (Generic Standard 33).

These Generic standards reinforce the holistic approach to health and social care improvement and reflect the importance of health promotion in preventing medical or social care issues occurring in the first place. Their inclusion ensures:

- equality of opportunity for all;
- the communication of consistent messages to service users and providers of HSC; and
- a consistent approach in the design and delivery of services.

[1] Generic Standards updated following CMO letter of 29 May 2013

Service Frameworks will be used by a range of stakeholders including commissioners, statutory and non-statutory providers, and the Regulation and Quality Improvement Authority (RQIA) to commission services, measure performance and monitor care.

The Frameworks will identify clear and consistent standards informed by expert advice, research evidence and by national standard setting bodies such as the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE). The auditing and measuring of these standards will be assisted by the Guidelines and Implementation Network (GAIN) which will facilitate regional audit linked to priority areas, including Service Frameworks.

The standards, in the context of the 10 year Quality Strategy[2], will aim to ensure that health and social care services are:

i. **Safe** – health and social care which minimises risk and harm to service users and staff;

ii. **Effective** – health and social care that is informed by an evidence base (resulting in improved health and wellbeing outcomes for individuals and communities), is commissioned and delivered in an **efficient** manner (maximising resource use and avoiding waste), is **accessible** (is timely, geographically reasonable and provided in a setting where skills and resources are appropriate to need) and **equitable** (does not vary in quality because of personal characteristics such as age, gender, ethnicity, race, disability (physical disability, sensory impairment and learning disability), geographical location or socioeconomic status).

iii. **Person centred** – health and social care that gives due regard to the preferences and aspirations of those who use services, their family and

[2] Quality 2020: A 10-Year Quality Strategy for Health and Social Care in Northern Ireland

carers and respects the culture of their communities. A person of any age should have the opportunity to give account of how they feel and be involved in choices and decisions about their care and treatment dependent on their capacity to make decisions. In absence of the capacity to make decisions they should listen to those who know and care for the person best.

Involving and communicating with service users, carers and the public

The Department has produced guidance, "Strengthening Personal and Public Involvement in Health and Social Services"[3], which sets out values and principles which all health and social care organisations and staff should adopt when engaging with the public and service users. These include the need to involve people at all stages in the planning and development of health and social care services. This policy position has been strengthened by the introduction of the Health and Social Care (Reform) Act (Northern Ireland) 2009 and the statutory duty it places on HSC organisations to involve and consult with the public. (Art 19)

It is important that the views of service users and carers are taken into account when planning and delivering health and social care. The integration of the views of service users, carers and local communities into all stages of the planning, development and review of Service Frameworks is an important part of the continuous quality improvement and the open culture which should be promoted in HSC.

The Department is committed to involving those who use learning disability services (experts by experience), their carers and wider families. Through the proactive involvement of the service users and carers in the planning of Service Frameworks, it is hoped that concerns and ideas for improvement can be shared and that the standards developed in partnership with service users,

[3] DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07) http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

carers and the public will focus on the issues that really matter to them.

It is also important that Service Frameworks provide service users and carers with clear and concise information, which is sensitive to their needs and abilities, so that they can understand their own health and wellbeing needs. To facilitate this, easy access versions will be made available for all Service Frameworks. Service Frameworks will also be made available in various other formats e.g. Braille, large print and audio tape. The Department will also consider requests for other formats or translation into ethnic minority languages.

People are ultimately responsible for their own health and wellbeing and that of their dependents, and it is important that service users, their carers and wider family are made aware of the role they have to play in promoting health and wellbeing.

Involving other agencies in promoting health and wellbeing

Improving the health and wellbeing of the population requires action right across society and it is acknowledged that health and wellbeing is influenced by many other factors such as poverty, housing, education and employment. While Service Frameworks set standards for providers of health and social care services it is essential that HSC services work in partnership with other government departments and agencies both statutory and non-statutory to seek to influence and improve the health and social wellbeing of the public.

People who use health and social care services, including learning disability services, may have complex needs which require inputs from a range of health and social care professionals and other agencies.

The benefits of multidisciplinary team working and multiagency working, including voluntary and community organisations, are well recognised and it is a key component of decision making regarding prevention, diagnosis,

treatment and ongoing care. This will be a key theme underpinning the development and implementation of Service Frameworks.

Data Collection

As Service Frameworks are implemented it is important that timely, accurate information is available to support decision-making and service improvement.

To support this, data sources are identified, early in the development stage, to match the key performance indicator (KPI) data definitions. It is through the data source that progress can be monitored. Where robust baseline data is not available Frameworks will be looking to audits, including Self Assessment Audit Tools (SAATs), to gather information, establish baselines and set future performance levels.

Research and Development

It is important that Service Frameworks are based on valid, relevant published research, where available, and other evidence.

Education and Workforce

Education and workforce development occur at individual, team, organisational, regional and national levels: they are part of the drive to promote quality. The ongoing development and implementation of Service Frameworks will influence the education and training agenda and curricula content for all staff involved in the delivery of health and social care. This will require a commitment to lifelong learning and personal development alongside a focus on specific skill areas to ensure that newly qualified and existing staff are in a position to deliver on quality services.

Leadership

Effective leadership is one of the key requirements for the implementation of Service Frameworks and will require health and social care professionals from primary, community and secondary care to work together across organisational boundaries, including other governmental departments and the voluntary and community sectors. It is essential that Service Frameworks are given priority at senior, clinical and managerial level and implemented throughout all HSC organisations.

Affordability

Extensive discussions have been held with key stakeholders on the overall costs of delivering the Service Framework for Learning Disability in the context of the very significant challenges facing health and social care services. Many of the standards do not require additional resources and should be capable of delivery by optimising the use of existing funding. Where there are additional costs associated with specific standards, performance indicators and targets will be reviewed and adjusted as necessary, in the light of the available resources in any one year.

Securing additional funding that may be needed to advance some standards will undoubtedly create challenges. However, Service Frameworks constitute the distillation of the best advice and guidance available and there is great value in setting out our aspirations to improve quality in the care of people with a learning disability, even if we cannot commit to achieving every standard fully or as quickly as we would like. Even in the most difficult of times we must continue to set challenging targets in an effort to improve services.

The Department will work closely with the HSC Board, and other stakeholders, in developing an achievable, prioritised implementation plan for this Service Framework that will deliver real benefits and improved quality of services.

SECTION 2: SERVICE FRAMEWORK FOR LEARNING DISABILITY

Introduction

The aim of the Service Framework for Learning Disability is to improve the health and wellbeing of people with a learning disability, their carers and their families by promoting social inclusion, reducing inequalities in health and social wellbeing, and improving the quality of care.

The Service Framework for Learning Disability sets standards in relation to:

- safeguarding and communication and involvement in the planning and delivery of services
- children and young people
- entering adulthood
- inclusion in community life
- meeting general physical and mental health needs
- meeting complex physical and mental health needs
- at home in the community
- ageing well
- palliative and end of life care

The Service Framework for Learning Disability is initially for a three-year period from 2013 – 2016. It will be the subject of further review and continuing development as a living document as performance indicators are achieved, evidence of changed priorities emerge and new performance indicators are identified.

Process for developing the Service Framework for Learning Disability

The development of Service Frameworks is overseen by a multi-disciplinary Programme Board, which is jointly chaired by the Chief Medical Officer and the Deputy Secretary of the Department. The Service Framework for Learning Disability was lead by a Project Board who were accountable to the

Department's Programme Board for ensuring the completion of the project within agreed timescales and to DHSSPS guidelines. The Project Board was informed by a project team with representation from all aspects of the service including service users, carers, advocates and voluntary organisations. The full project membership is set out in Annex B.

In order to develop the standards, 5 working groups were established which ensured broader representation and expertise. These groups and their membership are set out in Annex C. These groups produced the preliminary reports that informed the development of the standards.

External quality assurance was provided by Mr Rob Greig, National Development Team for Inclusion (NDTi) and Dr Margaret Whoriskey, Scottish Executive.

Equality Screening

The Framework has been screened to take account of Section 75 of the Northern Ireland Act 1998 and any potential impact that the Framework might have on Human Rights. It is the recommendation of the Project Team that the Framework does not negatively impact on equality of opportunity and therefore does not require a full Equality Impact Assessment.

Values

The core values outlined in the Equal Lives Review (2005) have been adopted in full in the development of the Service Framework for Learning Disability. These core values when enshrined in practice will ensure that independence is promoted for all people with a learning disability. (Annexe D)

Policy and Legislative Context

The Service Framework for Learning Disability is congruent with the legal and policy context for the delivery of supports to people with a learning disability.

This has over recent years increasingly been underpinned by concepts of rights, inclusion and citizenship.

The onus on public authorities to promote equality of opportunity is also enshrined in the Northern Ireland Act (1998) which states that "*a public authority shall, in carrying out its functions in Northern Ireland, have due regard to the need to promote equality of opportunity between persons with a disability and persons without."*

The Reform and Modernisation of Mental Health and Learning Disability Services Review (Bamford - May 2007)

A review of policy, practice and legislation relating to Mental Health and Learning Disability was commissioned by DHSSPS in October 2002. The Review concluded in August 2007 and produced ten reports (Annex E) that detailed the vision for supporting people with a learning disability, promoting mental health and wellbeing at all levels of society and for the delivery of specialist health and social care for everyone who needs it.

The DHSSPS response to Bamford, 'Delivering the Bamford Vision' (2008) (the Action Plan) states, "*the Northern Ireland Executive accepts the thrust of the recommendations"*, and sets out proposals to take the recommendations forward over the next 10 – 15 years.

The Service Framework for Learning Disability builds on the approaches to supporting people with a learning disability proposed in the Bamford Review and the subsequent Action Plan.

Consistency with other documents

The Service Framework for Learning Disability has taken cognisance of reports and documents that have been or are being developed by DHSSPS and other regional groups, including:

- Transforming Your Care (DHSSPS, 2011)
- *Investing for Health* strategies;
- The Quality Framework – as outlined in *Best Practice Best Care (2001);*

- The *Reform and Modernisation* of HSC;
- Personal and Public Involvement (PPI) (DHSSPS, 2007)
- National Institute for Health and Clinical Excellence guidance (NICE)
- Social Care Institute for Excellence guidance (SCIE)

Human Rights and Social Inclusion

A key priority for health and social care services and the wider community is to tackle stigma, discrimination and inequality and to empower and support people with a learning disability and their families to be actively engaged in the process. This is underpinned by legislation from Europe and the United Kingdom (UK) as well as international law. A summary of all the relevant documentation can be found in "Promoting Social Inclusion" (including the UN Convention on the Rights of People with Disabilities[4] (UNCRPD)), The Reform and Modernisation of Mental Health and Learning Disability Services (Bamford - May 2007) and the "Human Rights and Equality" Report (Bamford - October 2006).

Human rights, as enshrined in the Human Rights Act (1998) UK, derive from the fundamental principles that:

- human beings have value and should be treated equally based on the fact that they are human beings first and foremost; and
- human worth is not based on either capacity or incapacity.

Human rights include the right to life, liberty and security and respect for a private and family life.

As this Framework also aims to address the particular issues facing children and young people with a learning disability and their family carers it is also underpinned by the four core principles of the UN Convention on the Rights of Children:[5]

- non-discrimination;

[4] UNCRPD http://www.un.org/disabilities/default.asp?id=150
[5] UNCRC http://www.article12.org/pdf/UNCRC%20Official%20Document.pdf

- devotion to the best interests of the child;
- the right to life, survival and development; and
- respect for the views of the child.

How to read the rest of this document

Each Service Framework follows an individual's journey from infancy through to end of life care taking into account the different health and social care needs of children, adults and older people. In the Service Framework for Learning Disability each standard is accompanied by a statement written from the perspective of a person with a learning disability, in order to make them more meaningful to those for whom the Framework is primarily aimed.

Each standard sets out the evidence base and rationale for the development of the standard, the impact of the standard on quality improvement as well as the performance indicators that will be used to measure that the standard has been achieved within a specific timeframe. Each standard is presented in the same way. Figure 1 shows the information that is included in each standard.

Explaining the Standards

Overarching Standard This is a short statement that outlines what will be delivered and includes a statement written from the perspective of a person with a learning disability
Rationale This is a short section that outlines why/how the standard will make a difference for people using learning disability services. **Evidence** This includes brief references for the research evidence or guidance that the standard is based on.
Responsibility for delivery/implementation
This lists the HSC organisations tasked with responsibility for delivering the standard. It will include partners in care such as other government departments and agencies and voluntary organisations and community groups that have contractual or service level agreements with health and social care organisations.
Quality Dimensions
The impact of the standard on quality improvement is identified in relation to the five core values outlined in the Equal Lives Review (2005) (Annexe D). These include: • Citizenship • Social Inclusion • Empowerment • Working Together • Individual Support

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
This information will be monitored to show if the standard is being delivered.	This identifies where the information will be derived from.	This describes how well the service must perform against this indicator.	This specifies when the anticipated performance level should be reached.

Figure 1

Many of the standards apply to both adult services and services for children and young people. Each standard has been colour coded for ease of reference. It should be noted that there are some standards that may apply to both adults and young people, for example, Standard 13 (meaningful relationships) but will continue to be colour coded for adult services.

Standard applies to children, young people and adults with a learning disability

Standard applies only to children and young people with a learning disability

Standard applies only to adults with a learning disability

The rest of this document is divided into the following Sections:

- **Section 3** sets out the rationale for developing a Service Framework for Learning Disability
- **Section 4** sets out the standards for safeguarding and communication and involvement in the planning and delivery of services
- **Section 5** sets out the standards for children and young people
- **Section 6** sets out the standards for entering adulthood
- **Section 7** sets out the standards for inclusion in community life
- **Section 8** sets out the standards for meeting general physical and mental health needs
- **Section 9** sets out the standards for meeting complex physical and mental health needs
- **Section 10** sets out the standards for at home in the community
- **Section 11** sets out the standards for ageing well
- **Section 12** sets out the standards for palliative and end of life care

SECTION 3: WHY DEVELOP A SERVICE FRAMEWORK FOR LEARNING DISABILITY?

Introduction

Learning disability may be defined as follows:

> *A 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.* (Equal Lives, 2005)

Prevalence of Learning Disability

In determining the prevalence of learning disability in NI the Bamford Review (2005) cited a study based on information held by the former Health and Social Services Trusts, which estimated the numbers as shown in Table 1.

Table 1: Prevalence Rates (per 1,000) (15)

Age Bands	Mild/Moderate	Severe/Profound	Total
0-19	6,432	1,718	8,150
20-34	2,504	1,047	3,551
35-49	1,489	949	2,438
50+	1,473	753	2,226
Totals	**11,898**	**4,467**	**16,365**

However, the Review notes that these figures may be an underestimate as many people classed as *possibly having learning disability* may not be making any demands on health and social care services at present but could do so in the future.

Nonetheless, the overall prevalence rate of 9.7 persons per 1000 is higher than that reported for the Republic of Ireland (RoI) and for regions of Great Britain (GB).

The Review also anticipates that there will be increased numbers of people with a learning disability in the next 15 years. In addition, it notes the likelihood that higher proportions of these individuals will have increased care and support needs due to old age or additional complex needs.

Of particular importance to their quality of life is the need to promote their inclusion in society so that individuals with a learning disability can participate in the communities in which they live and access the full range of opportunities open to everyone else.

Developing a Service Framework for people with a learning disability serves a number of functions:

- For people with a learning disability, it details what it is they can expect in terms of care and support to meet their individual needs in ways that they understand and are accessible.
- For carers and families of people with a learning disability, it outlines what it is they can expect in terms of access to services for their family member and of their involvement as partners in the planning processes.
- For staff in front line service delivery, it enables them to communicate effectively in assisting people with a learning disability to access mainstream and specialist HSC services appropriately.
- For commissioners and those with responsibility for the delivery of services in the statutory and independent sectors, it assists them in achieving an integrated model of services and supports around the person in line with the expectations of service users and their families.

Relating the Service Framework for Learning Disability to other Service Frameworks

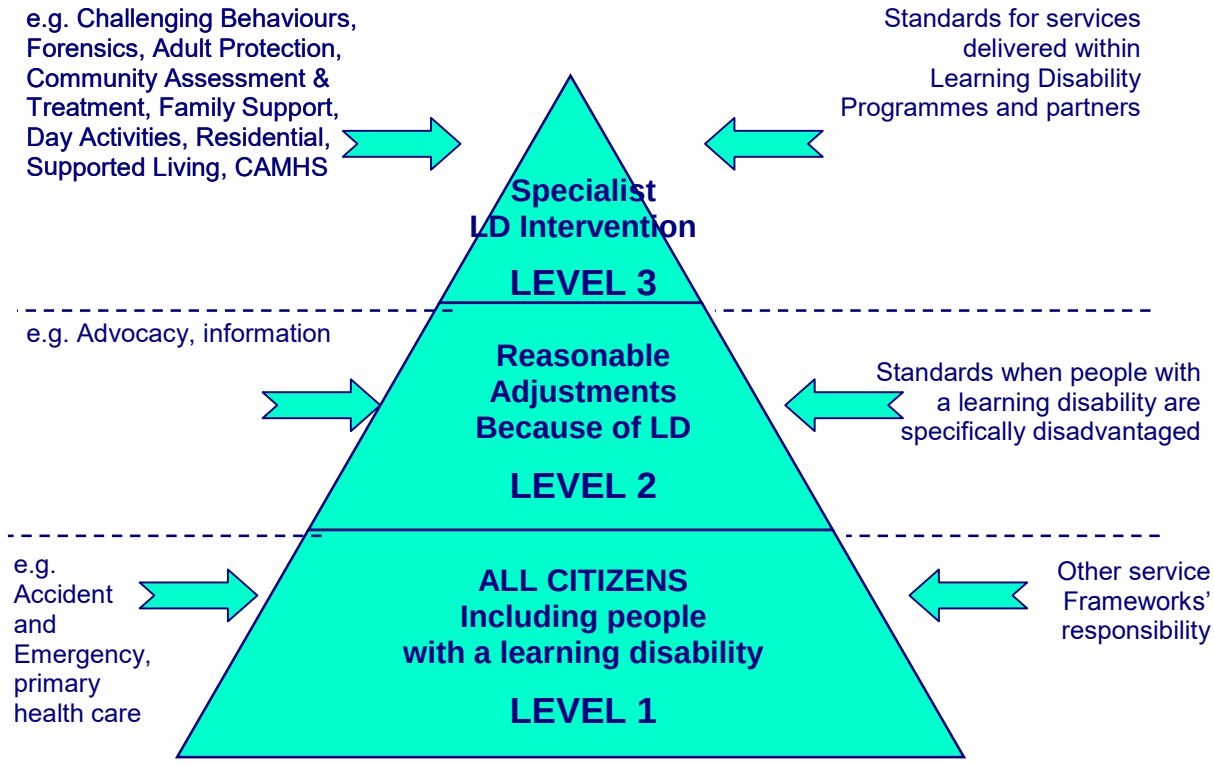


Figure 2

Figure 2 above describes the relationship between the Service Framework for Learning Disability and other service frameworks. Each service framework identifies standards related to a specific aspect of health and social care. The needs of people with a learning disability will also be addressed through these frameworks (Level 1).

In many instances HSC providers will need to make adjustments to the care and support they offer in order to make them accessible to people with a learning disability and their families. Current evidence indicates that these necessary adjustments are not consistently in place within HSC services. Standards in the Service Framework for Learning Disability will therefore require all HSC services to take the needs of people with a learning disability into account when designing and delivering services (Level 2).

While the basic premise of the Service Framework for Learning Disability is that people with a learning disability should access the same HSC services as other people, there are occasions when special expertise or support is required. As services become more inclusive it is anticipated that the volume and range of separate services will decrease as learning disability expertise is developed within mainstream HSC services.

The Service Framework for Learning Disability identifies a range of minimum standards that reflect the current service configuration in order to ensure that people with a learning disability and their families are clear about the care and support they can expect from these services (Level 3). Services provided through the non-statutory sector through contractual or service level agreements with HSC Trusts are also expected to meet these standards.

SECTION 4: SAFEGUARDING AND COMMUNICATION AND INVOLVEMENT IN THE PLANNING AND DELIVERY OF SERVICES

A wide range of people, for a variety of reasons, have been shown to be at risk of harm through abuse, exploitation or neglect. People of all ages, and from all social groupings, have the right to be safeguarded from such harm; to have their welfare promoted; and their human rights upheld. All HSC staff and staff providing services on behalf of the HSC have a dual responsibility with regard to safeguarding: (a) to ensure that all service users are treated with respect and dignity and are kept safe from poor practice that could lead to harm; and (b) that all staff are alert to the indicators of harm wherever it occurs and whoever is responsible; and know how and where to report concerns.

Effective communication is fundamental to the delivery of high quality health and social care. Without it there can be no meaningful partnership with service users and carers. Poor communication is often a significant contributory factor in complaints against HSC organisations and underpins many of the negative user experiences reported in research.

Involving people with a learning disability and their carers in the planning, delivery and monitoring of services helps to ensure that the care and support received meets their needs and aspirations. Involvement has to occur at all levels in HSC from ensuring service users' and carer's views are represented in organisational structures for the design and delivery of services, to securing a person-centred approach in all individual care and support arrangements.

There are particular challenges in meaningfully involving people with learning disability given the communication impairments they may experience and the legacy of discrimination which has served to exclude them from decision making fora in the past. Effective service user involvement needs to be underpinned by access to advocacy and information, alongside a clear understanding of issues related to capacity and informed consent.

Standard 1: (Generic)
All HSC staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.

Service user perspective:

"I am protected from harm"

Rationale:
A wide range of people, for a variety of reasons, have been shown to be at risk of harm through abuse, exploitation or neglect. People of all ages have the right to be safeguarded from such harm; to have their welfare promoted; and their human rights upheld. At the same time, they have the right to choose how to lead their lives, provided their lifestyle choices do not impact adversely on the safeguarding needs of others or, within the requirements of the law, of themselves. Decision making in this regard will have to pay due consideration to the age, maturity and capacity of the person. In this Standard, the term safeguarding is intended to be used in its widest sense, that is, to encompass both **preventive** activity, which aims to keep people safe and prevent harm occurring, and **protective** activity, which aims to provide an effective response in the event that there is a concern that harm has occurred or is likely to occur.

All HSC staff and staff providing services on behalf of the HSC have a dual responsibility with regard to safeguarding: (a) to ensure that all service users are treated with respect and dignity and are kept safe from poor practice that could lead to harm; and (b) that all staff are alert to the indicators of harm from abuse, exploitation or neglect wherever it occurs and whoever is responsible; and know how and where to report concerns about possible harm from abuse, exploitation or neglect whether these relate to the workplace or the wider community.

Effective safeguarding can ensure that people are safeguarded and their welfare promoted whether in their own homes; in the community; in families; and in establishments such as children's homes; secure accommodation; residential care and nursing homes; and hospitals. Through safeguarding, and in conjunction with positive engagement of individuals (and as appropriate their family and carers), effective prevention and potential for early intervention is enhanced and promoted and care and service plans are supported to deliver better outcomes. Where safeguarding is promoted, staff are empowered to act as advocates to safeguard vulnerable individuals and professional advocacy and counselling services are provided where required. A learning culture is also evident and staff are knowledgeable about safeguarding and keep abreast of local and national developments and learning, including enquiries, serious case reviews, case management reviews, inquiries and reports.

The quality of outcomes is more consistent, regardless of age, disability, gender, ethnic origin, religion, language, sexuality, political opinion, who pays for their care or their access to HSC provided or purchased services. Application in the wider community of knowledge and expertise gained in the

workplace serves to safeguard people more broadly and more generally.
The cycle of abusive behaviour(s) and/or neglect is broken.

Evidence:

World Health Organisation (2011) European Report on Preventing Elder Maltreatment
http://www.euro.who.int/__data/assets/pdf_file/0010/144676/e95110.pdf

OFMDFM (2009) Report of the Promoting Social Inclusion Working Group on Disability
http://www.ofmdfmni.gov.uk/report_of_the_promoting_social_inclusion_working_group_on_disability__pdf_1.38mb_.pdf

DHSSPS (2008) Improving the Patient & Client Experience 5 Standards: Respect, Attitude, Behaviour, Communication and Privacy and Dignity
http://www.dhsspsni.gov.uk/improving_the_patient_and_client_experience.pdf

The Joint Committee on Human Rights (2008) A Life Like Any Other? Human Rights of Adults with Learning Disabilities, Seventh Report of Session 2007-08 Volume 1
http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf

Council of Europe (2007) Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse
http://conventions.coe.int/Treaty/EN/treaties/html/201.htm

OHCHR (2006) UN Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment http://www2.ohchr.org/english/law/cat-one.htm

OFMDFM (2005) Ageing in An Inclusive Society – Promoting the Social Inclusion of Older People (currently under review)
http://www.ofmdfmni.gov.uk/ageing-strategy.pdf

DHSSPS (2003) Co-operating to Safeguard Children
http://www.dhsspsni.gov.uk/show_publications?txtid=14022

United Nations (2000) The Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children
http://www.uncjin.org/Documents/Conventions/dcatoc/final_documents_2/convention_%20traff_eng.pdf

European Convention on Human Rights http://www.hri.org/docs/ECHR50.html

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board & LCGs • Public Health Agency (PHA) • HSC Trusts • Primary Care	• PCC • RQIA • SBNI, NIASP & LASPs • PSNI • Other statutory agencies & voluntary, community & private sector

Quality Dimension
Citizenship People of all ages will be safeguarded from harm and have their welfare promoted and their human rights upheld. Safeguarding responses are non-discriminatory, and seek to ensure that people of all ages at risk of harm are offered support to keep them safe from harm and to protect them when harm occurs. **Empowerment** Safeguarding interventions must be tailored to the presenting circumstances and to the needs and choices of the individual (provided these do not impact adversely on the safeguarding needs of others or, within the requirements of the law, of him or herself) and his/her circumstance. Decision making in this regard will have to pay due consideration to the age, maturity and capacity of the person. **Working Together** Promotion of self-reliance and personal and professional safeguarding behaviours; builds personal and professional safeguarding capacity; promotion of the welfare of individuals; protection from mistreatment; impairment of health and development is prevented; and individuals are kept safe from harm. **Individual Support** Promotion of self-aware practice; supportive of person-centred engagement; fosters awareness and opportunity for early intervention in poor practice/potentially abusive dynamics; and promotion of individualised safety plans where these are indicated, thereby enhancing services and safeguarding awareness and responses

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. All HSC organisations and organisations providing services on behalf of the HSC have a **Safeguarding Policy** in place, which is effectively aligned with other organisational policies (e.g. recruitment, governance, complaints, SAIs, training, supervision, etc). The Safeguarding Policy is supported	HSC and provider Organisation annual reports HSC Governance Reviews, e.g. Complaints; SAIs, etc HSC Statutory Functions Reports and Corporate Parent Reports SBNI, NIASP & LASP Annual Reports RQIA Reports &	Establish baseline Performance level to be determined once baseline established	March 2014 March 2015

by robust procedures and guidelines	Reviews Case Management Reviews (CMRs) Serious Case Reviews (SCRs)		
2. All HSC organisations and organisations providing services on behalf of the HSC have **Safeguarding Plans** in place	As above	Establish baseline Performance level to be determined once baseline established	March 2014 March 2015
3. All HSC organisations and organisations providing services on behalf of the HSC have **safeguarding champions** in place to promote awareness of safeguarding issues in their workplace	As above	Establish baseline Performance levels to be determined once baseline established	March 2014 March 2015

Standard 2:
People with a learning disability should as a matter of course make choices or decisions about their individual health and social care needs. This needs to be balanced with the individual's ability to make such decisions and then the views of their family, carers and advocates should be taken into account in the planning and delivery of services unless there are explicit and valid reasons to the contrary agreed with the person.

Service user perspective:

"I am involved as a matter of course in making choices or decisions about my health and social care needs."

"My family, other carers and advocates are involved as partners."

"Staff ask for my views and the views of family carers when they are planning and delivering services."

Rationale:
People with a learning disability and family carers report a lack of engagement and exclusion from the planning and decision-making processes, which can result in services being unresponsive to individual needs, strengths and aspirations. It is important to ensure that people with a learning disability and their families are involved as partners in their health and social care.

Services must be delivered in ways that appropriately manage risk for service users, carers and their families. It is acknowledged, however, that in some situations, living with an identified risk can be outweighed by the benefit of having a lifestyle that the individual really wants and values. In such circumstances, risk taking (when it is appropriately managed) can be considered to be a positive action. HSC staff need to work in partnership with service users and carers to explore choices, identify and assess risks and agree on how these will be managed and minimised for the benefit of individual service users, their carers and families.

Evidence:
DHSSPS (2010) Care Management, Provision of Services and Charging Guidance http://www.dhsspsni.gov.uk/hsc-eccu-1-2010.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

DHSSPS (2005) A Healthier Future: A Twenty Year Vision for Health and Well

being in Northern Ireland 2005-2025
http://www.dhsspsni.gov.uk/healthyfuture-main.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Trusts	• Other service providers • Advocacy organisations • Families and carers

Quality Dimension

Citizenship
Service users will be involved as partners in the planning and delivery of health and social care services.

Social Inclusion
Involvement will ensure that service users are enabled to access mainstream services and be fully included in the life of the community.

Empowerment
Involving service users in the design and delivery of HSC services ensures that their expertise effectively informs the development of appropriate services.

Working Together
Partnership with service users, their families and carers is only possible if they are proactively involved in decision-making processes. Effective partnerships will contribute to positive health and social care outcomes.

Individual Support
Person-centred support relies on individuals being supported to share their views, hopes and concerns. Involvement is a necessity for the development of person-centred approaches and planning.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Evidence that people with a learning disability, their family and carers have been involved in making choices or decisions about their individual health and social care needs.	HSC Trust reports (care plans)	Establish baseline Performance level to be determined once baseline established	March 2015 March 2016

Standard 3: (Generic)
All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.

Service user perspective:

"I will have an opportunity to be actively involved at all levels of health and social care."

Rationale:
Actively involving patients and the public in the planning and provision of health care in general has been noted to bring many advantages to both those who receive and those who provide care. These include:

- Increased patient satisfaction and reduction in anxiety with positive health effects
- Improved communication between service users and professional staff
- Better outcomes of care with greater accessibility and acceptability of services
- Bridging of the gap between those who avail of services and those who provide care
- Recognition of the expertise of the recipient of care developed through experience

Evidence:
DHSSPS (2007) Guidance on strengthening Personal and Public Involvement in Health and Social Care http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

NHS (2006) Healthy Democracy
http://www.nhscentreforinvolvement.nhs.uk/index.cfm?content=90

DHSSPS (2005) A Healthier Future: A Twenty Year Vision for Health and Well being in Northern Ireland 2005-2025
http://www.dhsspsni.gov.uk/healthyfuture-main.pdf

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • HSC Trusts • Primary Care	• Other Service providers • Advocacy organisations • Families & carers

Quality Dimension			
Citizenship Effective involvement ensures that the diverse needs of people with a learning disability are taken account of in service planning and delivery. The development of partnerships with service users and carers ensures that their views and aspirations are respected and valued. **Social Inclusion** Involvement helps to address the legacy of disadvantage for people with a learning disability which has led to their voices not being heard effectively in service planning. **Empowerment** Involvement gives a voice to the people most directly affected by decisions within health and social care. Involving them will enable them to have an influence over decisions made that affect their lives. **Working Together** Partnership with service users and carers is only possible if they are proactively involved in decision-making processes. Effective partnerships will contribute to positive health and social care outcomes. **Individual Support** Person-centred support relies on individuals being supported to share their views, hopes and concerns. Involvement is a necessity for the development of person-centred approaches and planning.			
Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of job descriptions containing PPI as responsibility March 2014: senior and middle management March 2015: designated PPI leads at all levels of HSC organisations March 2016: all new job descriptions	Audit sample of job descriptions	Establish baseline and set target Monitor progress 100% - in all new job descriptions	March 2014 March 2015 March 2016
2.Percentage of patients and clients expressing	Patient & Client Experience monitoring	Establish baseline and set target	March 2014

satisfaction		Report percentage increase of patient and client satisfaction	March 2015
	Annual Accountability Report	Report percentage increase of patient and client satisfaction	March 2016
3. Percentage of staff who have gained PPI training (details to be agreed for 2014/2015)	Annual Accountability Report Training Report	Conduct training needs assessment for PPI, commission design of PPI training programme	March 2014
		Establish baseline and set target	March 2015
		Monitor percentage of staff trained at different levels in PPI	March 2016

Standard 4:
Adults with a learning disability should be helped by HSC professionals to develop their capacity to give or refuse informed consent.

Service User Perspective*:*

"I am helped to give or refuse my consent when decisions are being made that will affect my health or well being"

Rationale:
Respecting peoples' right to determine what happens to them is a fundamental aspect of good practice and a legal requirement. Research shows that people with a learning disability are often denied this right. Health and social care staff report uncertainty about how to ensure capacity and informed consent. This covers a wide range of areas from managing personal finances to consenting to surgery and other medical interventions. A major legislative reform process is underway that will strengthen the legal framework for work in the area of mental capacity and consent. HSC organisations should be working within the spirit of this legislative direction.

Evidence:
DHSSPS (2009) Legislative Framework For Mental Capacity And Mental Health Legislation In Northern Ireland – A Policy Consultation Document www.dhsspsni.gov.uk/legislative-framework-for-mental-capacity.pdf

Equality Commission Northern Ireland (2008) – A Formal Investigation under Disability Discrimination Legislation to Evaluate the Accessibility of Health Information in NI for People with a Learning Disability www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

SCIE (2008) Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities (The Michael Inquiry) Tizard Learning Disability Review, 13(4), December 2008, pp.28-34. http://www.scie-socialcareonline.org.uk/profile.asp?guid=4f9f7333-2539-4004-af21-26ed14db5f5d

Mencap (2007) Death by Indifference www.mencap.org.uk/case.asp?id=52&menuId=53&pageno

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

DHSSPS (2003) Reference Guide to Consent for Examination, Treatment or Care www.dhsspsni.gov.uk/consent-referenceguide.pdf

DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities: http://www.dhsspsni.gov.uk/consent-guidepart4.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary & Acute Care Teams	• DHSSPS • Independent sector • Service users, carers and families

Quality Dimension

Citizenship
The right to self determination is respected and capacity to consent is presumed to exist unless proven otherwise

Empowerment
Paying attention to correct processes for securing consent ensures that the views of people with a learning disability are adequately addressed in decision making.

Individual Support
All health and social care interventions are based on best practice in capacity and consent issues.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Develop and agree a regional training plan that ensures that relevant HSC staff are trained in consent and capacity issues.	HSC reports	All HSC Organisations	March 2016
2 Evidence that robust processes are in place where capacity has been judged to be an issue within HSC services or services commissioned by HSC	SAAT	Development and implementation of SAAT Performance levels to be determined based on outcomes of SAAT	March 2015 March 2016

Standard 5: (Generic)
All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.

Service user perspective:

"I am supported by staff who can communicate well with me."

Rationale:
Effective communication (clear, accessible, timely, focused and informative) has a significant impact on all aspects of care provision from disease prevention, to diagnosis, to self-management of long-term conditions.

Poor communication is a significant factor in most complaints against HSC organisations.

Evidence:
DHSSPS (2007) Guidance on strengthening Personal and Public Involvement in Health and Social Care http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

GMC (2013) Good Medical Practice
http://www.gmc-uk.org/guidance/good_medical_practice.asp

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland Order) 2003: www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• DHSSPS • DE • Other service providers • Service Users & carers

Quality Dimension

Citizenship
As a universal requirement, good communication helps to ensure input by all service users on all aspects of the services they receive assisting in the highlighting of gaps in provision and areas for improvement.

Social Inclusion
Good communication helps to deliver and sustain appropriate patient/client/carer access to services and a clear understanding of the role and responsibilities of the service user in achieving health and care outcomes.

Empowerment
Good communication with patients/clients/carers enables adequate understanding of, consent to and compliance with treatment and care and contributes to audit and monitoring

Working together
Health and care outcomes themselves are enhanced through improved patient partnership and dialogue, including, but not limited to – diagnosis, self-referral, health promotion, disease prevention and management of long term conditions

Individual Support
Person-centredness cannot be delivered or claimed in the absence of good communication with service users. Good communication is a prerequisite of person-centredness.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of patients and clients expressing satisfaction with communication	Patient & Client Experience monitoring report Annual Accountability Report	Establish baseline and set target Report percentage increase of patient and client satisfaction with communication Report percentage increase of patient and client satisfaction with communication	March 2014 March 2015 March 2016

Standard 6:
People with a learning disability should expect effective communication with them by HSC organisations as an essential and universal component of the planning and delivery of health and social care

Service user perspective:

"I am supported by staff who can communicate well with me."

Rationale:
Between 50% and 90% of people with a learning disability have some form of communication difficulty. Effective communication has a significant impact on all aspects of care and support provision across the full range of activities that promote health and social wellbeing. Poor communication is often a significant contributory factor in complaints against HSC organisations.

People with speech, language and communication needs, in addition to their learning disability, are amongst the most vulnerable and most in need of effective care and support to reach their potential. Early identification and effective intervention are essential. The current system is characterised by high variability and a lack of equity.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Equality Commission (2008) A Formal Investigation under the Disability Discrimination Legislation to Evaluate the Accessibility of Health Information in Northern Ireland for People with a Learning Disability
http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

DSCF (2008) Bercow Report: A Review of services for children and young people (0-19) with speech, language and communication needs
www.dcsf.gov.uk/bercowreview/docs/7771-DCSF-BERCOW%20Summary.pdf

DoH (2008) Better Communication: Improving services for children and young people with speech, language and communication needs. Action Plan to the Bercow Report
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091972

DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07)
http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

GMC (2006) Good Medical Practice
http://www.gmc-uk.org/guidance/good_medical_practice/index.asp

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• DHSSPS • DE • Other Service Providers • Service users and carers

Quality Dimension

Citizenship
Good communication helps to ensure input by people with a learning disability on all aspects of the services that they receive, assisting in the highlighting of gaps in provision and areas for improvement.

Social Inclusion
People with communication difficulties are supported to access mainstream leisure and social activities that promote their integration into mainstream community living and promote their psychological and emotional wellbeing.

Empowerment
Good communication with service users, carers and family enables adequate understanding of, and consent to, the care, support and treatment arrangements offered.

Working Together
There is evidence of good communication between professionals that can determine early identification of communication difficulties and planning to provide the necessary supports to the person with a learning disability, their carer and family and that this is reviewed regularly with particular attention at transition points.

Individual Support
Good communication is a prerequisite of person-centredness.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of people with a learning disability who do not use speech as their main form of communication,	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2015 March 2016

who have been supported to establish a functional communication system.			
2 Develop and agree a regional training plan for staff in both HSC and services commissioned by HSC to raise awareness of communication difficulties and how they may be addressed	HSC reports	Regional Training Plan in place Training is delivered in accordance with Regional Training Plan.	March 2015 March 2016

Standard 7:
People with a learning disability should receive information about services and issues that affect their health and social wellbeing in a way that is meaningful to them and their family.

Service user perspective:

"I receive information about services and issues that affect my health and wellbeing in a way that my family and I can understand."

Rationale:
The particular communication difficulties experienced by many people with a learning disability create additional challenges in accessing information on which to make informed choices and access appropriate supports. Access to HSC services depends on people having information on what is available and how the care and support offered will impact on them. This places an onus on HSC organisations to ensure that people with a learning disability, their carers and their families are informed in a way that takes account of their particular circumstances.

This process will be enhanced by the availability of a named staff member to assist people in understanding the services available.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Equality Commission (2008) A Formal Investigation under the Disability Discrimination Legislation to Evaluate the Accessibility of Health Information in Northern Ireland for People with a Learning Disability
http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07)
http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

Foundation for People with Learning Disabilities (2005) Communication for person-centred planning
http://www.learningdisabilities.org.uk/?view=Search+results&search=Communication+for+person-centred+planning

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board (including Commissioning Groups) • Public Health Agency (PHA) • HSC Trusts	• DHSSPS, DSD, DE, DEL, DoJ • Other service providers • Advocacy partners • Service users and carers

Quality Dimension

Citizenship
People with a learning disability can only exercise their rights as citizens if they have accessible information about entitlements and services offered.

Social Inclusion
A major barrier to inclusion is the lack of information on which to base informed decision making.

Empowerment
Access to information enables people to speak out about what they need and what is being offered.

Working Together
Provision of information in an accessible manner is a key step towards enabling effective partnership between those who work in services and those who use them.

Individual Support
The development of effective person-centred support relies on individuals being well informed about choices that are open to them.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 All HSC organisations should provide evidence that they are making information accessible to people with a learning disability	SAAT	Development and implementation of SAAT Performance levels to be determined once baseline established	March 2015 March 2016
2 Each person with a learning disability can access a named person who can signpost them to relevant services.	Sample survey of families and service users.	Establish baseline of information provided Performance levels to be determined once baseline established	March 2016

Standard 8:
People with a learning disability, or their carer, should be able to access self directed support in order to give them more control and choice over the type of care and support they receive.

Service user perspective:

"I, or my carer, can request self-directed support in order to give me more control and choice over the type of care and support I receive."

Rationale:
There is growing evidence of the positive outcomes that may be gained by people with a learning disability when they have direct financial control over their supports. Access to Direct Payments as a means of delivering social services in NI has been available since 1996 under the Personal Social Services (Direct Payments) (Northern Ireland) Order 1996. The Carers and Direct Payment Act (NI) 2002 extended access to a much wider group of people. Direct Payments increase choice and promote independence. They provide for a more flexible response than may otherwise be possible for the service user and carer. They allow individuals to decide when and in what form services are provided and who provides them, who comes into their home and who becomes involved in very personal aspects of their lives. Direct Payments put real power into the hands of service users and carers, and allow them to take control over their lives. Whilst uptake of this provision has been low, it has been steadily increasing over recent years.

In England, direct payments have paved the way for investigation into how individual budgets could work to promote choice and control for people using adult social care services. The introduction of individual or personal budgets is part of the wider personalisation agenda in adult social care. At the time of preparing the Service Framework for Learning Disability an equivalent policy directive relating to the use of individual budgets is not in place. However, DHSSPS have indicated its commitment, in the Bamford Action Plan, to exploring the benefits of increasing users' direct control over services. The implementation (and review) of this standard will, therefore, evolve alongside future policy developments in this area.

Evidence:
HSC Board/ PHA (2011) Draft Commissioning Plan 2011/12
http://www.publichealth.hscni.net/sites/default/files/Draft%20HSCB%20PHA%20Commissioning%20Plan%202011-2012_0.pdf

DoH (2009) New Horizons: A Shared Vision for Mental Health
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_109708.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)

http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

SCIE (2009) Research briefing 20: The implementation of individual budget schemes in adult social care. Published Jan 2007, Updated Feb 2009, Addendum 2009
http://www.scie.org.uk/publications/briefings/briefing20/index.asp

PSSRU (2007) Direct Payments: A National Survey of Direct Payments Policy and Practice http://www.pssru.ac.uk/pdf/dprla_es.pdf

DoH (2007) Valuing People Now: From Progress to Transformation – A consultation on the next three years of learning disability policy
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/LiveConsultations/DH_081014

DHSSPS (2005) Direct Payments: Policy and Practice Review Report
http://www.dhsspsni.gov.uk/direct_payments_policy_and_practice_review_report.pdf

Bamford (2005) Equal Lives (Section 10 - Ensuring Personal Outcomes): Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

DoH (2005) Independence, Wellbeing and Choice: Our Vision for the Future of Social Care for Adults in England – Social Care Green Paper
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/Closedconsultations/DH_4116631

Joseph Rowntree Foundation (1999) Implementing Direct Payments for People with Learning Disabilities http://www.jrf.org.uk/sites/files/jrf/F349.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Welfare Rights Advisers • Advocacy organisations • DEL/DHSSPS/DCAL • Service users and carers.

Quality Dimension

Citizenship
Increased equity exists between service users and service providers where human rights have been respected.

Social Inclusion
Quality of life and wellbeing are improved through being able to have direct control over funding available to support social inclusion activities

Empowerment
Service users and carers experience more choice and control within processes and access services that they have requested and, where necessary, have the support of independent advocates.

Working Together
Change in attitudes and culture with renewed engagement between agencies on joint support planning providing greater flexibility in the way in which supports can be accessed.

Individual Support
People demonstrate improved health and wellbeing from having greater control over how they are supported and having their aspirations met in a more individualised way.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Evidence of provision of accessible information on Direct Payments within HSC organisations.	SAAT	Develop and implement SAAT Establish performance levels based on outcomes from SAAT	March 2015 March 2016
2 Percentage of requests for direct payments from people with a learning disability that were approved	SAAT	Develop and implement SAAT Establish performance levels based on outcomes from SAAT	March 2015 March 2016
3 Number of adults with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 2.25%)	HSC Board and Trust Reports	Performance levels to be determined based on available resources and included in final Framework	
4 Number of children with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 3.50%)	HSC Board and Trust Reports	Performance levels to be determined based on available resources and included in final Framework	

5 The HSC Board and Trusts have plans in place to extend the range and scope of self directed support including how they will develop skills and expertise in relevant staff	HSC Board and Trust reports	HSCB and all Trusts	March 2017

Standard 9: (Generic)
Service users and their carers should have access to independent advocacy as required.

Service user perspective:

"I can get an advocate to support me to speak out about worries I have about the care and support I receive"

Rationale:
People engage with health and social care services at times in their lives when they might be vulnerable or in need of support and / or guidance in relation to decisions about their health and wellbeing. For a whole raft of reasons (age, disability, mental health issues, gender, ethnic origin, sexual orientation, social exclusion, reputation, abuse and family breakdown and living away from home or in institutions), they may also feel discriminated against or simply excluded from major decisions affecting their health and wellbeing. It is at such times that independent advocacy can make a real difference because it gives people a voice; helps them access information so that they can make informed decisions and participate in their own care or treatment.

Independent advocacy is also a means of securing and protecting a person's human rights; representing their interests; and ensuring that decisions are taken with due regard to a person's preferences or perspectives where, for whatever reason, they are unable to speak up for themselves. In strategic terms independent advocacy can contribute to increased social inclusion and justice; service improvements in health and wellbeing; reductions in inequalities across the health and social care sector; and enhanced safeguarding arrangements. Independent advocacy can be delivered in a number of different ways and people may need different types of advocacy at different times in their lives. The most common models are self/group advocacy; peer advocacy; citizen advocacy; and individual/issue-based advocacy (also known as professional advocacy).

In this context, independence means structurally independent from statutory department or agency providing the service. The advocacy provider must be free from conflict of interest as possible both in design and operation and must actively seek to reduce any conflicting interests.

Independent advocacy should be available throughout the care pathway and, in particular, should be available early in the process as this may prevent a crisis developing. An advocacy service should apply not just to service users but to their carers and families. To be effective users need to be aware of advocacy services. Therefore they need to be promoted through accurate and accessible information. Relevant health and social care staff should be aware of the benefits of independent advocacy and the particular importance of independence from service provision.

There is currently a proposal to introduce a statutory right to an independent

advocate in the proposed Mental Capacity Bill. Guidance on this right will be issued once the Bill has been finalised.

Evidence

DHSSPS (2012) Developing Advocacy Services – A Policy Guide for Commissioners
http://www.dhsspsni.gov.uk/developing-advocacy-services-a-guide-for-commissioners-may-2012.pdf

DHSSPS (2010) Advocacy Research: Summary Paper
http://www.dhsspsni.gov.uk/advocacy-research-summary-paper-of-advocacy-provision-october-2010.pdf

Knox, C. (2010) Policy Advocacy in Northern Ireland. University of Ulster, Jordanstown

Alzheimer's Society (2009) Listening Well http://www.alzheimers.org.uk

Horton, C (2009) Creating a Stronger Information, Advice and Advocacy System for Older People. London; Joseph Rowntree Foundation

SCIE (2009) At A Glance 12: Implications for Advocacy Workers available at http://www.scie.org.uk/publications/ataglance/ataglance12.asp

Seal, M. (2007) Patient Advocacy and Advance Care Planning in the Acute Hospital Setting – Australian Journal of Advanced Nursing Vol 24, No 4, pp29-36

Wright, M. (2006) A Voice That Wasn't Speaking: Older People Using Advocacy and Shaping it's Development, Stoke-on-Trent, OPAAL UK (Older People's Advocacy Alliance)

Bamford Review (2006) Review of Mental Health and Learning Disability (NI), Human Rights and Equality of Opportunity Available at www.dhsspsni.gov.uk/bamford

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts • Public Health Agency (PHA)	• Local Commissioning Groups • Primary Care Partnerships • GPs • Voluntary and Community Sector • Independent Sector • PCC

Quality Dimensions

Citizenship

An advocacy service can promote equality, social justice and inclusion of the most vulnerable and disadvantaged. Advocacy can enhance capacity building

at a community and individual level, which can ultimately reduce dependency on other health and social care services.

Empowerment
Advocacy services can enable individuals to access information, express their views and wishes and make informed choices about their own health and well being. The service is geared to needs of the individual. The service user will receive a service that best meets their needs at a time, which evidence shows, to be effective and to have maximum impact.

Individual Support
Advocacy services can safeguard users from abuse and exploitation by ensuring that their rights are upheld and their voice heard. An advocacy service can promote equality, social justice and inclusion of the most vulnerable and disadvantaged.

Performance Indicator	Data Source	Anticipated Performance Level	Date to be achieved by
To be determined			To be determined

SECTION 5: CHILDREN AND YOUNG PEOPLE

Work is ongoing in the development of a Children and Young People's Service Framework. It is anticipated that that Framework will address the universal needs of children and young people in Northern Ireland.

This Section aims to address the particular issues facing children and young people with a learning disability and their family carers and acknowledges the role played by schools and Education and Library Board in the assessment, intervention, support and onward referral of children & young people who may or do have a learning disability. This Section should be read alongside the other standards set out in this Framework.

Support to families tends to be fragmented and parents report difficulty in accessing services and understanding the range of roles and services that are in place.

It is crucial when concerns emerge that a child may have a learning disability, that a clear action plan is agreed as to how the concerns will be investigated. It is essential that planning and support systems are used to wrap around the child and family to ensure a seamless and co-ordinated approach. Where children have to live away from their family the arrangements in place must take account of their learning disability.

The Service Framework for Learning Disability reflects the fundamental position that regardless of diagnosis, a child/young person is a child/young person first, and that children and their families should be fully supported to participate in valued childhood experiences. They should also have access to the same opportunities, life experiences and services as other children and families.

Standard 10:
From the point at which concerns are raised that a child or young person may have a learning disability, there is an action plan in place to determine the nature and impact of the learning disability.

Service User Perspective:

Parents will have an action plan that clearly sets out the steps to be taken for discovering the nature and impact of learning disability their son or daughter may have.

Rationale:
Parents report dissatisfaction with the manner in which supports are organised when concerns begin to emerge that their son or daughter may have a learning disability. Professional efforts are often not well co-ordinated resulting in parents having to manage multiple appointments and, at times, conflicting advice.

Long delays are reported for appointments to specialists and parents can experience great difficulties in accessing the information they need and in understanding the roles that various professionals and organisations play.

Assessment needs to be timely, comprehensive and conducted in a co-ordinated manner.

Evidence:
Power, A (2008) 'It's the system working for the system': carers' experiences of learning disability services in Ireland: *Health and Social Care in the Community* (2008) http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2008.00807.x/abstract

SCIE (2008) Guide 24: Learning together to safeguard children: developing a multi-agency systems approach for case reviews. www.scie.org.uk/publications/guides/guide24/index.asp

SCIE (2007) Knowledge Review 18: 'Necessary Stuff' – The social care needs of children with complex healthcare needs and their families. www.scie.org.uk/publications/knowledgereviews/kr18.asp

DHSSPS (2007) Complex Needs – The Nursing Response to Children & Young People with Complex Physical Healthcare needs. www.dhsspsni.gov.uk/complex_needs_report.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• Families • DHSSPS, DE • Early Years providers

Quality Dimension

Social Inclusion
Assessment takes account of the need for the child or young person to have as normal a life as possible and be socially included within the communities in which they live.

Empowerment
Children, young people and their families receive co-ordinated essential information about the services they can expect to receive and the roles that professionals will have in delivering these services and have an identified link person to whom they can refer any problems and with whom they can develop effective relationships.

Working Together
Professionals work together with families to determine a child/young person's condition within a required timeframe and systems are put in place for effective ongoing communication and delivery of supports.

Individual Support
Assessments are co-ordinated effectively between professionals and families and parents are clear as to actions planned by HSC professionals.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of parents who express satisfaction with the assessment process and how the outcomes were conveyed.	Audit of sample family carers	Establish baseline of information provided Performance levels to be determined once baseline established	March 2016 March 2017

Standard 11:
Children and young people should receive child-centred and coordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability.

Service user perspective:

"*My son or daughter receives services that are child-centred, appropriate and co-ordinated."*

Rationale:
The Children Order (NI) 1995 outlines that a child is a 'child in need' by virtue of the fact that he/she is disabled (Art17(C)). Trusts and statutory bodies are required to comply with their statutory duties in respect of children in need, including those in relation to carers needs under this legislation.

Getting the right care and support for children, young people and their families makes a significant impact on positive outcomes in adulthood. A child's needs cover the whole range of public services and resources including play, leisure, housing and education. The involvement of all these interests is essential if we are to avoid confining the lives of children with a learning disability within the health and social care system.

Evidence:
DHSSPS (2009) NI Single Assessment Tool
http://www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-northern-ireland-single-assessment-tool.htm

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2009) Integrated Care Pathway for Children & Young People with Complex Physical Healthcare Needs
http://www.dhsspsni.gov.uk/integrated_care_pathway-july09.pdf

DHSSPS (2008) UNOCINI Guidance
http://www.dhsspsni.gov.uk/microsoft_word_-_unocini_guidance_revised_june_2011_inc_mh_domain_elements.pdf

Black, LA *et al* (2008) Lifelines Report An Evaluation Report of the Impact of the Families Services delivered by Positive Futures in Rural and Urban Areas of Northern Ireland. http://www.positive-futures.net/sites/default/files/LIFELINES%20Full%20Report.pdf

Kenny, K and McGilloway, S. (2007) Caring for children with learning disabilities: an exploratory study of parental strain and coping, British Journal

of Learning Disabilities, p221-8.
http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3156.2007.00445.x/abstract

SCIE (2007) Knowledge Review 18: 'Necessary Stuff' – The social care needs of children with complex healthcare needs and their families
www.scie.org.uk/publications/knowledgereviews/kr18.asp

DHSSPS (2007) Complex Needs – The Nursing Response to Children & Young People with Complex Physical Healthcare needs.
www.dhsspsni.gov.uk/complex_needs_report.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts/Children's Services	• Families • DHSSPS, DE, DCAL • Voluntary and community sector providers

Quality Dimension

Social Inclusion
Assessment and supports take account of the need for the child or young person to have as normal a life as possible and be socially included within the communities in which they live.

Empowerment
Children, young people and their families receive co-ordinated essential information about the services they can expect to receive and the roles that professionals will have in delivering these services and have an identified link person to whom they can refer any problems and with whom they can develop effective relationships.

Working Together
Professionals work together with parents as partners in developing family centred plans to meet the care and support needs of the child and his/her family. Plans must take account that the needs of children and young people with a learning disability cannot be met by health and social care alone and will involve close working with other interests including housing, leisure and education.

Individual Support
Supports are co-ordinated effectively between professionals and the family and the child/young person has a plan in place that is regularly reviewed to ensure that supports remain appropriate.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of children and young people with a learning disability and carers who have been offered an annual assessment either under the Family Health Needs Assessment or UNOCINI assessments.	Audit/Sampling	Establish baseline Performance levels to be determined once baseline established	March 2016 March 2017
2 Percentage of children and young people who have an agreed care plan detailing a pathway to receiving appropriate care and support.	Audit to include UNOCINI referrals and completed family support and Looked After Children (LAC) pathway assessments following initial referral	Establish baseline Performance levels to be determined once baseline established	March 2016 March 2017

Standard 12:
HSC services should respond to the needs of children and young people who have a learning disability and complex physical health needs in a manner that is personalised, developmentally appropriate and which support access to appropriate care.

Service User Perspective:

"If my son or daughter has complex physical health needs we will receive care and support in a flexible way through services that are age appropriate."

Rationale:
Current services often lack the responsiveness and flexibility required to ensure that children and young people with a learning disability enjoy equal access to the full range of supports that are required to effectively address the needs arising from additional health problems they have. This can result in them receiving care and treatment that is less than optimum, is poorly coordinated, and sometimes delivered in settings, which are not developmentally appropriate.

Children and young people with a learning disability benefit greatly from effective transitions between hospital and community services and sensitive, detailed assessment and care planning across the range of HSC professionals involved with the family.

Evidence:
DHSSPS (2009) Integrated Care Pathway for Children & Young People with Complex Physical Healthcare Needs
http://www.dhsspsni.gov.uk/integrated_care_pathway-july09.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2009) Families Matter: Supporting Families in Northern Ireland
http://www.dhsspsni.gov.uk/families_matter_strategy.pdf

The Council for Disabled Children (CDC) (August 2009) The use of eligibility criteria in social care services for disabled children
http://www.ncb.org.uk/cdc/home.aspx

DHSSPS (2008) UNOCINI Guidance
http://www.dhsspsni.gov.uk/microsoft_word_-_unocini_guidance_revised_june_2011_inc_mh_domain_elements.pdf

DHSSPS (2007) Complex Needs – The Nursing Response to Children & Young People with Complex Physical Healthcare needs.
www.dhsspsni.gov.uk/complex_needs_report.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Beecham,J. et al. (2002) Children with Severe Learning Disabilities: Needs, Services and Costs *Children & Society* pp. 168–181 www.lse.ac.uk/collections/PSSRU/staff/beecham.htm

Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25 (2), 85-99. www.ncbi.nlm.nih.gov/pubmed/10188064

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts / Children's Services • Primary and Acute Services	• DHSSPS • Voluntary & Community Sector Providers • Families & carers

Quality Dimension

Citizenship
The rights of the child/young person/family are respected when assessing their needs and practical approaches are taken to meeting these needs that are equitable to the rest of the population.

Working Together
There is a coordinated approach to addressing health and social care needs where parents are clearly signposted to sources of care and support, particularly when the child/ young person moves between hospital and home.

Individual Support
Multi-disciplinary input is effective in providing assessment and supports that the child and family requires using person-centred and family centred approaches that are effective in maintaining, where possible, ordinary family life and are reviewed regularly or at least annually.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of parents whose child has a learning disability and complex physical health needs who have an identified key worker with co-ordinating responsibility	Annual Audit	Scope requirements and produce audit plan. Audit 50% of information available 100%	March 2015 March 2016 March 2017

2 Percentage of children and young people with complex physical health needs who have effective transition arrangements in place between hospital and community.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes. Fast track arrangements for access to hospital /community services to be audited following establishment of baseline	March 2015 March 2016
3 Percentage of children with a learning disability and complex physical health needs who have received a multi-professional assessment as per regional integrated care pathway.	Trust Reports	90% 95% 98%	March 2015 March 2016 March 2017

Standard 13:
Any child or young person who cannot live at home permanently should have their placement/ accommodation needs addressed in a way that takes full account of their learning disability.

Service User Perspective:

"If I cannot live at home permanently, my needs will be addressed in a way that takes full account of my learning disability."

Rationale:
A small number of children and young people who have a learning disability cannot live with their natural families. Many have severely challenging behaviours, specific health needs and/or Autistic Spectrum Disorders (ASD). They require support and living arrangements that are sufficiently expert to address their complex individual needs. Decisions about future care and support arrangements need to be taken in a timely manner and in a way that supports permanency.

Evidence:
DHSSPS (2009) Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11
http://www.dhsspsni.gov.uk/asd_strategic_action_plan.pdf

DoH (2005) Valuing People: The story so far (p44)
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4107059.pdf

McConkey *et al* (2004). The characteristics of children with a disability looked after away from home and their future service needs. British Journal of Social Work, 34 (4), 561-576. http://bjsw.oxfordjournals.org/content/34/4/561.abstract

Chadwick *et al* (2002) Respite Care for Children with Severe Intellectual Disability and their Families: Who Needs It? Who Receives It? Child and Adolescent Mental Health vol7 (2): 66-72.
http://onlinelibrary.wiley.com/doi/10.1111/1475-3588.00013/full

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts	• DHSSPS • Other Service Delivery Partners

Quality Dimension

Citizenship/Social Inclusion
Children & young people with a learning disability have their needs met within environments that promote social inclusion and full citizenship

Empowerment
Children, young people and their family members are supported to express their views on the care and support services that they require and are supported to maintain links with each other when a child/young person lives away from home.

Working Together
Professionals collaborate to provide responsive services through developing a person-centred Permanency Plan to meet the needs of the individual child/young person.

Individual Support
The Permanency Plan includes arrangements for specialist placements based on the short, medium and long term needs of the individual.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of looked after children or young people with a learning disability who cannot live with their families who have a Permanency Plan.	SOSCARE	Establish baseline Performance level to be determined once baseline established	March 2015 March 2016

SECTION 6: ENTERING ADULTHOOD

The manner in which young people are supported at the time of transition from adolescence to adulthood is a crucial component in determining the degree to which they are enabled to live full and valued lives in their communities.

Supporting effective transition is the responsibility, not only of HSC organisations, but also requires the effective engagement of other government departments, notably DEL and DE, and other agencies. There is scope for improvement in the quality of the transition experience. Many young people have unsatisfactory experiences during the move from school towards adulthood.

Parents and young people should be offered a transitions pathway that outlines their:

- individual interests;
- aspirations;
- strengths and needs including vocational training;
- education;
- employment;
- health profile;
- social supports;
- friendships (including meaningful relationships); and
- social development.

Standard 14:
Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18th birthday.

Service User Perspective:

"I will have a transition plan in place before my 15th birthday."

"I will know the arrangements that are in place for when I leave school before my 18th birthday."

Rationale:
Effective transition planning at an early stage is vital if young people are to move successfully from school towards fuller adult lives. This is a statutory requirement under special education legislation and a recommendation of the Bamford Review. These arrangements should be made in partnership with the young person, their family/carers and adult learning disability services for transition to appropriate adult services in accordance with agreed transition protocols. The objective of this transition planning is to support people into the same life chances as other non-disabled young people e.g. a job, relevant education, positive relationships and the start of living independently.

It is noted that increased numbers of children with statements of special education needs, including those with disabilities are accessing mainstream education. Under the Special Educational Needs and Disability (NI) Order 2005 (SENDO) Code of Practice, transition planning in schools commences for 'statemented' pupils at the first annual review following the child's 14th birthday. The Education and Library Board's (ELB) Transition Service will ensure, in the most complex of cases, that appropriate advice givers will be present as part of the annual review process. Transition planning and services should be available, with young people and carers made aware of them, and able to access transition supports following post primary education with sufficient forward planning to minimise apprehension and stress for those young people and their carers.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2008) Getting a Life 2008-11 http://www.gettingalife.org.uk

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Special Educational Needs and Disability (NI) Order 2005 (SENDO)

Education (NI) Order 1996 and Code of Practice
http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_needs-codes_of_practice_pg.htm

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• DHSSPS, DE (ELBs, schools and FE colleges), DEL • Education Transitions Co-ordinators • Voluntary agencies • Youth services • Councils • Independent providers • RQIA • Young people and their families • Advocacy organisations

Quality Dimension

Citizenship
A common assessment pathway will help to ensure equity of services for all.

Social Inclusion
Accessible information will be provided to allow young people, their carers and relevant others to participate fully in the development of a transition plan. Such information is available in a range of media and from a wide range of sources. Young people's involvement will create a move away from a narrow focus on services to a broader expression of aspirations for the future.

Empowerment
The process of preparing the Transitions Plan will place the young person and his/her family at the centre of planning for the future

Working Together
Decisions about eligibility for services will be the outcome of a multi-disciplinary assessment, and will be open and transparent for parents. The plan will be developed on a multi-disciplinary/multi agency basis with clear accountability lines for delivery by all the contributors.

Individual Support
A preliminary assessment will feed into an individualised transitions plan. Each plan will reflect the young person's aims and objectives in life including specific individual needs and interests, continuing education and training, employment, social and leisure activities and day opportunities.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of young people who express satisfaction that their transition plan has been implemented within 2 years of leaving school.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2016 March 2017
2 Evidence of transfer to DES, where appropriate, for health checks for children on transition to adult services	DES	90% 95% 98%	March 2015 March 2016 March 2017

Standard 15:
People with a learning disability should be supported to have meaningful relationships, which may include marriage and individual, unique, sexual expression within the law, balancing their rights with responsibilities.

Service User Perspective*:*

"I will be supported to enjoy meaningful relationships."

Rationale:
The Bamford Review promotes the importance of people with a learning disability benefiting from meaningful relationships and the need to offer support, guidance, training and related services to ensure that this happens.

The Human Rights Act 1998 includes the right to respect for privacy and family life, freedom of expression, the right to marry and to found a family and the right not to be discriminated against in respect of these rights and freedoms. This has to be balanced with positive risk taking strategies. Safeguards need to be put in place, where necessary and appropriate, but within a framework that ensures the objective is to support people who are having positive relationships whenever possible.

People with a learning disability have a right to learn about sexuality and the responsibilities that go along with exploring and experiencing one's own sexuality. They have to know how to protect themselves from unplanned pregnancy, HIV and other sexually transmitted infections, and sexual and gender-based violence. Education programmes for people with a learning disability should begin during adolescence as part of their general education. The implementation of this standard will need to be supported by the provisions detailed in Standard 3 (Consent and Capacity).

Evidence:
DHSSPS (2010) Adult Safeguarding: Regional & Local Partnership Arrangements http://www.dhsspsni.gov.uk/asva-__2010.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2008) Sexual Health Promotion Strategy & Action Plan 2008-2013
http://www.dhsspsni.gov.uk/dhssps_sexual_health_plan_front_cvr.pdf

Simpson, A et al (2006) Out of the shadows: A report of the sexual health and well being of people with learning disabilities in Northern Ireland. Newnorth Print Ltd.

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

SCIE (2004) The Road Ahead: Information for Young people with Learning Difficulties, their Families and Supporters at Transition
http://www.scie.org.uk/publications/tra/index.asp

The Human Rights Act, 1998
http://www.direct.gov.uk/en/Governmentcitizensandrights/Yourrightsandresponsibilities/DG_4002951

Responsibility for delivery/implementation	**Deliver and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• DHSSPS, DE (Education and Library Boards and Schools) • Voluntary sector • Service Users • Families

Quality Dimension

Citizenship
The right to personal relationships is enshrined in Human Rights legislation. Meaningful relationships are a fundamental component of health and social wellbeing.

Social Inclusion
People will be supported to access social and leisure opportunities where friendships may be developed.

Empowerment
People will be supported to appreciate the rights, risks and responsibilities involved in personal relationships

Working Together
Staff and family carers will contribute to the development of policies and best practice guidelines in this area.

HSC Trusts will implement the Adult Safeguarding arrangements and staff will be trained appropriately to discharge it.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Regional guidelines on sexuality and personal relationships are developed to ensure a consistent approach	HSC Board Report	HSC Board policy developed and agreed	March 2015

2 Trusts to facilitate appropriate training for staff.	Trust Reports	40% 80%	March 2016 March 2017
3 Trusts to facilitate appropriate training for service users and family carers.	Trust Reports	Level to be established pending development of regional policy	March 2017
4 Increase in the number of people with a learning disability accessing sexual health & reproductive healthcare services.	SAAT	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016

SECTION 7: INCLUSION IN COMMUNITY LIFE

Emotional and social wellbeing are directly related to the degree to which people are able to live valued lives and participate in community opportunities.

For people with a learning disability barriers can exist which prevent them from accessing the opportunities that are open to the rest of society. Many of these barriers do not relate directly to the disability, but rather are the result of discrimination and approaches based on a belief that social education and leisure opportunities need to be provided within the context of HSC provision. This has resulted in the social exclusion of people with a learning disability and the development of services that group people together on the basis of a shared learning disability, rather than addressing individual needs and aspirations.

The HSC has a role in working with others in employment, housing, leisure and education to maximise opportunities that enable people with a learning disability to actively participate in their communities and engage in meaningful daytime activities, friendships, employment and leisure.

The majority of men and women with a learning disability live at home with their families. Appropriate short breaks are often an important component in supporting these arrangements.

Increasingly people with a learning disability express an aspiration to have children. HSC services must work together to ensure that people who have a learning disability are appropriately supported in their parenting role.

Standard 16:
Adults with a learning disability should be able to access support in order that they can achieve and maintain employment opportunities in productive work.

Service User Perspective:

"I will be able to get support to help me find and keep a job."

Rationale:
The Lisbon Agenda (2000) promotes the integration of people traditionally excluded from the labour market. The Bamford Review recommends that agencies should work in partnership to promote and deliver supported employment services. HSC Trust day opportunities strategies promote the development of supported employment as an integral part of service development.

A cultural shift away from a reliance on day centres should be encouraged, towards alternative options which enable individuals with a learning disability to participate in society through day opportunities and work placements that will improve their skills and allow them the opportunity to integrate with others. Those involved in person centred planning should actively consider employment as one of these options.

Evidence:
Beyer S, (2010) Using a Cost Benefit Framework for Supported Employment Policy and Practice: an analysis of 2 UK agencies Journal Appl Res Intellect, Volume 23, 5 (September 2010) pp.447-447
http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2010.00584.x/pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2009) Valuing Employment Now – Real Jobs for People with Learning Disabilities
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101401

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

DELNI (2008) Pathways to Work (New Deal)
http://www.delni.gov.uk/index/finding-employment-finding-staff/fe-fs-help-to-find-employment/stepstowork.htm (Accessed 15 April 2011)

OFMDFM Promoting Social Inclusion (PSI) Disability
http://www.ofmdfmni.gov.uk/index/equality/disability/disability-promoting-

social-inclusion.htm

Lisbon Agenda (2000) http://www.euractiv.com/en/future-eu/lisbon-agenda/article-117510

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • HSC Trusts	• DEL, OFMDFM • Supported employment providers • Northern Ireland Union of Supported Employment (NIUSE)

Quality Dimension

Working Together
HSC staff, in partnership with DEL and others, will enable people with a learning disability to achieve and maintain employment opportunities with ongoing professional support.

Social Inclusion
Historically there have been barriers to opportunities for meaningful employment for men and women with a learning disability. Increasing such opportunities will be a key contributor to improving social inclusion.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of school leavers with a learning disability who access work placements or employment within one year of leaving school (as percentage of total learning disabled school leaving population).	ELB Transition Service	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016
2 Percentage of adults with a learning disability who receive HSC support to help them secure employment (as a measure of those who request support).	Audit	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016

Standard 17:
All adults with a severe or profound learning disability should be able to access a range of meaningful day opportunities appropriate to their needs.

Service User Perspective:

"I will be supported to take part in a range of activities during the day"

Rationale:
There is a need for a radical reconfiguration of existing day service provision based on a progressive shift towards a resource model. As alternative provision develops there should be a reduction in the number of people who attend Adult Centres on a full-time basis. It is anticipated that these centres will, in the future, be providing a service to men and women with increasingly complex needs who should also be enabled to access opportunities for community integration. Adult Centres will need to explore the potential to develop sites for meeting the particular needs of people with more complex needs. The potential for Adult Centres to be used as a community resource is particularly under-utilised at present. Partnerships with community and voluntary groups should involve promoting the inclusion of people with a learning disability.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

SCIE (2007) Knowledge Review 14: Having A Good Day? A study of community-based day activities for people with learning disabilities
www.scie.org.uk/publications/knowledgereviews/kr14.asp

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

PCC (2011) My Day, My Way The Bamford Monitoring Group's Report on Day Opportunities
http://www.patientclientcouncil.hscni.net/uploads/research/My_Day_My_Way_FINAL.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts	• Local community organisations • DHSSPS, DEL • FE providers • Local economy

Quality Dimension

Social Inclusion
Reconfiguration of day centres may reduce the number of days attended and an

expansion of wider community options for individuals.

Working Together
Each person will have a person-centred plan which will identify the multi-disciplinary and community inputs required to deliver on that plan. A lead person will be accountable for the delivery of the plan, which must be reviewed 6 monthly.

Individual Support
Admission criteria and processes in day centres will be in line with the standard and clear processes will be in place to consider intake and development of opportunities in local communities.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of adults with a severe or profound learning disability who have meaningful day opportunities in mainstream community settings, outside of their building based service.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016
2 Percentage of adults with a severe or profound learning disability receiving support in a building based service, who express satisfaction with the opportunity to experience day opportunities.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016

Standard 18:
All parents with a learning disability should be supported to carry out their parenting role effectively.

Service User Perspective:

"If I have children I will get support to be a good parent."

Rationale:
An increasing number of adults with a learning disability are becoming parents. In about 50% of cases their children are removed from them largely because of concerns about the children's wellbeing or the lack of appropriate support.

Barriers to the provision of appropriate supports include negative and stereotypical attitudes. Men and women with a learning disability have a right to be parents and where they choose to exercise this right, effective support should be in place to avoid adverse outcomes for them and their children.

If support is provided early it is more likely that the family unit will be successfully supported to stay together.

Evidence:
DoH (2009) New Horizons: A Shared Vision for Mental Health
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_109708.pdf

Aunos, M *et al* (2008) Mothering with Intellectual Disabilities: Relationship Between Social Support, Health and Wellbeing, Parenting and Child Behaviour Outcomes. http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2008.00447.x/abstract

Tarleton, B *et al* (2006) Finding the right support? A Review of Issues and Positive Practice in Supporting Parents with Learning Difficulties and Their Children. The Baring Foundation
www.bristol.ac.uk/norahfry/research/completed-projects/rightsupport.pdf

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008) Parents labelled with Intellectual Disability. Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 21: 296–307. http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2008.00435.x/abstract

Booth T *et al* (2006) Temporal discrimination and parents with learning difficulties in the child protection system. *British Journal of Social Work* 36(6), 997–1015. http://bjsw.oxfordjournals.org/content/36/6/997.abstract

SCIE (2006) Knowledge Review 11: Supporting disabled parents and parents with additional support needs.
http://www.scie.org.uk/publications/knowledgereviews/kr11.asp

CSCI (2006) Supporting Parents, Safeguarding Children: Meeting the needs of parents with children on the child protection register http://www.pmhcwn.org.uk/files/supporting_safeguarding.pdf (Accessed 15 April 2011)

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• DHSSPS • Community and voluntary sector providers • Advocacy services

Quality Dimension

Citizenship
Independent advocacy support is provided to enable parents with a learning disability to be involved in the decision making process within multi-disciplinary meetings and other decision making fora.

Social Inclusion
Supports provided promote and encourage the parents to become less isolated from the community in which they live.

Empowerment
More parents and their children will be receiving appropriate care and support resulting in a smaller percentage of children of parents with learning disabilities being subject to Care Orders.

Working Together
Professionals work collaboratively across children's and adult's services to provide effective support to the parent and work will continue to develop policy on positively supporting parents with a learning disability to continue caring for their children.

Individual Support
Parents will be better enabled to care for themselves and their children through having their needs properly assessed and being appropriately supported in their parenting role.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Develop and agree a regional protocol between children's and adult services for joint working and care pathways.	HSC Board Report	HSC Board in collaboration with all HSC Trusts	March 2015

2 Percentage of parents with a learning disability who have a multi-professional/agency competence based assessment and subsequently receive appropriate support services	Trust Report	Establish baseline Performance level to be determined once baseline established	March 2016 March 2017
3 Percentage of parents with a learning disability involved in child protection or judicial processes who have received locally based skills training.	Trust Reports	85% 90% 95%	March 2015 March 2016 March 2017
4 Percentage of parents with a learning disability involved in child protection or judicial processes who have access to the services of an independent advocate.	Trust Reports	Establish baseline Performance level to be determined once baseline established	March 2015 March 2016

SECTION 8: MEETING GENERAL PHYSICAL AND MENTAL HEALTH NEEDS

Physical and mental health are inextricably linked with each impacting upon the other. The World Health Organisation (WHO) gives equal value to physical and mental health in the definition of health as “a complete state of physical, mental and social wellbeing, not just the absence of disease and infirmity”. People with poor physical health are at higher risk of experiencing common mental health problems and people with mental health problems are more likely to have poor physical health. Many factors influence the health of individuals and communities. Whether people are healthy or not depends a great deal on their circumstances and the environment in which they live. The determinants of health and wellbeing include:

- social environment
- the physical environment
- the person’s individual characteristics and behaviour

Many of these factors of health are not under the direct control of the individual and therefore one person’s health may differ from another’s depending on their circumstances.

Evidence demonstrates that there are significant disparities in health outcomes for people with a learning disability. They experience higher levels of physical and mental ill health, yet have lower access to primary care services, health screening and health promotion activities.

People with a learning disability can experience difficulties when using general health services, hospitals and primary care services. There is a need to proactively ensure that there is equity of access to the full range of health care services enjoyed by the general population. This is enshrined in disability discrimination and human rights legislation.

Standard 19:
All people with a learning disability should have equal access to the full range of health services, including services designed to promote positive health and wellbeing.

Service User Perspective:

"I have equal access to the full range of health services as other people in the community."

Rationale:
It is known that people with a learning disability often experience difficulties when using health services and this can result in their health needs not being effectively assessed or met.

Most people with a learning disability do not require specialist services to address their health needs but many will require a range of reasonable adjustments to help them make use of generic health services such as primary care, acute hospitals and dentistry. Specialist learning disability services are a key resource to support mainstream health services develop the knowledge and skills to do this effectively.

Reasonable adjustments can be many and are wide ranging, but it is important to remember that they must be individualised to the person, and may include such things as:

- longer appointment times
- offering the first or last appointment
- the provision of easy read information to enhance understanding
- close involvement and support of family carers
- appropriate waiting facilities
- pre-admission visits
- fast tracking arrangements when appropriate (e.g. in A&E Departments)

The standard links closely to Standards 4 and 5 (Communication and Involvement in the Planning and Delivery of Services).

Evidence:
Learning Disabilities Observatory: Improving Health and Lives (2010) Health Inequalities Report
http://www.improvinghealthandlives.org.uk/projects/particularhealthproblems

GAIN (2010) Guidelines: Caring For People With A Learning Disability In General Hospital Settings
http://www.gain-ni.org/Library/Guidelines/Gain%20learning.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and

Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Mencap (2007) Death by Indifference
www.mencap.org.uk/case.asp?id=52&menuId=53&pageno

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care (including pharmacy and dental)	• DHSSPS • Service users and carers

Quality Dimension

Citizenship
People with a learning disability are equal citizens and must be able to readily access the full range of services that support their health and social wellbeing as are available to the rest of the population.

Social Inclusion
Primary care services, acute hospital services and other specialist services, such as, palliative care should have knowledge of the specific issues for people with a learning disability accessing these services and make reasonable adjustments accordingly.

Working Together
All generic services should have knowledge of local learning disability specific services and how to access them when required. This includes access to advocacy services.

Individual Support
The provision of all services should be tailored to the individual needs of the person with a learning disability, and reasonable adjustments made accordingly. An individual with a learning disability should be able to make round the clock contact with services and receive the care needed to meet their needs.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 All acute hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan.	Trust report	All HSC trusts establish baseline Performance levels to be determined once baseline established	March 2015 March 2016
2 Percentage of GPs who have a system for identifying people with a learning disability on their register.	DES	Baseline as per learning disability DES Performance levels to be determined once baseline established	March 2015 March 2016
3 Each GP practice has a designated link professional within local learning disability services.	Trust report as per GAIN Guidelines	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016
4 Evidence of reasonable adjustments by health service providers.	Report from HSC Trust learning disability services	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016

Standard 20: (Generic)
All HSC staff, as appropriate, should advise people who smoke of the risks associated with smoking and signpost them to well developed specialist smoking cessation services.

Service user perspective:

"I will be advised on the dangers of smoking"

Rationale:
Smoking is a major risk factor for a number of chronic diseases including a range of cancers, coronary heart disease, strokes and other diseases of the circulatory system. Its effects are related to the amount of tobacco smoked daily and the duration of smoking.

A number of specialist smoking cessation services have been commissioned in a range of settings across Northern Ireland. These services offer counselling and support in addition to the use of pharmacotherapy by trained specialist advisors.

Evidence:
DHSSPS (2010) Tobacco Control Strategy for Northern Ireland
http://www.dhsspsni.gov.uk/tobacco-strategy-consultation.doc

NICE (2008) Smoking cessation services in primary care, pharmacies, local authorities and workplaces, particularly for manual working groups, pregnant women and hard to reach communities http://www.nice.org.uk/Guidance/PH10

NICE (2006) Brief Interventions and Referral for Smoking Cessation in Primary Care and Other Settings http://www.nice.org.uk/Guidance/PH1

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts • Public Health Agency (PHA) • Primary Care	• DHSSPS • Families & carers • Voluntary, education, youth and community organisations

Quality Dimension

Citizenship
People with a learning disability can exercise their rights as citizens if they have accessible information to inform decision-making.

Empowerment
All members of the public will benefit from access to public information and education campaigns that raise awareness of issues relating to tobacco use, such as, the health risks to smokers and non-smokers. People who are ready to stop smoking are able to access specialist smoking cessation services in a choice of settings.

Working together
Brief Intervention Training for Health and Social Care Staff will ensure patients and clients receive consistent and timely advice on smoking cessation. Specialist smoking cessation services will be delivered to regional quality standards ensuring equitable service provision. Provision of information in an accessible format is a key step towards enabling effective partnership between those who work in services and those who use them. HSC professionals should take account of what is important to the person, their relationships and activities in working with them to address issues around smoking. Brief Intervention training for HSC staff will ensure that service users receive consistent and timely advice.

Individual Support
Effective person-centred support should take account of balancing what is important to people with what is important to them in regard to their health and wellbeing. Specialist smoking cessation services will be delivered to regional quality standards ensuring equitable service provision.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Number of people who are accessing Stop Smoking Services	ELITE (PHA Stop Smoking Services Performance Report)	Baseline 2011/12 = 39204 4 % year on year increase	 March 2014 March 2015 March 2016
Proportion of the smoking population who are accessing Stop Smoking Services.	ELITE (PHA Stop Smoking Services Performance Report)	Baseline 2011/12 =10.8%. NICE guidance and the ten year tobacco strategy call for a target of over 5% of the smoking population to be reached, hence target to maintain at >/= 5%	 March 2014 March 2015 March 2016
Number of people using stop smoking services who have quit at 4 weeks and 52 weeks.	ELITE (PHA Stop Smoking Services Performance Report)	Baseline 2011/12 = 20,299 for those quit at 4 weeks and 5,889 for those quit at 52 weeks. Target 4% increase in respective numbers year on year	 March 2014 March 2015 March 2016

Standard 21:
All people with a learning disability should be supported to achieve optimum physical and mental health.

Service User Perspective

I will be helped to stay as physically and mentally healthy as possible.

Rationale:
People with a learning disability are more likely to experience major illnesses, to develop them younger and die of them sooner than the population as a whole. They have higher rates of obesity, respiratory disease, some cancers, osteoporosis, sensory impairment, dementia and epilepsy. It is estimated that people with learning disability are 58 times more likely to die prematurely. However, even with such a dramatic health profile, the learning disabled population are less likely to get some of the evidence-based treatments and checks they need, and continue to face real barriers in accessing services. This contributes to preventable ill health, poor quality of life and potentially, premature death.

Effective screening and regular health checks help to identify unmet need and prevent health problems arising. People with a learning disability participate less in screening and regular health checks than the rest of the population. Information on, and activities in, health promotion can be difficult to access.

Evidence:

Learning Disabilities Observatory (2011) The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK
http://www.improvinghealthandlives.org.uk/publications/

DoH (2009) Improving the health and well being of people with learning disabilities: world class commissioning www.dh.gov.uk/commissioning

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2009) Valuing People Now: A new three-year strategy for people with learning disability
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

DoH (2009) Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505

DoH (2009) Delivering Better Oral Health: An evidence- based toolkit for

prevention – second edition

DoH (2008) High quality care for all: NHS Next Stage Review Final Report
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07)
http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

DHSSPS (2007) Oral Health Strategy for Northern Ireland
http://www.dhsspsni.gov.uk/2007_06_25_ohs_full_7.0.pdf

Disability Rights Commission (2007) Equal Treatment: Closing the Gap: A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems
http://onlinelibrary.wiley.com/doi/10.1111/j.1741-1130.2006.00100.x/abstract

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Foundation for People with Learning Disabilities (2005) Communication for person-centred planning
http://www.learningdisabilities.org.uk/publications/communication-person-centred-planning/

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • Primary Care • HSC Trust (Learning Disability Teams)	• Families • Voluntary and Community providers

Quality Dimension

Citizenship
People with a learning disability are supported to access the full range of screening and health checks as the rest of the population of NI.

Social Inclusion
Screening and health checks are made accessible to people with a learning disability and they are facilitated to participate in these activities.

Empowerment/Individual Support
Individuals will be supported to have regular screening and health checks on all the major illnesses and facilitated to make lifestyle choices that promote their good health and have in place a Health Action Plan as part of their person centred plan.

Working Together
There should be effective liaison and evidence of advance planning between HSC staff and family carers to fully embrace people with learning disabilities into the system of regular screening and health checks and health promotion activities. This should incorporate the development of Health Action Plans which includes details of health interventions, oral health, fitness and mobility, emotional needs and records of screening tests and identification of those responsible for taking action.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 The PHA and each HSC Trust has a health improvement strategy for people with a learning disability (children and adults) to address all relevant physical and mental health promotion and improvement needs.	Public Health Agency/ Trust Reports (to include reports from voluntary and community organisations Trust has commissioned services from)	All Trusts have in place a health improvement strategy for people with a learning disability.	March 2015
2 Percentage of adults with a learning disability who have an annual health check.	GP Records Health Facilitator records	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016
3 Percentage of adults with a learning disability who have an up to date and active Health Action Plan (HAP) following the annual health check.	GP records Health Facilitator records Learning Disability Teams	Establish baseline Performance levels to be determined once baseline is established	March 2015 March 2016
4 Percentage of people with a learning disability who have been examined by a dentist in the past year.	Audit	Establish Baseline Performance Levels to be determined once baseline established	March 2015 March 2016

5 Percentage of females with a learning disability who access cervical and breast screening services.	GP records Health facilitators	Establish Baseline Performance levels to be determined once baseline established	March 2015 March 2016
6. Percentage of people with a learning disability who have had a sight test with an optometrist in the past year.	Audit	Establish Baseline Performance levels to be determined once baseline established	March 2015 March 2016

Standard 22:
All people with a learning disability who experience mental ill health should be able to access appropriate support.

Service User Perspective

"If I have mental illness I can get appropriate support."

Rationale:
People with a learning disability and mental health needs require a co-ordinated multi-disciplinary approach to having their needs met through integrated services responding flexibly to the demands of their conditions with clear pathways of care identified so that the most appropriate supports are immediately available to the person and their family carers when required.

Refer also to standard 56 in Service Framework for Mental Health and Wellbeing

Evidence:
DHSSPS (2011) Service Framework for Mental Health and Wellbeing Consultation Document
http://www.dhsspsni.gov.uk/service_framework_for_mental_health_and_wellbeing_-_consultation_version.pdf

DoH (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities A report by Professor Jim Mansell
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Emerson, E. and Hatton, C. (2007) The Mental Health of Children and Adolescents with Intellectual Disabilities in Britain. *British Journal of Psychiatry* 191, 493-499.
http://bjp.rcpsych.org/cgi/content/abstract/191/6/493

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

NHS QIS (2004) Learning Disability Quality Indicators
http://www.healthcareimprovementscotland.org/previous_resources/indicators/learning_disability_quality_in.aspx

Carpenter, B. (2002) Count Us In: report of the inquiry into meeting the mental health needs of young people with learning disabilities. London: Foundation for People with Learning Disabilities London:
http://www.learningdisabilities.org.uk/publications/count-us-in/

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts • RQIA	• DHSSPS • Other service providers

Quality Dimension

Citizenship
Addressing the mental health needs of people with a learning disability requires a combination of services that are consistently available to enable their full participation within the structures of society

Social Inclusion
The mental health needs of people with a learning disability are met in the most appropriate setting.

Empowerment/Individual Support
People with a learning disability and mental illness have person-centred plans in place with clear pathways of care identified and planned to enable them to lead as normal a life as is possible given the conditions of their illness. To involve the person, their parents or family carer in this process empowers the family and the person with a learning disability to make informed choices

Working Together
Services surrounding the person with a mental illness should be co-ordinated and resourced appropriately with a lead person identified to effectively manage and promote the mental health and wellbeing of the person requiring services.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1. A regional protocol is developed to ensure that people with a learning disability can access mainstream mental health services.	HSC Board	Protocol in place	March 2015
2. Percentage of people with a learning disability and mental health needs who access mainstream mental health services e.g. psychological and talking therapies	Audit	Establish baseline Performance levels to be determined once baseline established	March 2016 March 2017

where indicated in their treatment plan.			
3. Percentage of Health Action Plans and health checks which include mental health assessment and mental health promotion	GP Records	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016

Standard 23: (Generic)
All HSC staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.

Service user perspective:

"I will be provided with healthy eating support and guidance"

Rationale:
Reducing fat and salt in the diet and increasing fruit and vegetable consumption is associated with a reduction in the risk of cardiovascular disease and hypertension.

Having a well balanced and nutritious diet will also help prevent many diseases which are linked to being overweight and obese such as high blood pressure, heart problems, risk of stroke, some cancers and Type 2 Diabetes. In addition, an improved diet can also contribute to an improvement in an individual's mental health and wellbeing.

Evidence:
DHSSPS Draft Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2011-2021)
http://www.dhsspsni.gov.uk/showconsultations?txtid=44910

DHSSPS (2005) Fit Futures http://www.dhsspsni.gov.uk/ifh-fitfutures.pdf

WHO (2004) Global Strategy on Diet, Physical Activity and Health
http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

SCAN (2008) Scientific Advisory Committee on Nutrition. The Nutritional Wellbeing of the British population
http://www.sacn.gov.uk/pdfs/nutritional_health_of_the_population_final_oct_08.pdf

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Primary care team, inclusive of social care

Quality Dimension

Citizenship
People with a learning disability are provided with healthy eating support and advice as are the rest of the population.

Empowerment/ Individual support
Individuals will receive support and advice, appropriate to their needs, in a range of settings to develop skills for healthy eating and be facilitated to make lifestyle choices that promote their good health and wellbeing as part of person-centred planning.

Lifestyle issues including eating and physical activity choices should be explored through knowledge of what is important to the person. This should take account of what has worked and what has not worked in the past.

Working Together
There should be effective liaison and evidence of advance planning between staff and family carers to fully embrace people with a learning disability into the system of health promotion activities. All stakeholders should promote a consistent nutrition message by using the Eat Well – getting the balance right model. Training and education should be available for child carers / group care workers.

Schools / hospitals / residential care and nursing homes should be supported in the implementation of nutrition standards. Support and advice to develop skills for healthy eating in a range of settings should be available.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of people eating the recommended 5 portions of fruit or vegetables each day.	To be determined	Baseline for 2011/12 = 32% overall, 26% for males and 36% for females Target: maintain or at best increase percentage by 1% year on year	 March 2014 March 2015 March 2016

Standard 24: (Generic)
All HSC staff, as appropriate, should provide support and advice on recommended levels of physical activity.

Service user perspective:

"I will be provided with support and advice on physical activity"

Rationale:
The National Institute for Health and Clinical Excellence (NICE) has fully endorsed the importance of physical activity as a means of promoting good health and preventing disease. Lack of physical activity is associated with an increase in the risk of coronary heart disease.

The recently reviewed and updated UK Physical Activity Guidelines, supported by all four CMO's, provide advice and guidance on the recommended levels of physical activity throughout the life course. The report also presents the first time guidelines have been produced in the UK for early years (under fives) as well as sedentary behaviour, for which there is now evidence that this is an independent risk factor for ill health.

Evidence:
DHSSPS Draft Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2011-2021)
http://www.dhsspsni.gov.uk/showconsultations?txtid=44910

DoH (2011) New UK Physical Activity Guidelines
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127931

NICE (2006) Public Health Intervention Guidance No.2 Four commonly used methods to increase physical activity: Brief intervention in primary care, exercise referral schemes, pedometers and community-based exercise programmes for walking and cycling http://www.nice.org.uk/nicemedia/pdf/word/PH002_physical_activity.doc

DHSSPS (2005) Fit Futures http://www.dhsspsni.gov.uk/ifh-fitfutures.pdf

WHO (2004) Global Strategy on Diet, Physical Activity and Health
http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Primary care team, inclusive of social care

Quality Dimension			
Empowerment People with a learning disability will benefit from access to appropriate information and advice on physical activity. **Working Together** HSC staff recognise their responsibility to ensure service users receive consistent and timely health promotion messages. Appropriate physical activity brief intervention training should be provided for HSC staff to ensure patients and clients receive consistent and timely advice. **Individual Support** Lifestyle issues including physical activity choices should be explored through knowledge of what is important to the person. Paying attention to what works best for the person in undertaking physical activity, working with their interests. This should take account of what has worked in the past and what does not work**.**			
Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of people meeting the recommended level of physical activity per week.	Northern Ireland Health Survey	New physical activity guidelines were launched in 2011 and as such a new suite of questions to establish the percentage of people meeting the recommended level of physical activity per week has been integrated within the 2012/13 Northern Ireland Health Survey. It is anticipated these new baseline results will be available in Nov / Dec 2013. Performance level to be agreed thereafter.	March 2014

Standard 25: (Generic)
All HSC staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.

Service user perspective:

"I will receive support and advice on the use of alcohol"

Rationale:
Excessive alcohol consumption is associated with many diseases such as cancers (oesophagus, liver etc), cirrhosis of the liver and pancreatitis. There are also direct effects of alcohol and an increased association with injuries and violence.

Excessive alcohol consumption can affect the cardiovascular system, and is associated with high blood pressure, abnormal heart rhythms, cardiomyopathy and haemorrhagic stroke.

Evidence:
DHSSPS (2006) New Strategic Direction for Alcohol and Drugs (2006-2011)
http://www.dhsspsni.gov.uk/nsdad-finalversion-may06.pdf

SIGN (2003) Scottish Intercollegiate Guidelines Network The Management of harmful drinking and alcohol dependence in Primary Care No 74
http://www.sign.ac.uk/pdf/sign74.pdf

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Primary care team, inclusive of social care

Quality Dimension

Citizenship
People with a learning disability and alcohol related issues should be able to access mainstream services. They are likely to require the support of learning disability personnel to utilise the services offered by the mainstream addiction teams.

Working Together
Appropriate alcohol brief intervention training should be provided for HSC staff to ensure patients and clients receive consistent and timely advice.

Individual Support
HSC staff should take account of what and who is important to the person now and in the future in relation to lifestyle and where alcohol fits in. Explore how alcohol can be managed in the person's life by taking account of what has worked and what has not worked in the past for this person.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of people who receive screening in primary care settings in relation to their alcohol consumption.	Northern Ireland Local Enhanced Service	Establish baseline Performance level to be determined once baseline established	March 2014 March 2015

SECTION 9: MEETING COMPLEX PHYSICAL AND MENTAL HEALTH NEEDS

Children and adults with a learning disability may experience significant additional, complex health needs. Complex physical and mental health needs may be defined as those requiring a range of additional support services beyond the type and amount required by people generally and those usually experienced by people with impairments and long-term illnesses. These needs require a high level of effective integration between specialised and general services.

Supports to children, young people and adults who have complex physical and mental health needs will be most effective if they are based on person-centred planning approaches and within an ethos of ensuring bridging between learning disability expertise and other service settings. (Standard 10 sets out the specific standard for children and young people with complex physical health needs).

Standard 26:
All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services, as appropriate, based on assessed need.

Service User Perspective:

I can get support locally from specialist learning disability services if my behaviour challenges services and/or my carers

Rationale:
Emerson (1995) defines 'challenging behaviour' as behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.

People who present behaviours that challenge services are generally well known to staff working within specialist learning disability services and they are therefore in a position to provide relevant information to other services and support the person and family carers to enable him/her to continue to access these services.

The specialist supports available should include social work, psychiatry, psychology, speech and language therapy, physiotherapy, nursing and any other relevant disciplines and these should be available 24 hours a day, 7 days a week. Should crises occur there needs to be the capacity to respond with appropriate interventions that maintain the person in the community/home in which he/she resides and/or short breaks that provides time out from the situation.

Whilst significant evidence exists as to the need for timely, flexible, home-based support to address challenging behaviours and to prevent unnecessary inpatient admission, work is not complete on the optimum service configuration and models required in Northern Ireland. To develop community based supports and move away from a traditional model of hospital admission will require resource investment and future detailed service planning.

Evidence:
NDTi (2010) Guide for Commissioners of Services for People With Learning Disabilities Who Challenge Services
http://www.ndti.org.uk/uploads/files/Challenging_behaviour_report_v7.pdf

DoH (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities A report by Professor Jim Mansell
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability

http://www.dhsspsni.gov.uk/equallivesreport.pdf

NHS QIS (2004) Learning Disability Quality Indicators
http://www.healthcareimprovementscotland.org/previous_resources/indicators/learning_disability_quality_in.aspx

Emerson, E (1995) Challenging behaviour - analysis and intervention in people with a learning disability Cambridge University Press

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• Commissioning organisations • HSC Trusts • RQIA	• DHSSPS • Family carers • Advocacy providers • Other service providers

Quality Dimension

Citizenship
Providing support to an individual who presents behaviours that are challenging to access mainstream health and social care services maintains their equity with the rest of the population of NI.

Social Inclusion
There are community-based services to meet the needs of people with challenging behaviour.

Empowerment
Incidents of challenging behaviours are reduced when appropriate support mechanisms are available so that they can continue to receive the community - based services they require.

Working Together
Mainstream and specialist services should be collaborating on the needs of people with a learning disability who present behaviours that challenge mainstream services so that the person can access the healthcare services they require and services comply with regional guidelines on the management of challenging behaviours.

Individual Support
Management and intervention for challenging behaviour is practised and the approaches used have proven evidence-based effectiveness and social validity.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of individuals with significant challenging behaviours who have a Behaviour Support Plan including advance directives in	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016

place that detail actions to be undertaken in the event of their challenging behaviours escalating.			
2 Where challenging behaviours present a significant risk to the individual or others or a risk of breakdown in accommodation arrangements, a specialist assessment has been completed within 24 hours.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016
3 Where challenging behaviours present a significant risk to the individual, a Management Plan has been developed and implemented within 48 hours.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016
4 Evidence that HSC has engaged with other relevant delivery partners in developing and implementing consistent approaches in individual cases.	Trust report Audit of voluntary/ community sector	All HSC Trusts	March 2016
5 Percentage of people labelled as challenging who are not living in a congregate setting described as a challenging behaviour or specialist assessment/ treatment service	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2017

Standard 27:
All people with a learning disability who come into contact with the Criminal Justice System should be able to access appropriate support.

Service User Perspective:

I will get support If I come in contact with the police, courts or prisons

Rationale:
Men and women with a learning disability can come into contact with the Criminal Justice System in a range of different ways. They can be suspects, remandees, prisoners or indeed witnesses. However, people with a learning disability can be particularly vulnerable as they may not understand the processes involved, the information given to them, or their rights. The Reed Report (1992) highlighted the needs of mentally disordered offenders and recommended that, where appropriate, people with a learning disability who offend should be directed to HSC services, while emphasizing the need for services to be based on a multi-agency needs assessment.

It is vital that an offender with a learning disability does not go unrecognised and unsupported whilst in the prison system and that care pathways are established between primary care, learning disability services and Criminal Justice Services.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2009) The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098698.pdf

RCSLT (2009) Locked Up and Locked Out: Communication Is The Key
http://www.rcslt.org/news/events/Locked_Up_NI_post_event_report

Prison Reform Trust (2008) No-One Knows. Police Responses to Suspects Learning Disabilities and Learning Difficulties: A Review of Policy and Practice
www.prisonreformtrust.org.uk

DHSSPS (2006) The Bamford Review of Mental Health and Learning Disability (NI): Forensic Services
http://www.dhsspsni.gov.uk/forensic_services_report.pdf

Reed Report (1992) Review of mental health and social services for mentally disordered offenders and others requiring similar services: Vol. 1: Final summary report. (Cm. 2088) London: HMSO ISBN 0101208820

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • HSC Trusts • General Practitioners	• DHSSPS, DoJ • Police Service of Northern Ireland (PSNI) • Probation Board for Northern Ireland (PBNI) • NI Prison Service • NI Courts Service • Youth Justice Agencies • Voluntary and community providers

Quality Dimension

Citizenship
People with a learning disability going through the Criminal Justice System have the same rights as other members of society and there is evidence of good practice available to ensure that this is the case.

Social Inclusion
Offending behaviours have the potential to increase the person's social exclusion and measures must be evidenced within their person-centred plan (PCP) that promotes their social inclusion in mainstream activities upon discharge from any institutional setting.

Empowerment
Measures are in place to minimise the person's vulnerability when they are in contact with the Criminal Justice System

Working Together
There is evidence of multi-disciplinary working practices to ensure that people with a learning disability are supported within the Criminal Justice System.

Individual Support
Community based services are in place which support people, prevent admissions where possible, and facilitate discharge from inpatient and other secure settings. The least restrictive options for individuals should be available.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Evidence that HSC has engaged and developed local protocols with relevant delivery partners to achieve consistent and	HSC Board Report	Protocols in place	March 2015

coordinated approaches to working with people with a learning disability who have offended or are at risk of offending.			

SECTION 10: AT HOME IN THE COMMUNITY

To maximise their health and social wellbeing, people with a learning disability should be supported to live in the community close to family, friends and community resources. Where they currently live with family they (the family) should be supported to provide the necessary care and support.

A greater focus on ‘purposeful lives’ will support people with a learning disability to live as independently as possible. It is vital that people are supported to live in the community and that inappropriate admission to hospital is avoided. People with a learning disability who require hospital treatment should be speedily discharged when the treatment ends to community homes with appropriate care and support. Resettlement of long stay populations, the development of innovative approaches to prevent delayed discharges and the promotion of ‘purposeful respite’ will enhance outcomes for people with a learning disability, their families and carers.

Standard 28:
HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed.

Service User Perspective:

"My accommodation needs will be met by staff from different agencies who work well together"

Rationale:
People with a learning disability aspire to have the same standard in living options that are available to their non-disabled peers.

In NI the majority of adult persons with a learning disability continue to live with family carers. As carers age, they may require extra support to maintain their caring role. In addition, people with a learning disability may need support to participate in community activities with their peers.

Person-centred support plans should identify the person's preferred living arrangements and these should be regularly reviewed. It is important that as family carers age they are supported to plan for the future to allow for a smooth transition to new care arrangements either within the family or in supported accommodation (refer to Section 12: Ageing Well).

Small-scale, supported living arrangements (5 persons or less) have been shown to offer a better quality of life for people with a learning disability as compared to congregated living arrangements.

People living outside of family care should have a tenancy or occupancy agreement to offer them security of tenure along with an agreement to the number of support hours available to them individually.

People should be involved in decisions about sharing their homes with others. As far as possible they should be offered a choice of accommodation in a locality of their choosing.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

SCIE (2009) At a glance 8: Personalisation Briefing: Implications for housing providers www.scie.org.uk/publications/ataglance/ataglance08.asp

DHSSPS (2008) Residential Care Homes: Minimum Standards
http://www.dhsspsni.gov.uk/care_standards_-_residential_care_homes.pdf

NDA (2007) Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in different various settings (Walsh, PN *et al*, 2007)
http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/929ECD4441474CA280257872004B8619/$File/SupportedAccommodation.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

McConkey, R (2005) Fair shares? Supporting families caring for adult persons with intellectual disabilities. Journal of Intellectual Disability Research, vol 49, Issue 8, 600 – 612
http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2005.00697.x/full

NIHE (2003) Supporting People
http://www.nihe.gov.uk/index/sp_home/strategies/independent_living-2/supporting_people_strategy.htm

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • HSC Trusts	• DSD • NIHE • Other service and housing providers

Quality Dimension

Citizenship
People with a learning disability have equity of access to housing options similar to the general adult population.

Social Inclusion
People with a learning disability are living in communities.

Empowerment
People with a learning disability are supported to access information and advice to exercise their preference of where they live and who they wish to live with, through the help of independent advocates where necessary and, tailoring support to people's individual needs to enable them to live full, independent lives.

Working Together
HSC professionals are involved in developing strategies, information and advice to housing providers on identified housing needs of people with a learning disability. Joint planning and partnership working is promoted towards meeting a person's housing need.

Individual Support
Support Plans are in place that support the person with a learning disability and their carers' independence. Funding sources are maximised that support this position and planning for the future is incorporated into this process.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of support plans that take account of people's aspirations in relation to future accommodation needs, including independent living	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2015 March 2016
2 Percentage of adults who are living with a single carer or where there are 2 carers and the primary carer is aged over 65 who have a futures plan in place	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2015 March 2016
3 Percentage of people in receipt of public funding living in households of 5 people or less with a learning disability	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2015 March 2016
4 Percentage of people leaving learning disability hospital within one week after treatment has been completed	PfA monitoring	95% 97% 100%	March 2015 March 2016 March 2017

Standard 29: (Generic)
All HSC staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed.

Service user perspective:

" My carer's needs will be considered and supported"

Rationale:
Carers are central to providing health and social care. People want to live in their own homes as independently as possible and family caring is critical in achieving this goal. Breakdown in caring has a major impact on readmission rates to hospital and unnecessary admissions to residential and nursing home care placements.

Caring is both a demanding and rewarding activity. Evidence shows that unsupported caring can have a negative impact on the physical, social and emotional well being of an adult carer. It is in everyone's interest to ensure that carers can continue to care for as long as they wish and are able to, without jeopardising their own health and wellbeing or financial security, or reducing their expectations of a reasonable quality of life.

Young carers (children and young people up to the age of 18 years who have a substantive caring role for a member of their family) often do not have an alternative but to be a carer. These children can be lonely, isolated, lose friendships and miss out on education and social activities. Young carers are frequently involved in activities that are developmentally inappropriate and the impact on their lives is unknown. Many young carers go unidentified. This highlights the need to identify young carers and provide support and assistance which will promote their health, development and inclusion in educational and social activities.

Early intervention, individually tailored to the needs of the carer and the cared for person, can be crucial in avoiding breakdown in the caring role. Forming meaningful partnerships with carers and making agreements with them about support to be provided is essential. Carers identify their requirements as respite care, information, personal care for the cared for person and practical and emotional support to continue in their role. This highlights the need for service planning and commissioning based on partnership working between statutory and independent sector and involvement of carers or their representatives to shape future services.

To enable carers to access the right information, support and services, current methods for identifying carers and encouraging them to acknowledge their caring role need to be enhanced. Under the Carers and Direct payments Act, all staff have a duty to inform carers. Staff should be particularly proactive in identifying the presence of younger and older carers.

One of the most important and far-reaching improvements in the lives of carers will be brought about by how health and social care staff view and treat them. Changes in staff knowledge of carers' issues could promote a more positive attitude to carers and this would make a significant difference to the lives of carers. Services should recognise carers both as individuals in their own right and as key partners in the provision of care and support.

Evidence:

PCC(2011) Young Carers in Northern Ireland: A report of the experiences and circumstances of 16 year old carers
http://www.patientclientcouncil.hscni.net/uploads/research/Young_carers_in_Northern_Ireland.pdf

Schubotz & McMullan (2010) The Mental and Emotional Health of 16-Year Olds in Northern Ireland: Evidence from the Young Life and Times Survey. Belfast: Patient and Client Council Report

DSD/ DHSSPS (2009) Review of Support Provision for Carers
http://www.dsdni.gov.uk/ssani-review-support-provision-carers.pdf

DHSSPS (2009) Regional Carer's Support and Needs Assessment Tool
http://www.dhsspsni.gov.uk/eccu2-09.pdf

DHSSPS (2008) Implementation of the Carers Strategy (Training for Carers)
http://www.dhsspsni.gov.uk/microsoft_word_-_circular_hss__eccu__3_2008_-_implementation_of_carers__strategy.pdf

Earley L *et al* (2007) Children's perceptions and experiences of care giving: A focus group study. *Counselling Psychology Quarterly.* 20. 1. pp.69–80

Evason, E. (2007) Who Cares Now? Changes in Informal Caring 1994 and 2006. Research Update 51. Belfast: ARK Publications www.ark.ac.uk

DHSSPS (2006) Caring for Carers Recognising, Valuing and Supporting the Caring Role http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

DHSSPS (2006) Implementation of the Carers Strategy (Identification of Carers) http://www.dhsspsni.gov.uk/hss__eccu__4-2006_carers_circular_-_signed.doc.pdf

SPRU (2004) Hearts and Minds: The health effects of caring
http://www.york.ac.uk/inst/spru/pubs/pdf/Hearts&Minds.pdf

Olsen R (1996) Young Carers: challenging the facts and politics of research into children and caring. Disability and Society, 11 (1), 41-54

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency • HSC Trusts	• Primary Care – GPs, LCGs • Independent Sector • DSD, DENI

Quality Dimension

Citizenship
Carers will feel valued and able to access the support they need. Staff will be facilitated to understand and value the role of carers.

Social Inclusion
Carers will be recognised as real and equal partners in the delivery of care. All carers, irrespective of age, who they care for or where they live will be directed toward appropriate agencies that can offer advice and support.

Empowerment
Carers will be encouraged to identify themselves as carers and to access information and support to protect and promote their own health and well-being and minimise the negative impact of caring

Working Together
Involving carers in the planning, delivery and evaluation of services improves outcomes for the carer and cared for person. Carers will be identified and supported best through partnerships between the statutory and voluntary sector and by good referral processes

Individual Support
Carers will be identified and signposted to help and support as early as possible in their journey and at times of crisis/transition.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Number of front line staff in a range of settings participating in Carer Awareness Training Programmes	Trust Training Report (including Induction programmes)	20% 50%	March 2015 March 2016
2. The number of carers who are offered Carers Assessments	HSC Board/ DHSSPS returns	Improvement targets set by HSC Board in conjunction with Carers Strategy Implementation Group	Reviewed annually
3. The percentage of carers who participate in Carers Assessments	HSC Board/ DHSSPS returns	Improvement targets set by HSC Board in conjunction with Carers Strategy Implementation Group	Reviewed annually

Standard 30:
All family carers should be offered the opportunity to have their needs assessed and reviewed annually.

Service User Perspective:

"The needs of family members who care for and support me will be assessed and regularly reviewed"

Rationale:
The majority of people with a learning disability live with their families. Nearly one-third live with a single carer and over 25% live with carers aged over 65 years. The pressures of caring can cause stress and ill health. Family carers report difficulties in accessing breaks from their caring responsibilities. The types of short breaks valued by family carers and people with a learning disability are wide ranging and needs to be flexible and responsive to the individual circumstances. This should include adult placement, drop-in services for people with a learning disability and support for the disabled family member to access social and recreational opportunities. A move away from an over reliance on short breaks in residential facilities is therefore signalled. Short breaks should be a positive experience for the person with a learning disability, adding to their lives' experiences as well as giving the family member a break.

Evidence:
NDTi (2010) Short Breaks Pathfinder Evaluation Greig, R., Chapman P., Clayson A., Goodey C., and Marsland D. http://www.education.gov.uk/publications/eOrderingDownload/DCSF-RR223.pdf

DHSSPS (2010) Care Management, Provision of Services and Charging Guidance http://www.dhsspsni.gov.uk/hsc-eccu-1-2010.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011) http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2009) Regional Carer's Support and Needs Assessment Tool http://www.dhsspsni.gov.uk/eccu2-09.pdf

Black, LA *et al* (2008) Lifelines Report: An Evaluation Report of the Impact of the Families Services delivered by Positive Futures in Rural and Urban Areas of Northern Ireland. http://www.positive-futures.net/sites/default/files/LIFELINES%20Full%20Report.pdf

Kenny, K and McGilloway, S. (2007) Caring for children with learning disabilities: an exploratory study of parental strain and coping, British Journal of Learning Disabilities, p221-8.

http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3156.2007.00445.x/abstract

DHSSPS (2006) Caring for Carers: Recognising, Valuing and Supporting the Caring Role http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Bamford (2004) University of Ulster Audit of Learning Disability Research in NI http://www.dhsspsni.gov.uk/learning-disability-consultation

Mencap (2003) Breaking point: A report on caring without a break for children and adults with profound learning disabilities. Mencap. London. http://www.mencap.org.uk/campaigns/take-action/our-other-campaigns/breaking-point

Responsibility for delivery/implementation	**Delivery Partners**
• HSC Board • HSC Trusts	• DHSSPS, DSD • Other Service Providers

Quality Dimension

Citizenship
Family carers have a voice in the development of strategies that impact on their role and ability to continue caring for their child, young person or adult

Social Inclusion
Carers are not left in isolation to cope with their role of caring for their child, young person or adult

Empowerment
Carers are better informed of their entitlements through the support and information they receive from professionals and /or independent advocates.

Working Together
Carers are involved in working as equal partners with statutory/other agencies in planning services that are flexible and responsive to meeting their needs and the needs of the person with a learning disability.

Individual Support
Carers of a person with a learning disability will have their support needs assessed and be provided with the services that support the family and / or the individual carer.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of carers who express satisfaction at their annual review that their needs as identified in the carers' assessment have been met.	User and carer feedback	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016

SECTION 11: AGEING WELL

Life expectancy for men and women with a learning disability has increased markedly over recent years. Growing older is likely to present additional challenges for people with a learning disability owing to the impact of their disability.

People with Down's syndrome are at high risk of Alzheimer's disease as they grow older and virtually all people with Down's syndrome who live long enough will develop this type of dementia. In addition, it is estimated that between 20% – 40% of older people with a learning disability are liable to have a mental health problem.

The number of older family carers is also increasing which can create particular challenges, for example, older carers:

- are under greater physical and mental pressures because of their age;
- may be particularly anxious about the future;
- are more likely to be caring alone; and
- may have smaller social support networks.

There has been little emphasis on health and wellbeing for older people with a learning disability or indeed their ageing carers. Ageing well has not been proactively encouraged by service providers. This is reflected in the low number of older people with a learning disability who participate in leisure activities and in concerns about unhealthy life styles.

Standard 31:

All people with a learning disability should have the impact of ageing taken into account in having their future needs assessed and proactively managed.

Service User Perspective:

"As I get older HSC staff will support me to plan for the future taking account of my age"

Rationale:
To avoid unnecessary anxiety to the person with a learning disability and their ageing family carer they both need to think about and plan for the changes that are likely to happen in their lives. Where this is done, crisis intervention should be eliminated in all situations where a person is known to social services and their needs met when there is a requirement to do so. At the same time, plans should also be considered for the family carer, in line with the statutory entitlement to an assessment of carer's needs (as with Standard 29).

People with a learning disability should be enabled to remain in their own home with their family carer for as long as possible with appropriate care and support to do so.

People with a learning disability have the same needs for autonomy, continuity of support, relationships and leisure as other older people.

Evidence:
The Alzheimer's Society (2011) Adaptations, improvements and repairs to the home www.alzheimers.org.uk/factsheet/428

DHSSPS (2010) Improving Dementia Services in NI: A Regional Strategy Consultation Document http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-consultation-may-2010.pdf

DHSSPS (2009) Regional Carer's Support and Needs Assessment Tool http://www.dhsspsni.gov.uk/eccu2-09.pdf

DHSSPS (2008) Standards for Adult Social Care Support Services for Carers http://www.dhsspsni.gov.uk/standards_for_adult_social_carer_support_services_for_carers.pdf

DHSSPS (2007) Living Fuller Lives: Dementia and Mental Health Issues in Older Age Report (Bamford) http://www.dhsspsni.gov.uk/living_fuller_lives.pdf

Tinker, Prof (1999) Ageing in place: What can we learn from each other? Kings College London www.sisr.net/events/docs/obo6.pdf

McQuillan *et al* (2003) Adults with Down's Syndrome and Alzheimer's Disease.

Tizard Learning Disability Review 8(4): 4-13.
http://pierprofessional.metapress.com/content/41u62857klh37m32/

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • HSC Trusts	• DHSSPS, DSD • Other service providers

Quality Dimension

Citizenship
People with a learning disability have the same right of access to Allied Health Professionals and specialist services, including equitable access to equipment aids and adaptations that assist daily living. They should not be discriminated against because of their learning disability.

Empowerment
People with a learning disability are facilitated to ensure that they have support to express their views and wishes as they plan for their future. People with a learning disability are provided with accessible information and support to understand and make their decisions about the future including information about age-related benefits.

Working Together
People with a learning disability have the right to a seamless transition towards increasing involvement and co-operation with services for older people and this should include any changes between programmes of care/team/Directorates in a pro-active manner.

Individual Support
Plans are in place and reviewed for the time when the carer is unable to continue to care, and is considered as part of the ongoing assessment of client and carers needs.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of people whose care plan has been reviewed taking account of issues associated with ageing.	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2015 March 2016

2 Percentage of carers aged 65 years and over receiving domiciliary or short break support services.	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2015 March 2016

Standard 32:

All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.

Service User Perspective:

"I can get care and support from dementia services when I need it"

Rationale:
The early stages of dementia in people with a learning disability are more likely to be missed or misinterpreted – particularly if several professionals are involved in the person's care. The person may find it hard to express how they feel their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change. It is vital that people who understand the person's usual methods of communication are involved when a diagnosis is being explored – particularly where the person involved does not use words to communicate. It is important that any prescribed medicine is monitored closely and that other ways of dealing with the situation are thoroughly explored.

People who have Down's Syndrome develop signs of dementia at a much younger age than others resulting in their needs being planned for much earlier.

Carers should be provided with information that helps them identify the earlier onset of dementia symptoms and be provided with appropriate support to continue to care for their adult with a learning disability. Carer's assessments should seek to identify any psychological distress and the psychosocial impact on the carer, including after the person with dementia has been provided with alternative care options.

Understanding a person's past history is crucial to providing person-centred care for someone with a learning disability and dementia.

Evidence:
DHSSPS (2010) Improving Dementia Services in NI: A Regional Strategy Consultation Document
http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-consultation-may-2010.pdf

DHSSPS (2010) Adult Safeguarding in NI: Regional & Local Partnership Arrangements http://www.dhsspsni.gov.uk/asva-__2010.pdf

Brooker, D (2007) Person-centred Dementia Care – Making Services Better.
http://books.google.co.uk/books?id=FQ3CdTblObwC&pg=Brooker+2007

NICE (2006) Clinical Guideline 42: Dementia - Supporting people with dementia and their carers in health and social care (Revised 2011)

http://www.nice.org.uk/nicemedia/live/10998/30317/30317.pdf

Regional Adult Protection Forum (2006) Safeguarding Vulnerable Adults: Regional Adult Protection Policy & Procedural Guidance http://www.shssb.org/filestore/documents/Safeguarding_Vulnerable_Adults_-_3_Nov_06.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Alzheimer's Society (2011) – Learning Disabilities and Dementia http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing TILDA. Measures will address health, cognitive status, activities of daily living, living situations, social life and overall quality of life within which a descriptive statistical picture of the life experiences of adult persons of ID will be developed. Prof. Mc Carron's research. Commenced September 2008. Due to complete in October 2011. http://people.tcd.ie/mccarrm

Responsibility for delivery/implementation	**Delivery and implementation partner**
• HSC Board • HSC Trusts Dementia Services • Primary Care • RQIA	• DHSSPS • Other service providers • Family carers

Quality Dimension

Citizenship
People with a learning disability and dementia should have the same access to dementia services as everyone else. People with a learning disability and those supporting them should have access to specialist advice and support for dementia. People with a learning disability and dementia should feel equally valued and should not experience barriers to person-centred care.

Social Inclusion
Every effort should be made to ensure people with a learning disability and dementia are cared for at home. When a move is necessary a specific care plan should be drawn up to ensure continuity of care and support for the person and successful transfer of expertise to the new service. People with a learning disability and dementia should not be excluded from services because of their diagnosis, age (whether regarded as too young or too old) or any learning disability.

Empowerment
Treatment and care should take into account each person's individual needs and preferences. Individuals must be given all available support before it is concluded that they cannot make decisions for themselves. Advocacy services and voluntary support should be available to people with a learning disability and dementia and carers separately if required.

Working Together
There should be sharing of skills and expertise between dementia services and learning disability services with equity of access to the most appropriate service delivery area. Referral protocols and pathways need to be clearly defined to facilitate people receiving the right care and attention in the right place at the right time.

Individual Support
Carers (family, staff, statutory and independent residential and nursing care providers) should be provided with information including inter-agency working, support and training to enable them to continue to care for the person with a learning disability and dementia. Care plans should incorporate individual person centred planning principles and should reflect individually assessed dementia care related needs.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of people with a learning disability and dementia who can access appropriate dementia services as required.	Trust generic dementia service	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016
2 Percentage of people with a learning disability and dementia who have received additional supports following a dementia diagnosis.	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	March 2016 March 2017
3 Percentage of HSC professionals and other support providers who have received awareness training on the needs of people with a learning disability and dementia	HSC Trust report	Establish baseline Performance levels to be determined once baseline established	March 2015 March 2016

SECTION 12: PALLIATIVE AND END OF LIFE CARE

Palliative and end of life care focuses on all aspects of care needed by patients and their families, physical, emotional and spiritual. It involves relief of symptoms, making thoughtful decisions, supporting families and providing ongoing care in the appropriate setting. It is important that people in the last phase of life get the appropriate care, at the right time, in the right place, in a way that they can rely on. The following standards are designed to improve the patient and family experience of palliative and end of life care through *holistic assessment* of need, improved coordination of care and a greater focus on choice at end of life.

Standard 33: (Generic)
All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care.

Service User Perspective*:*

"I will be supported in my end of life care needs"

Rationale:
Most people would prefer to die at home (including residential and nursing home where this is the person's usual home) where this is possible.

In order to support this, identification of the possible last year/months/weeks of life should take place. Evidence shows that when end of life care needs are identified there is improved quality of life and even prolonged life, compared to when this stage of illness is not identified, particular in non-cancer conditions.

Advanced care planning allows more informed choice of care and enables people to be more supported to die in their preferred place of care.

Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (WHO, 2002)

End of life care refers to the possible last year of life. It helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the patient and the family to be identified and met throughout the last phase of life and into bereavement. At this stage however it is often still appropriate to provide acute treatment in conjunction with palliative care, particularly in long term conditions. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (National Council for Palliative Care, Focus on Commissioning, Feb 2007).

Evidence:
NCPC (2012) Palliative Care Explained
http://www.ncpc.org.uk/sites/default/files/PalliativeCareExplained.pdf (as accessed on 26 September 2012)

NICE (2011) Chronic Obstructive Pulmonary Disease (COPD): Quality Standard
http://guidance.nice.org.uk/QS10

DHSSPS (2010) Living Matters: Dying Matters – A Strategy for Palliative and End of Life Care for Adults in Northern Ireland.
http://www.dhsspsni.gov.uk/855_palliative_final.pdf

NICE (2010) Chronic Obstructive Pulmonary Disease; Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care http://www.nice.org.uk/Guidance/CG12

Harrison , S et al, (2008), Identifying Alternatives to Hospital for People at the End of Life, The Balance of Care Group / National Audit Office http://www.balanceofcare.co.uk/previous_projects.html

Khan, SA; Tarver, K; Fisher S; Butler C (2007), Inappropriate Admissions of Palliative Care Patients to Hospital: A Prospective Audit, London, Pilgrims Hospices

Pleschberger, S, (2007), Dignity and the Challenge of Dying in Nursing Homes: The Residents' View http://ageing.oxfordjournals.org/content/36/2/197.short

DHSSPS (2006) Regional Cancer Framework: A Cancer Control Programme for Northern Ireland http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf

NHS (England) (2006) Gold Standards Prognostic Framework Programme, NHS End of Life Care Programme. Prognostic Indicator Papers vs 2.25 http://www.endoflifecare.nhs.uk/eolc/files/GSF-Guide-Prognostic_Indicators-Jul06.pdf

NICE (2004) Improving Supportive and Palliative Care for Adults with Cancer http://guidance.nice.org.uk/CSGSP

NICE (2004) Supportive and Palliative Care (CSGSP): Improving supportive and palliative care for adults with cancer http://www.nice.org.uk/Guidance/CSGSP

NHS Modernisation Agency (2004) Coronary Heart Disease Collaborative: Supportive and Palliative Care for Advanced Heart Failure http://www.improvement.nhs.uk/heart/Portals/0/documents/supportiveandpalliativecare.pdf

NICE (2003) Chronic Heart Failure; Management of Chronic Heart Failure in Adults in Primary and Secondary Care http://www.nice.org.uk/Guidance/CG5

Ellershaw & Wilkinson (2003), Care of the Dying: a Pathway to Excellence, Oxford University Press

Foote, C & Stanners, S, (2002), Integrating Care for Older People – New Care for Old – A Systems Approach, London, Jessica Kingsley

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• NICaN Supportive and Palliative Care Network • Primary care team, inclusive of social care • Voluntary palliative care

	organisations • Private nursing home and care providers

Quality Dimension

Citizenship
Earlier identification of palliative care needs and advance care planning will help improve quality of life and support a good death. Inappropriate admissions to hospital at the very end of life will be avoided.

Social Inclusion
People with non cancer conditions will have access to care and services traditionally available mainly to those with cancer conditions only

Empowerment
Involving service users, carers and families ensures that choices and preferences are taken into account in the planning and delivery of services

Working Together
HSC staff work in partnership with learning disability teams in order to ensure that appropriate reasonable adjustments are made to meet the specific needs of people with a learning disability.

Individual Support
Effective joint working between palliative care services and learning disability teams will ensure that the impact of learning disability is appropriately addressed in individual treatment plans.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of the population that is enabled to die in their preferred place of care.	NISRA survey for baseline of the population's preference Registrar General and PAS information for actual place of death	Establish baseline Performance indicator to be determined when baseline established	March 2014 March 2015
2. Percentage of the population with an understanding of advance care planning	NISRA survey for baseline levels	Establish baseline Performance indicator to be determined when baseline established	March 2014 March 2015

Standard 34:
All people with a learning disability being assessed for supportive and palliative care should have their learning disability taken into account in consultation with them, their carers and learning disability services when appropriate.

Service User Perspective*:*

If my health is getting worse and I need extra support towards the end of life staff will take into account my learning disability

Rationale:
Early identification of the supportive, palliative and end of life care needs of patients, their care-givers and family, through a holistic assessment, maximise quality of life for all in terms of physical, emotional, social, financial, and spiritual health and wellbeing.

People with a learning disability are entitled to the same services and respect throughout life as anyone else. Good palliative and end of life care is about enabling the individual to live out their potential when faced with an advanced progressive illness. By addressing the physical, emotional, spiritual and social issues which often make us fearful of death, it ensures that all individuals regardless of clinical diagnosis, get the appropriate care, at the right time, in the right place, in a way they can rely on.

Where necessary, reasonable adjustments should be made to take account of the impact of learning disability. Reasonable adjustments can be many and are wide ranging, but it is important to remember that they must be individualised to the person, and may include such things as:

- longer appointment times
- offering the first or last appointment
- the provision of easy read information to enhance understanding
- close involvement and support of family carers
- partnership working between learning disability services and other service providers.
- appropriate waiting facilities
- pre-admission visits
- fast tracking arrangements when appropriate (e.g. in A&E Departments)

Evidence:
Department of Health, Social Services and Public Safety (2010) *Living Matters: Dying Matters: A palliative and end of life care strategy for adults in Northern Ireland.* DHSSPS, Belfast.

Mencap (2008) Healthcare for All (The Michael Report) Report of the Independent Inquiry into access to healthcare for people with learning disabilities

National Institute for Clinical Excellence (2004) Improving Supportive and

Palliative Care for Adult with Cancer.
NHS (England) (2006) Gold Standards Prognostic Framework Programme, NHS End of Life Care Programme. Prognostic Indicator Papers vs. 2.25
http://www.endoflifecare.nhs.uk/eolc/files/GSF-Guide-Prognostic_Indicators-Jul06.pdf

NICE (2004) Improving Supportive and Palliative Care for Adult with Cancer.
National Institute for Clinical Excellence: London
http://www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf

NICE (2004) Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care.
National Institute for Clinical Excellence: London
http://guidance.nice.org.uk/CG12

Responsibility for delivery/implementation	**Delivery and implementation partners**
• Primary Care • HSC Trusts • Public Health Agency	• Voluntary Palliative Care Organisations • Private nursing home and care providers

Quality Dimension

Empowerment
Involving service users, their carers and families ensures that their choices and preferences are taken into account in the design and delivery of services.

Working Together
Partnership with service users, their carers and families is only possible if they are proactively involved in decision-making processes. Effective partnerships will contribute to positive health and social care outcomes.

Individual Support
Effective person-centred support will ensure that individuals are appropriately assessed for supportive and palliative care.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Palliative care services have mechanisms to identify whether people have a learning disability.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes.	March 2015 March 2016

2 Evidence of specific actions in service delivery that make reasonable adjustment for their learning disability.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes.	March 2015 March 2016

ANNEX A

GLOSSARY OF TERMS

TERM	DEFINITION
Acute Care	Health care and treatment provided mainly in hospitals
Advocacy	A service that provides someone to represent your views or support you in expressing your own views
Allied Health Professionals	Allied health professionals (AHPs) work with all age groups and within all specialties. AHPs work in a range of surroundings including hospitals, people's homes, clinics, surgeries and schools.
Augmented forms of communication	Better more accessible communication
Autonomy	Freedom of will
Capacity (mental)	Being able to understand and use information to make a decision
Care order	Care order is a court order made on the application of a HSC Trust and granted where the court finds the child has suffered or is likely to suffer significant harm.
Care pathway	A plan for the care needed to help a person with a learning disability to move through the different services they may need.
Challenging behaviour	When someone is behaving in a way that might cause harm to themselves or other people. Services are challenged to find a way of managing the behaviour so the chance of harm is reduced.
Citizenship	People with a learning disability being treated equally with other people.
Commissioners	A term used to describe organisations or groups who have been given responsibility for purchasing of health and social services.

Community Care	Services provided outside the hospital setting by HSC professionals and other organisations in the community.
Competency – based	An ability to do something, especially measured against a standard
Crisis intervention	A situation or period in which things are very uncertain, difficult, or painful, especially a time when action must be taken to avoid things getting much worse.
Cross-sectoral	Links between organisations managed by Government and voluntary/ community organisations and private business
Direct Enhanced Services	A Directly Enhanced Service is a specialised service provided by all GPs in N Ireland for adults with severe learning disability
Direct Payments	Direct Payments have been available since 1996 and aim to promote independence by giving people flexibility, choice and control over the purchase and delivery of services that support them. Individuals can opt to purchase services tailored to suit them by means of a Direct Payment from the Trust. From 19 April 2004 Direct Payments were extended to a wider range of service users under the Carers and Direct Payments Act (Northern Ireland) 2002 to include carers, parents of disabled children and disabled parents.
Disparities	A lack of equality between people or things
Domiciliary care	Support or care provided to a person in their own home
Dual diagnosis	Two different illnesses
Eligibility	To meet requirements for a certain criteria
Empowerment	Supporting people to take a full part in making decisions about their life.
Evidence-based practice	Doing things that have been shown to work
Health Action Plan	Describes the care and support you need to look after yourself and stay healthy.

Holistic care	Comprehensive care that addresses the social, psychological, emotional, physical and spiritual needs of the individual.
Independent sector	Organisations that are not managed by Government – includes voluntary organisations, community organisations and private business
Informed consent	Agreement by you to undergo treatment or care after being informed of and having understood the risks involved.
Integrated care pathway (ICP)	A multi-disciplinary outline of anticipated care which identifies how a patient with a specific condition will be supported by a number of professionals or agencies.
Integration	Equal access for all
Inter-agency	Links between different organisations
Legislative	To do with law
Mainstream Services	Services that anyone can use.
Methodologies	Different way of doing research.
Multi-Agency	Staff from different agencies, for example health and social care, education and employment, working together.
Multi-disciplinary	Staff from different professions, for example, nurses, doctors, social workers, working together.
Optimum	Most suitable
Palliative care	The active, holistic care of patients with advanced progressive illness. The goal of palliative care is to achieve the best quality of life for patients and their families.
Partnership working	Different organisations working together to achieve something
Person-Centred	The person and their family and friends are central and fully involved in all aspects of their care. The service, the organisation and its systems are focused on the needs of (what is important to) the individual.

Preliminary reports	Reports done at the start.
Prevalence	How many people in the population have a particular problem
Primary Care	Health and social care services that are generally available to everyone, for example, GP, dentist.
Reasonable adjustments	Actions that service providers should take to make sure people with a learning disability can use their services.
Respite	Support which gives carers a break from their usual caring roles and duties.
SAAT	Self Assessment Audit Tool – a performance management tool designed to measure the delivery of key objectives
Secondary Care	Health and social care services that help people with more complicated needs than those that primary care deal with, but mostly in the community.
Self-determination	A right to decide for self
Self-directed support	Helping people be in control of the support they need to live their life as they chose.
Service Framework	A document that sets out what people can expect the service to provide.
Service User	Anyone who uses, requests, applies for, or benefits from health and social care services.
Social inclusion	Making people with a learning disability feel part of the community they live in.
Statutory sector	Those organisations that are managed by government
Stereotypical	To categorise individuals or groups according to an oversimplified standardised image or idea
Transition	A time in a person's life when big changes are happening, for example, leaving school
Universal	Meaning all

ANNEX B

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ANNEX C

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ANNEX D

The five core values outlined in the Equal Lives Review (2005):

Citizenship	People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen.
Social Inclusion	People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community.
Empowerment	People with a learning disability must be enabled to actively participate in decisions affecting their lives.
Working Together	Conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability.
Individual Support	People with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible

ANNEX E

Bamford Review of Mental Health and Learning Disability Reports

• Mental Health Improvement and Wellbeing	May 2006
• Child and Adolescent Mental Health	July 2006
• Adult Mental Health	June 2005
• Dementia and Mental Health of Older People	June 2007
• Alcohol and Substance Misuse	Dec 2005
• Forensic Services	Oct 2006
• Learning Disability	Sept 2005
• Promoting Social Inclusion	Aug 2007
• A Comprehensive Legislative Framework	Aug 2007
• Human Rights and Equality	Oct 2006
• Delivering the Bamford Vision	2008

ANNEXE F

ABBREVIATIONS

A&E	Accident and Emergency
ASD	Autistic Spectrum Disorders
BMI	Body Mass Index
CSCI	Commission for Social Care Inspection (now Care Quality Commission)
CSR	Comprehensive Spending Review
DCAL	Department of Culture, Arts & Leisure
DE	Department of Education
DEL	Department of Employment & Learning
DES	Direct Enhanced Services
DfES	Department for Education and Skills (England)
DHSSPS	Department of Health, Social Services and Public Safety
DNAR	Do Not Attempt Resuscitation
DoH	Department of Health
DoJ	Department of Justice
DSCF	Department for Children Schools and Families (England)
DSD	Department of Social Development
ELB	Education and Library Board
FE	Further Education
GAIN	Guidelines and Audit Implementation Network
GMC	General Medical Council
GP	General Practitioner
HSC	Health and Social Care
IASSID	International Association for the Scientific Study of Intellectual Disabilities
LASPs	Local Adult Safeguarding Partnerships
LCG	Local Commissioning Group
NDA	National Disability Authority
NDTi	National Development Team for Inclusion

NHS	National Health Service
NIASP	Northern Ireland Adult Safeguarding Partnership
NICaN	Northern Ireland Cancer Network
NICE	National Institute for Health and Clinical Excellence
NIHE	Northern Ireland Housing Executive
NIUSE	Northern Ireland Union of Supported Employment
OFMDFM	Office of First Minister and Deputy First Minister
PBNI	Probation Board for Northern Ireland
PCC	Patient and Client Council
PCP	Patient-centred Plan
PfA	Priorities for Action
PHA	Public Health Agency
PPI	Personal & Public Involvement
PSNI	Police Service of Northern Ireland
QIS	Quality Improvement Scotland
RCSLT	Royal College of Speech and Language Therapists
RoI	Republic of Ireland
RQIA	Regulation & Quality Improvement Authority
PSSRU	Personal Social Services Research Unit
SAAT	Self Assessment Audit Tool
SACN	Scientific Advisory Committee on Nutrition
SBNI	Safeguarding Board for Northern Ireland
SCIE	Social Care Institute for Excellence
SENDO	Special Educational Needs and Disability Order
SIGN	Scottish Intercollegiate Guidelines Network
UNOCINI	Understanding the Needs of Children Northern Ireland
WHO	World Health Organisation

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157

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ROYAL COLLEGE OF PSYCHIATRISTS

FR/ID/06

Community-based services for people with intellectual disability and mental health problems

Literature review and survey results

Faculty of Psychiatry of Intellectual Disability

FACULTY REPORT

Faculty Report ID/06

May 2015

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Contents

Executive summary	5
Introduction	8
Literature review: community-based mental health services	11
Survey: community-based services	24
Appendix 1. Literature review tables	30
Appendix 2. Survey questions	34
References	37

Executive summary

This report summarises the current evidence on existing community service models for adults with intellectual disability and mental health, behaviour or forensic problems and reports the findings of a survey of community-based psychiatrists.

This complements the Royal College of Psychiatrists' (2013) Faculty of Psychiatry of Intellectual Disability's report on in-patient services, *People with Learning Disability and Mental Health, Behavioural or Forensic Problems: The Role of In-Patient Services*. Community services for people with intellectual disability have frequently been poorly planned in the UK and internationally. Despite the strong comorbidity of intellectual disability with other mental and physical health conditions, along with the increased recognition of the needs of this group, there is significant variation in the commissioning of services to target those needs and in how services interpret policy guidance. There is now a recommendation for a national mandatory commissioning framework.

Service models can be categorised as either specialist, stand-alone services or services integrated with mainstream mental health services. People with intellectual disability are diverse in terms of their presenting problems, from individuals with severe intellectual disability presenting with behaviours that pose a significant risk to themselves, to mild intellectual disability who have committed serious offences.

The literature review showed there are diverse models in place; however, there is insufficient evidence to determine which model provides the most effective care. Key findings were as follows.

- Services work better when delivered around individual need in a person-centred approach.
- People with severe mental illness and borderline intellectual functioning benefit from intensive community-based care in terms of reduced length of time in hospital.
- Positive behavioural support works well in community-based settings.
- A multi-agency approach reduces at-risk behaviours.
- There is little evidence of routine collection of outcome data by community services.

All papers included in the review recommended further investigation of the service models and the interventions offered in order to clarify whether it was the whole service model or the individual interventions offered that proved effective.

There was evidence that staff in generic mental health services and community forensic teams lack the knowledge and skills to support patients with intellectual disability. In addition, those working in the specialist community intellectual disability teams might not have the skills to assess and manage individuals presenting with offending behaviour in the community or being discharged from a secure hospital.

A small number of psychiatrists working in community intellectual disability services across England were surveyed. Several important messages emerged. There is geographical variation in the integration of health and social services: London is more integrated and other parts of the country are less integrated. Challenging behaviour teams are the most common specialist type of community service. Psychological therapies (e.g. cognitive–behavioural therapy) and specialist memory assessments are now a feature of the range of services provided by community intellectual disability teams. The most commonly reported care pathways are those for the care of people with dementia and people with challenging behaviour. Outcome measures are not used routinely, but the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) tool was by far the most commonly completed. The single most common development reported is the closure of National Health Service (NHS) in-patient units.

Recommendations

1. There is no one-size-fits-all model, but community-based intellectual disability services must take a person-centred approach in delivering care and treatment. Professionals across mainstream and specialist community teams must possess the skills and expertise to provide care for people with intellectual disability who have additional mental health, behavioural and forensic problems.
2. A strategic approach to the local development of pathways between specialist, adult mental health and other services, such as social care, is required to ensure positive health outcomes and a reduction in inappropriate admissions.
3. Community intellectual disability services are key in supporting people in their homes and local communities. However, they need to be more outcomes-focused and commissioning should encourage this approach.
4. More research is needed into the effective components of community intellectual disability service models.
5. Community services need to be supported by local in-patient facilities for the assessment and treatment of people with intellectual disability and mental health problems and offending behaviour that present an unacceptably high risk to the individual or the community.

6 A comprehensive survey of community services is required to provide information on the existing configuration of services and community teams to develop an effective network of community services, which can further reduce the need for in-patient care.

7 There needs to be a strategic approach to the development of the workforce, building on existing training initiatives to ensure that services are personalised, effective and fit for purpose, supported by a national Workforce Academy.

Introduction

In response to the Winterbourne View Report (Department of Health, 2012a), a programme of action was agreed upon (Department of Health, 2012b), to be followed by health and care commissioners with regard to in-patients with intellectual disability or autism spectrum disorder. It was planned that 'health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than June 2014' (Department of Health, 2012b). Each region would put in place a locally agreed plan for high-quality care and support services for people with challenging behaviour that accords with the model of good care, to ensure that new patients do not take the place of current in-patients. Health Education England would provide appropriate staff training in supporting people with challenging behaviour. Skills for Care would improve patients' skills and qualifications so that patients can find employment. The Local Government Association would support commissioners to develop comprehensive local services and help community intellectual disability teams provide more integrated services. The Department of Health would review the prescription of antidepressants and antipsychotic medication for people with challenging behaviour and carry out an audit on challenging behaviour services to identify out-of-area placements and average length of stay in hospital.

The Bubb (2014) report revealed that progress towards achieving these objectives has been slow and highlighted the key role of community services for people with intellectual disability and mental health, behaviour and forensic problems in reducing or preventing inappropriate hospital placements.

This report summarises the current evidence on community services, including a description of current models. It aims to complement previous reports on in-patient services and people with intellectual disability in contact with the criminal justice system (Royal College of Psychiatrists, 2013, 2014a).

This document addresses the needs of adults with intellectual disability. Services for children with intellectual disability are usually provided by child and adolescent mental health services. However, many of the issues dealt with here are equally relevant to children, and we hope that our colleagues in children's services will find this document useful. Many of the behaviours and mental health problems seen in adults arose during childhood and it is vitally important that good community services are available to all young people to tackle issues

as they arise. Left unmanaged, these problems lead to additional handicaps and are harder to treat in adulthood. Transition between children and adult services is another important topic that is not discussed in this paper. There needs to be continuity of care between adolescent and adult services, with robust care pathways in place. The needs of adults with autism spectrum disorder are covered in College Report 191 (Royal College of Psychiatrists, 2014b).

There is a critical need for improvement in community mental health services offered to people with intellectual disability (Chaplin *et al*, 2009). These patients often present with comorbidities and significant mental health needs (Deb *et al*, 2001; Cooper *et al*, 2007; Morgan *et al*, 2008); the estimated prevalence of a comorbid mental health condition in this population is 30–50% (Smiley, 2005). However, people with intellectual disability and a comorbid mental health condition can have difficulty accessing the services they require. People with intellectual disability are placed into in-patient care that is usually away from their local area because of the lack of suitable community-based resources within their local services (Chaplin *et al*, 2010a).

The white paper *Valuing People* (Department of Health, 2001) advocated that more people with intellectual disability and a mental health condition should be treated within mainstream services. However, a mental health condition can be experienced differently by those with intellectual disability in terms of subjective experience and expression of the disorder (Lunsky *et al*, 2008). Additionally, when treated by mainstream mental health services, such patients can experience problems due to factors such as mental health professionals lacking knowledge and experience in dealing with patients with intellectual disability (Spiller *et al*, 2004) or challenging behaviour being attributed to the intellectual disability rather than a mental health condition (diagnostic overshadowing).

Community service models

There are a number of community service models for the treatment and care of people with intellectual disability and a mental health condition. Some of the most common models are described below.

Community intellectual disability teams/services

These multidisciplinary teams might include psychiatrists, psychologists, psychiatric/intellectual disability nurses, social workers, speech and language therapists, occupational therapists and physiotherapists. They can be run as a partnership between primary care services, social care services and specialist mental health teams. They intend to provide comprehensive support for all physical, social and mental health needs. Mental health needs can be obscured by the emphasis on social care (Chaplin *et al*, 2010b).

Generic community mental health services/ mainstream services

These multidisciplinary teams take on people with a variety of mental health conditions. The UK government's agenda is to improve access to these services for people with intellectual disability (Department of Health, 2001). However, it is often the case that staff in these services lack the skills and experience required to provide effective care for patients with intellectual disability (Werner & Stawski, 2012).

Specialist mental health in intellectual disability teams

These are often single-profession teams (e.g. nursing or psychiatry) or multidisciplinary teams with nursing, psychiatry and psychology components, whose focus is the treatment of mental health problems in people with intellectual disability. They can provide specialist assessment and treatment, along with support in accessing generic services (Sheehan & Paschos, 2013). In contrast to generic services, they usually offer a very specific range of treatments, have a fixed capacity and the staff have very well-defined roles and specific training (Bouras *et al*, 2003). Patients are often referred from primary care or generic mental health services. However, there is currently not enough of these services available and patients can have difficulty accessing them (Chaplin *et al*, 2010a).

Virtual teams

These multidisciplinary teams are composed of staff from different services/agencies who meet regularly (often via teleconference or video conference) to review people in the community whose intellectual disability is compounded by a mental health condition (Hall *et al*, 2006a). The team aims to implement person-centred care and have both preventive and treatment functions. Some might also provide inreach to in-patient services to facilitate discharge and improve contact with mainstream services. This model has been found to lead to improved functioning and reduced risk of self-neglect and harm to self or others in in-patients (Hall *et al*, 2006b).

Single point of entry

Fear *et al* (2012) described another service model offering integrated healthcare to all with a single entry point to mental health services. Following assessment, patients with or without intellectual disability are assigned to the most appropriate care pathway. This allows patients with intellectual disability to access a full range of services based on their needs rather than diagnosis. Interdisciplinary teams are supported by specialist intellectual disability services when required. This model emphasises adapting the service around the person's individual needs and engagement of the person's family in the care planning where possible.

Literature review: community-based mental health services

We followed a rapid review method and carried out searches using databases including Ovid, the Cochrane Library and Google Scholar. Search terms included 'community mental health services', 'community care models', 'mental health service models', 'challenging behaviour', 'services', 'outcomes', 'autism', 'ADHD', 'neurodevelopmental', 'intellectual disability' and 'learning disability'. Other literature included the Royal College of Psychiatrists' policy documents and national guidelines. We also consulted with co-authors and the members of the Faculty's Executive Committee about information on additional papers and local reports or service developments.

Community mental health services

In the UK, mental health services for people with intellectual disability have long been based on normalisation (Wolfensberger, 1991): encouraging people with intellectual disability to use mainstream mental health services. Community mental health services started to gain prominence in the 1970s following deinstitutionalisation, and policy initiatives increased patient numbers in the community over long-stay hospitals (Bouras *et al*, 1995). These early services were often poorly planned and few in number because the effects of mental health conditions on intellectual disability populations were underestimated (Hemmings *et al*, 2013).

In the early 1990s, there was a growing recognition of the lack of adequate care and treatment for people with intellectual disability and a coexisting mental health condition (Day, 1995). It became clear that mainstream mental health services were finding it difficult to provide adequate care for those patients and there was poor communication between intellectual disability and mainstream mental health services (Bouras, 1999). Therefore, strong working relationships and effective communication between these services was, and still is, crucial to improving the quality of care.

Despite frequent publications of reports on how to improve services (e.g. Department of Health, 1993; Royal College of Psychiatrists, 1996) many patients with intellectual disability and a mental health condition still do not receive adequate support. For example, one longitudinal

study on people with intellectual disability receiving community care found that many of these people had become excluded from mainstream care and that some services had become fragmented or diluted and unable to provide adequate support (Cambridge *et al*, 2005). The study suggested moving away from generic and diluted models to more intensive, integrated models and person-centred planning so that the patient is at the centre of the decision-making.

Community intellectual disability teams

Person-centred models have been gathering more attention. Fear *et al* (2012) implemented such a model in Gloucestershire, in which specialist mental health services were integrated to provide a single access point and care was delivered based on a person's needs rather than circumstances. They also devised 'locality hubs' composed of interdisciplinary teams (replacing community mental health teams) of 150 staff. These hubs are made up of smaller teams across different specialties working together to focus on particular patient clusters (as defined in the payment by results system; Department of Health, 2012c). This model has not been evaluated to date but it is hoped that it might allow a better response to patients across the range of intellectual disability.

There is evidence to suggest that community intellectual disability teams cannot meet the mental health needs of their patients because of barriers such as lack of teamwork, excessive caseloads, poor eligibility criteria leading to patients falling in between services, lack of staff and inadequate training of staff (Slevin *et al*, 2008). Chaplin *et al* (2009) identified a lack of strategic direction in commissioning community intellectual disability services, which leads to inadequate service provision.

The current evidence base for the organisation and delivery of mental healthcare for people with intellectual disability is inconclusive and inconsistent. It relies largely on retrospective reports and uncontrolled studies with small numbers of participants (Chaplin, 2004). A review by Slevin *et al* (2008) on the effectiveness of community intellectual disability teams found most publications were based on opinion rather than evidence. This lack of an evidence base has led to huge inconsistency in the service models implemented across the UK (Chaplin *et al*, 2009). Hemmings *et al* (2014) advocate that future research needs to focus on service components such as responses to crisis rather than whole-service models, and suggest that the way forward is to develop new ways of working with professionals in mainstream mental health and forensic services.

A survey by Moore & Thurley (2011) brought further insight into the inefficiency of community intellectual disability teams. It found that a large amount of time was spent on administration and inputting data

into IT systems and therefore less time could be spent on care management and face-to-face contact with patients. There were regional variations in time spent on patient contact and it was also found that while integrated teams did not differ from non-integrated teams in terms of time spent on patient contact and care management, more time was spent on administrative tasks. It was proposed from this survey that community intellectual disability teams could be more effective by implementing consistent IT systems across services, reducing administrative tasks and increasing time spent in contact with patients.

Moore & Thurley (2011) proposed the following roles/priorities for community intellectual disability teams:

- delivering specialist interventions and advice
- reducing health inequalities
- supporting health professionals in general and mental health services
- reducing out-of-area placements
- supporting personalisation
- improving safeguarding in services
- supporting patient transition between teams (e.g. child to adolescent)
- developing strong working ties with criminal justice system.

Generic mental health teams

Coehho *et al* (1993) looked at a mainstream community mental health team that randomly assigned patients to an active treatment model of increased contact with professionals or a standard case model. They found that in comparison with the standard model, the active model led to increased functional behaviours and reduced challenging behaviours. The researchers reasoned that this was because the more intensive active model allowed improved observation of mild symptoms and so it was easier to prevent the patients from reaching crisis. To this end, it was also observed that while patients treated by the active model used acute in-patient services more, fewer required long-term hospitalisation compared with those receiving standard care.

Specialist mental health in intellectual disability teams

Chaplin *et al* (2008) and Hemmings *et al* (2013) describe a team known as Mental Health in Learning Disability (MHiLD), which delivers care to targeted patient groups, offers a specific range of treatments, has a fixed capacity and has clear roles and responsibilities of staff

members (reducing role blurring and conflict). The MHiLD team is led by a consultant psychiatrist and also includes trainee psychiatrists and community mental health nurses with expertise in intellectual disability. The service is flexible and offers assessment, review and intervention via out-patient clinics, outreach work, day centres, home visits and telephone. The team is often involved in multidisciplinary reviews as well as providing advice to other services by expert consultation. The service also works with child and adolescent services to provide help for patients approaching 18 years of age and about to transition into adult services.

Intensive community-based services

Minnen *et al* (1997) compared 25 patients treated in a hospital with 25 patients who received outreach treatment from a community intellectual disability team. They found that outreach treatment was equally effective at reducing psychiatric symptoms and was also more cost-effective. In addition, Hassiotis *et al* (2000) found that, in people with psychosis and borderline intellectual functioning, intensive community care led to significantly less time spent in hospital in comparison with standard care.

Views of professionals

Hemmings *et al* (2009) used the Delphi method to gather a consensus opinion from mental health professionals on what should be provided by community services for patients with intellectual disability and psychosis. The highest-rated components were 'a focused approach to the presenting problem' (e.g. monitoring of mental state, medication and access to a crisis plan and out-of-hours support) and 'a need to work within a wider context' (e.g. improving patient access to social, leisure and occupational activities and accommodation, and support and advice for family/carers on mental health issues).

Another study collated data from semi-structured interviews with professionals from specialist intellectual disability services on the important components of community intellectual disability services (Hemmings & Al-Sheikh, 2013). Themes identified were clarity of purpose, training in assessment of dual diagnosis, providing a person-centred service, flexible delivery and care that is holistic, multidisciplinary and evidence based. It also identified a need for clear, local care pathways and improved joint working between mainstream mental health services and specialist intellectual disability services. See Appendix 1 for a summary of studies found in the literature for models of community mental health services.

Challenging behaviour services

'Challenging behaviour' is a term that covers many different forms of socially unacceptable behaviour, from self-harm and inappropriate verbal habits to physical violence (Naylor & Clifton, 1993). Challenging behaviour is fairly common, occurring in around 10–15% of people with intellectual disability (Royal College of Psychiatrists *et al*, 2011). Most importantly, people with intellectual disability and challenging behaviour need the most contact and resources from community services (Slevin & Sines, 2005). However, this group finds it harder to obtain help from these services (Emerson *et al*, 2000). The publication of the Mansell Report (Department of Health, 1993) led to the development of specialist, community-based, challenging behaviour services that could offer support to mainstream services. It was also suggested that the development of community support teams, residential services and occupational/employment schemes would be important in supporting the behavioural programmes.

There is currently a mismatch between the needs of patients with intellectual disability displaying challenging behaviour and the services available (Royal College of Psychiatrists *et al*, 2011). A government report made recommendations about the core principles that should guide services for challenging behaviour (Local Government Association, 2014). Specialist local services should have a clear positive behavioural support (PBS) pathway and local policies should reflect this. PBS is a multi-component framework that is known to work well in community-based settings and can lead to reductions in challenging behaviour and medication use and to improved quality of life for some patients (Carr *et al*, 1999; McClean *et al*, 2007). The report recommends that specialist services should also support generic services in using PBS alongside person-centred care, ensuring that patients are provided with meaningful activities and routines.

Challenging behaviour services can be either integrated into or separated from community intellectual disability services (Queensland Centre for Intellectual and Developmental Disability, 2002). An example of such a service is the intensive support service (ISS), which is located in Glamorgan, Wales. This is a small team of clinicians, with a ring-fenced budget, access to a six-bed admission unit and a peripatetic support team. This model has been found to significantly reduce challenging behaviour and mental health problems as well as improve patients' quality of life and adaptive behaviours (Lowe *et al*, 1996). Allen (1999) compared groups of patients who received treatment from this service and were either successfully (maintained group) or unsuccessfully (breakdown group) maintained in the community. They found few behavioural or psychiatric differences between the groups, but only 50% of the breakdown group received ISS input at the time they experienced placement breakdown, whereas 100% of the maintained group received ISS input. Overall, 93% of the breakdown group had previously received ISS input, suggesting that longer-term support

for these patients was needed. Additionally, the breakdown group were more likely to come from services that were poorly organised and had suboptimal resource utilisation. Therefore, while specialist services can lead to positive outcomes for patients with challenging behaviour, if managed inadequately they can result in no improvement or worse outcomes.

McGiill *et al* (2010) identified 46 peripatetic services of teams with two or more members of staff focused on addressing the behavioural needs of the individual and identified as additional service provision to the person (therefore, not part of the services that support them on a day-to-day basis). The teams were given the opportunity to complete an online questionnaire regarding how their team operated on a daily basis; 20 services responded to the survey. The results suggested services are similar throughout the country and that they perceived success in the services they offered. Further research is needed to ascertain if it is the individual peripatetic service that is effective or the interventions that it offers. Studies examining behavioural interventions across services would help identify which factors influence the effectiveness of the peripatetic teams.

Out-patient approach

Many factors can hinder the local treatment of patients presenting challenging behaviour, leading to a lack of integration into the community (Andrea Barron *et al*, 2011). Lehrer & Ott (2009) followed patients with persistent challenging behaviour who were referred to a university-affiliated, interdisciplinary out-patient hospital clinic. It was found that this approach allowed more consultations, more evaluation of professionals providing care and a more comprehensive treatment plan, leading to significantly reduced levels of challenging behaviour. Patients' family members also reported improved patient quality of life and more involvement in the community.

McKenzie (2011) noted that many staff working in community settings report that they lack knowledge of and training in dealing with challenging behaviour. Methods such as applied behaviour analysis were difficult to apply outside a structured environment. McKenzie *et al* (2009) implemented a community-based project for four individuals with challenging behaviour. Psychology graduates, supervised by a clinical psychologist, supported the patients in their own homes. The project, which ran for a year, showed a decrease in challenging behaviour; a positive experience was reported by both staff and patients. While these results are promising, the project needs to be evaluated on a larger scale.

Assertive community treatment

Originally developed as an alternative to in-patient hospital treatment (Stein & Test, 1980), assertive community treatment (ACT) teams act

as a support system for patients to help them increase autonomy and improve coping skills and community integration. These specialist teams form intensive, long-term relationships with patients who have had difficulty working with services. They offer a range of supports such as psychological therapy, medication management, help with daily living and supporting the patient's family. Meisler *et al* (2000) was the first to apply the ACT model to patients with intellectual disability and a mental health condition. This model is described as an interdisciplinary team with blurred roles and shared responsibilities. Treatment, rehabilitation and support services are fully integrated to provide high continuity of care. Assertive outreach can be carried out either by a select group of professionals within a community intellectual disability team or by a single independent team of specialists led by a consultant psychiatrist or psychologist (Hassiotis *et al*, 2003).

Two randomised, controlled trials have evaluated ACT in people with intellectual disability who present with both a mental health condition and challenging behaviour. Oliver *et al* (2005) found no significant differences in global function and burden/quality of life outcomes between ACT and standard care. Martin *et al* (2005) found a trend towards better outcomes (unmet needs, carer burden, functioning and quality of life) with standard care over ACT, but these differences were not statistically significant. Furthermore, the group receiving ACT showed more behavioural problems, as measured by the Aberrant Behavioural Checklist (Aman *et al*, 1985). Standard care and ACT in these studies seemed to differ mostly by intensity of the treatment, with ACT being more intensive. In both studies, the treatment received by the two groups was similar and both could be considered assertive (Oliver *et al*, 2005). Future studies must make sure to evaluate aspects of ACT that could actually benefit patients, rather than just the intensity of the treatment.

The ACT models used in these studies differed from each other and the original model (Hemmings *et al*, 2008). When Hemmings and colleagues interviewed professionals delivering ACT, these professionals felt their services should be more similar to the original model devised by Stein & Test (1980); for example, holding weekly team meetings and having a shared case-load, a practising team leader and good continuity of staff. The professionals also felt it was unrealistic and unnecessary to work too intensively with patients, such as providing 24 h coverage, having a low intake rate and having a no drop-out policy. It was concluded that, since the ACT model can be difficult to define and implement for this patient group, it might be more useful to evaluate broader models of specialist, community-based services.

Ayres & Roy (2009) described the benefits of a multi-agency approach and the development of a supported-living outreach team to enable people with complex and severe psychiatric and behavioural problems to be assessed, treated and given longer-term support in the local community. The amount of support offered varies depending on the patient's needs, but has the goal of developing independent living skills so that patients can function well within the community.

Ayres & Roy found that this approach provided value for money by significantly reducing patient risk/challenging behaviour and therefore reducing the need for high levels of support for patients with severe challenging behaviour.

Specialist forensic community services for adults with intellectual disability

Although the literature on challenging behaviour in people with intellectual disability is very extensive, the dividing line between challenging and offending behaviour can be imprecise (Royal College of Psychiatrists, 2013, 2014a). The assumption that all such behaviours are a consequence of institutional lifestyles, and would subsequently diminish once community care is introduced, might be flawed (Holland *et al*, 2002).

Although it is theoretically possible to provide services for those with intellectual disability in generic mental health settings, a lack of specialist skills in the diagnosis and treatment of mental disorders in people with intellectual disability within such teams is a sizeable obstacle (Cumella, 2009) and the relatively small numbers of cases give the staff little opportunity to gain the necessary skills (Moss *et al*, 1997). Similarly, staff within specialist community intellectual disability teams might not have the specialist skills to deal with the assessment and management of offending behaviour and forensic issues (Devapriam & Alexander, 2012). In-patient intellectual disability forensic services provide an environment that emphasises care and treatment rather than punishment (Hollins, 2000; Kingdon, 2005) and should really only be for the small number of patients who present risks above the threshold for safe management in the community. In light of the scrutiny of in-patient facilities for people with intellectual disability following the Winterbourne scandal and the national response to it (Department of Health, 2012a,b), it is imperative for clinicians to decide on the appropriateness and requirement of in-patient treatment.

Setting up community forensic services for those with intellectual disability can help modify some of these drivers and reduce the number of patients who end up in in-patient forensic services. Equally, these services can also facilitate the care pathway of those discharged from secure in-patient facilities to less restrictive settings and improve long-term outcomes. This is particularly important because people who are discharged from these facilities have problems and risks that continue well after discharge, with a small number remaining disturbed and challenging after many years (Alexander *et al*, 2006, 2011). In-patient forensic services that wish to provide good treatment outcomes for their patients should therefore see it as being in their own interest to have skilled community teams who can provide appropriate support to these patients long after discharge (Devapriam & Alexander, 2012).

Three community forensic intellectual disability teams have been described in the literature. Benton & Roy (2008) described the first 3 years of a community forensic service for people with intellectual disability in Birmingham. Dinani *et al* (2010) reported on the first 8 years of a tertiary community forensic team for people with intellectual disability in Avon. Devapriam & Alexander (2012) described a tiered model of community forensic provision established in collaboration between the NHS and the independent sector. These kinds of services are best understood within the framework of a tiered model of service and the categories of in-patient beds described by the Royal College of Psychiatrists (2011, 2013) and could greatly help to minimise the risk of inappropriate hospitalisation.

International literature

Ireland

Ireland's National Disability Authority (2003) found inequality in the mental health treatment provided for people with intellectual disability. It recommended the development of community intellectual disability teams: specialist teams for people with intellectual disability and a mental health condition that would receive referrals from and work closely with generic intellectual disability teams. These multidisciplinary teams would be integrated into the generic community mental health team and provide coordinated care for the individual, including assessment, treatment and reviews. They would also help the individual access the services required for treatment. Eight of these teams, each serving a population of around 450 000, was estimated to be sufficient to meet the mental health needs of people with intellectual disability in Ireland. These teams would offer liaison and education to other service providers. However, there have been no further publications on the implementation or progress of these teams.

USA

As in the UK, patients with intellectual disability in the USA have found it difficult to access mental health services because of a long-standing division between mental health and intellectual disability services (Hackerman *et al*, 2006). An early study by Torrey (1993) recognised that integration of mental health and intellectual disability community services is important in providing adequate care. Administrative distinctions left some people with intellectual disability and a mental health condition trapped in the gap between mental health and intellectual disability services. In 1999, the Developmental Disability Assistance and Bill of Rights Act led to the development of university centres for the treatment of people with intellectual disability and a mental health condition.

Mental health services for people with intellectual disability are usually offered by consultants, university-affiliated programmes and out-patient clinic services. The Rochester model, in which a

specialist out-patient team provides mental health support as part of a generic mental health team or a developmental disability service, is also implemented in some areas (Queensland Centre for Intellectual and Developmental Disability, 2002). After becoming involved in a class action lawsuit, the state of North Carolina devised an integrated and coordinated care system across services for those with a dual diagnosis of intellectual disability and mental illness.

Polgar *et al* (2000) surveyed 100 programme leaders and found that the networking of mental health and disability services allowed good coordination of facilities such as health, housing, social and occupational services. Good cooperation between programme leaders allowed increased service variety and interorganisation linkage, leading to better access to care for patients. Key areas of good practice included a single point of entry and special linkages of disability services to other services.

Australia

Overall, mental health services for adults with an intellectual disability in Australia are regarded as unsatisfactory (Molony, 1993; Trollor, 2014). This is due to problems with limited psychiatric input, negative attitudes and a lack of education among professionals around the mental health needs of patients with intellectual disability (Einfeld *et al*, 2006). Mental health conditions in those with intellectual disability often go undetected because of a number of barriers, such as general practitioners being unaware of the mental health needs of this group and carers/family being unable to relay psychiatric symptoms to professionals.

Service development across Australia has been poorly coordinated and varies widely between states (Queensland Centre for Intellectual and Developmental Disability, 2002). In Victoria, the Gippsland Dual Disability Evolution Project was implemented to conceptualise and analyse a model of service delivery for adults with dual diagnosis (Chesters *et al*, 1999). Victoria also has a state-wide psychiatric service specifically for those with a dual diagnosis. In some states, such as New South Wales, there are research centres for intellectual disability that also provide general health clinics for patients. Yet several states, for example Tasmania and Western Australia, do not have any specialist services specifically for those with a dual diagnosis.

Overall, it seems there needs to be improved networking and sharing of resources between states to provide consistent service and reach as many people as possible. A report has identified that, to improve how intellectual disability services deal with patients with mental health problems, there needs to be better access to mainstream services and specialist services available when this is not possible (Bennett, 2014). A national roundtable (NSW Council for Intellectual Disability, 2013) suggested several key areas for action: making reasonable adjustments; effective communication; interagency working; and more policy developments specifically addressing the needs of people with intellectual disability.

Europe

The BIOMED-MEROPE project compared mental health services for those with intellectual disability across five European countries: Austria, England, Greece, Ireland and Spain (Holt *et al*, 2000). This comparison was carried out via a literature search as well as collecting questionnaires from and interviewing service providers in each participating country. It was found that normalisation was taking effect across all five countries, with deinstitutionalisation and integration into communities becoming more common. However, although the mental health needs of people with intellectual disability were being recognised, there was often a failure to implement recommended guidelines because of unclear policies and a lack of planning.

Mansell (2006) examined the effect of deinstitutionalisation and the quality of community services across different countries in Europe, North America and Australasia. The main finding was that community-based models led to superior outcomes for patients in comparison with institutional care. However, Mansell also identified some problems with deinstitutionalisation: for example, he was critical of a market-based approach to managing health needs, which leads to internal competition between providers and an emphasis on quantity of places available over service quality.

See Appendix 1 for a summary of international studies related to models of community mental health services.

Commissioning for the future

The Learning Disability Professional Senate, which represents the views of professional bodies, commissioners and families of people with intellectual disability in the UK, summarises the core functions of community intellectual disability health teams and recommends that these are specified while commissioning community services as follows (National Learning Disability Professional Senate, 2014).

- Improving access by providing a positive link with mainstream health services through health promotion, facilitation and liaison.
- Providing direct, specialist, therapeutic input for people with mental and behavioural needs through assessment, formulation, treatment, training, advice and coordination of care and support.
- Supporting other services to deliver person-centred care through clinical advice, signposting, training, workforce and service development.
- Crisis response role through crisis prevention, crisis management and planning in partnership with other providers and with commissioners.
- Strategic service development and quality assurance function alongside commissioners.

The Joint Commissioning Panel for Mental Health (2013), in its guidance for commissioning community services for people with intellectual disability and mental health problems, highlights several needs.

- Working alongside local primary care and acute services to ensure good access and timely support for dealing with physical health problems.
- Working alongside local mental health services to ensure good access and effective treatment and support from mainstream mental health services.
- Providing specialist therapeutic input for the assessment and management of mental illnesses, behaviour problems, autism and developmental disorders as well as offending behaviour.

After the unsuccessful attempts to reduce reliance on in-patient care as recommended by the Bubb report on Winterbourne View (Bubb, 2014), it is even more important to enhance the role of specialist community services, including the systematic development of skills regarding effective management of challenging behaviour. This report highlights the role of community-based providers and the need to systematically develop the skills of the community workforce through the creation of a national Workforce Academy.

Commissioners must accept more responsibility for their commissioning decisions, decommission inappropriate services and encourage, rather than stifle, person-centred, innovative systems of care. Personalised services need not be more expensive, but standards must be actively improved. The Bubb report (Bubb, 2014) calls for a national mandatory commissioning framework for services for people with intellectual disability.

Conclusions

Community-based services for people with intellectual disability vary widely, both regionally and internationally. Research into the effectiveness of such models is limited and the evidence base is not strong enough to determine which model provides the most effective care. Some randomised, controlled trials have provided evidence that intensive care is superior to standard care.

Studies collating the opinions of mental health professionals emphasise that care should be patient-centred, holistic, multidisciplinary and evidence based. Other research evidence suggests that there is a need for improved staff training in the assessment of those with a dual diagnosis of intellectual disability and mental illness within mainstream mental health services and also improved expertise within forensic community teams for the care of offenders with intellectual disability. It is suggested that this, coupled with strong interagency working, will ensure patients are receiving appropriate care.

Further research is required and should focus on evaluating services by results and outcomes, not by their intentions. The structure of services should be respectful of the population served, skill mix and structures of staff available (with plans to enhance and develop skills) and be determined by local needs and the geography in which the service is delivered. The requirements of a dense city population differ vastly from those of a geographically dispersed rural population.

Survey: community-based services

Method

The Faculty of Psychiatry of Intellectual Disability at the Royal College of Psychiatrists carried out a survey of members about current community intellectual disability service models in England. Data for the survey were collected over 1 month. The survey was emailed to 310 members of the Faculty who are consultant psychiatrists with the psychiatry of intellectual disability as their main specialism. There were 65 respondents and 53 complete responses: the response rate was therefore 20%.

Results

There was a good geographical dispersion of respondents from across England, with the top four areas by number of respondents being the South East, Yorkshire, West Midlands and North Central/North East London (Table 1). For the purposes of this report, the areas are referred to as the South, North, Midlands and London.

Table 1 Location of survey respondents

Region	Respondents
South East (Kent, Surrey, Sussex)	14%
West Midlands	14%
Yorkshire	12%
London (North Central and North East)	12%
North West	6%
South West	6%
Trent	6%
Eastern	6%
London (South West)	4.5%
North East	4.5%
London (North West)	3%
South East (Oxford, Buckinghamshire, Berkshire)	3%
South West (Wessex)	3%
London (South East)	1.5%
North West (Mersey)	1.5%
East Midlands	1.5%

The most common model for community intellectual disability teams was the generic community intellectual disability team (84%; Fig. 1). Next were specialist challenging behaviour services (21.5%), stand-alone mental health intellectual disability teams (16%) and neurodevelopmental disorders services (16%). The 'other' category (11%) included two intensive support teams, two integrated teams, a child and adolescent mental health team and a specialist epilepsy service. These findings suggest that mainstreaming has become a regular feature of ordinary practice. It also suggests that the majority of teams (70%) categorise themselves under one particular model. Seventeen teams had multiple functions.

The majority of services (71%) were not integrated with social care. Service integration with social care had an effect on other variables within the survey. For example, integration differed markedly by area (Table 2), with London being the only area where teams integrated with social care (69%) outnumbered those who are not (31%). This is

Table 2 Services integrated with social care by regional area

Integration with social care	London	South	North	Midlands
Integrated	69%	20%	8%	20%
Not integrated	31%	80%	92%	80%

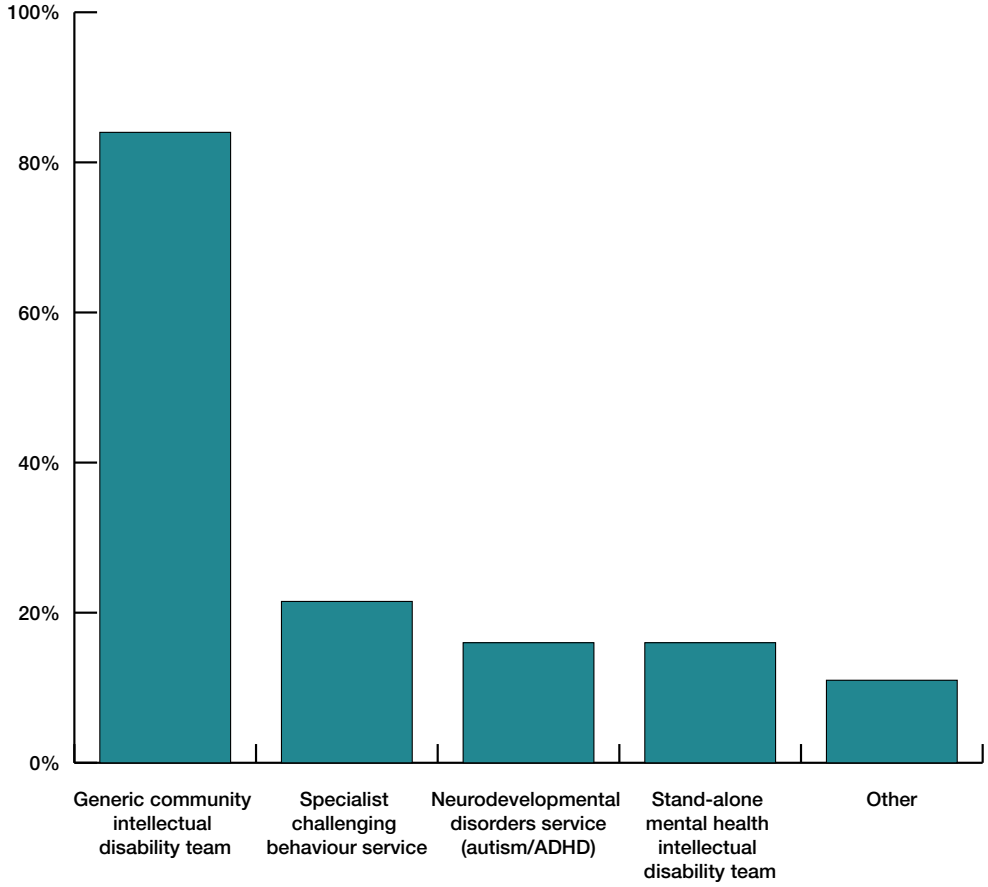


Fig. 1 Models of community intellectual disability services that respondents identified their teams as operating under (more than one answer could be selected). ADHD, attention-deficit hyperactivity disorder.

in contrast to the North, where only 8% of teams were integrated with social care. Likewise, only 20% of teams in the South and Midlands areas were integrated.

The most common intervention offered by the respondent's own team was psychological therapy (85%; Fig. 2). Acute in-patient services were also frequently part of community teams (54%). Some teams offered memory clinics (37%) and crisis intervention (31%), but assertive outreach (23%), rehabilitation (21%) and early intervention (12%) services were less frequently offered. Overall, 75% of community intellectual disability teams offered more than one type of intervention. Community intellectual disability teams integrated with social care offered a wider variety of services.

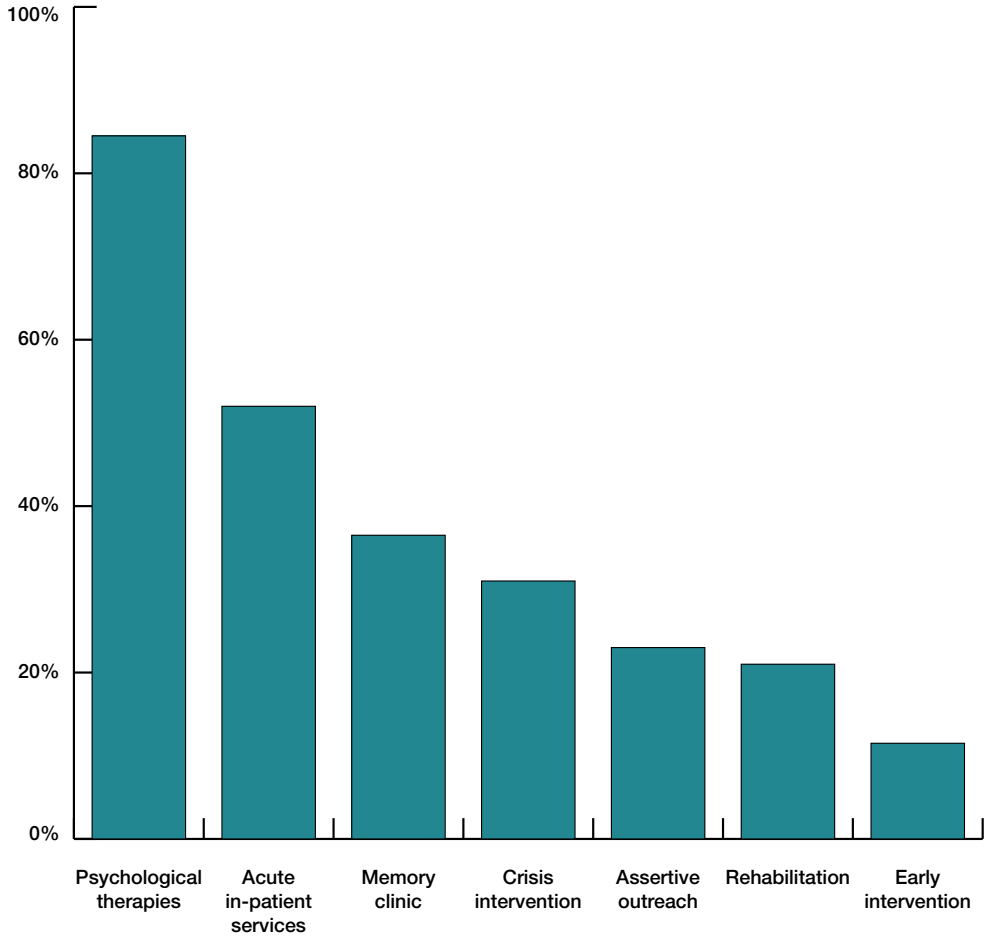


Fig. 2 Additional interventions offered by the respondent's service (more than one answer could be selected).

Table 3 Services offering mental health liaison by area

Mental health liaison status	London	South	North	Midlands
Offers a mental health liaison	85%	73%	69%	40%
Does not offer a mental health liaison	15%	27%	31%	60%

The majority of services offered liaison with mainstream mental health services (61%; Table 3). This was true of all regions except the Midlands, where the majority of services did not offer mental health liaison.

The most common types of external psychiatric services that respondents referred patients to (Fig. 3) were crisis and acute in-patient services (both 82%), followed by early intervention services (39%) and Improving Access to Psychological Therapies (34%). Respondents did not frequently refer patients to assertive outreach programmes (21.5%), assessment services (21.5%), memory clinics (19.5%) or rehabilitation services (16%).

The majority of respondents were aware of local care pathways related to mental health services for adults with intellectual disability (58%). In total, 26 respondents specified which local care pathways they were aware of: 8 respondents mentioned pathways related to joint working of mental health and intellectual disability teams; 7 respondents mentioned dementia/memory assessment pathways; 5 mentioned challenging behaviour pathways; and 1 respondent was aware of an autism pathway (Fig. 4).

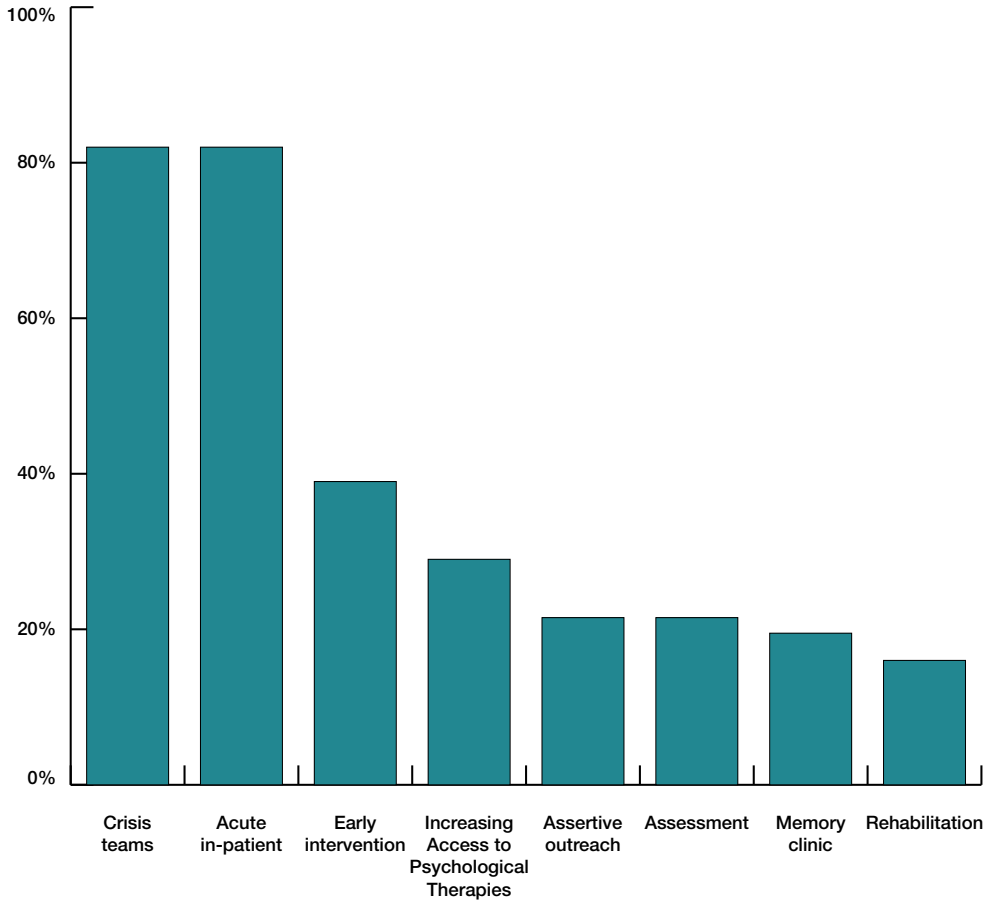


Fig. 3 External psychiatric services used (more than one answer could be selected).

The majority of community intellectual disability teams implemented outcome measures in routine practice (66%). The most commonly used tools were:

- HoNOS-LD (Roy *et al*, 2002) – 78%
- Aberrant Behaviour Checklist (Aman *et al*, 1985) – 27%
- Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss *et al*, 1996) – 16%
- Early Detection of Dementia in Adults with Learning Disabilities (Eurlings *et al*, 2006) – 5%
- Assessments of Motor and Processing Skills (www.innovativeotsolutions.com/content/amps) – 3%.

The majority of respondents were not aware of any plans for commissioning or decommissioning services in their local area (76%). For those who were aware of such plans, they most frequently reported the closure of in-patient beds/services (56%). This was often reported to be coupled with the commissioning of intensive, community support services in compensation. Setting up accommodation/housing for people with intellectual disability was also mentioned.

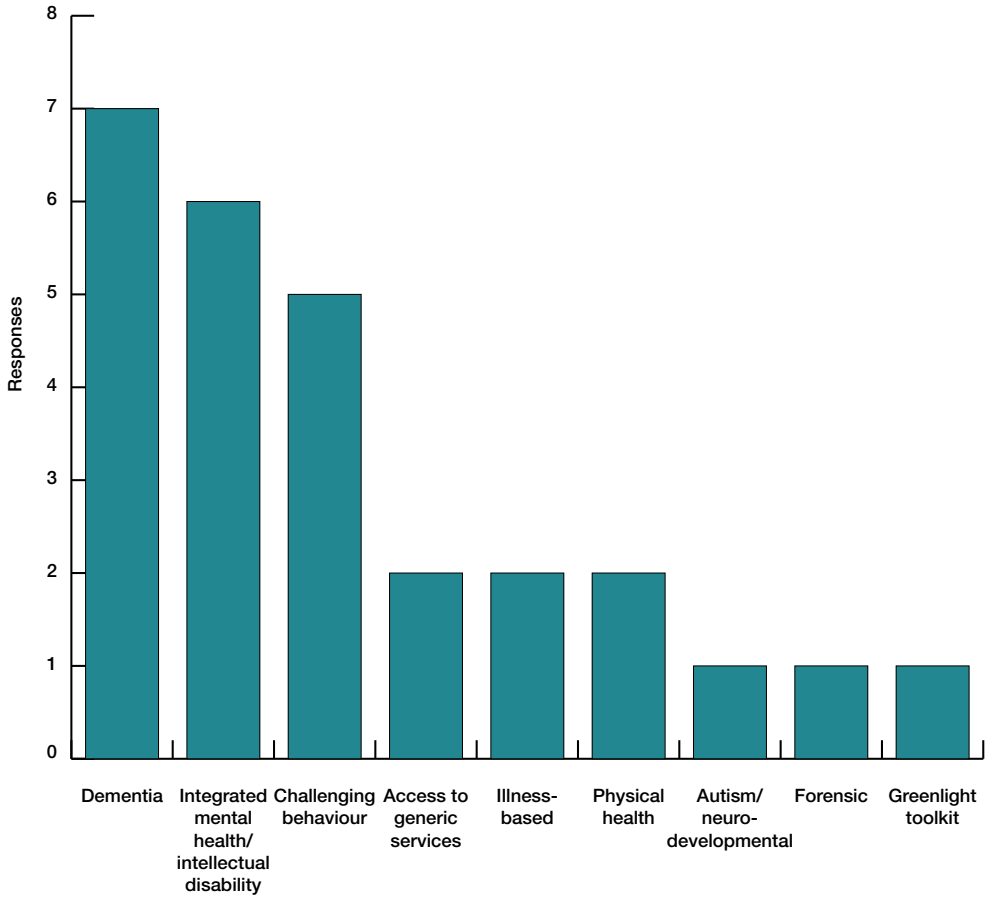


Fig. 4 Local care pathways that respondents worked within or were aware of.

A variety of opinions were offered in this survey regarding the service developments respondents felt would be important for their local area:

- increasing numbers of intensive support teams and greater integration
- increased access to mainstream mental health services and growing awareness of intellectual disability within these services
- developing more robust community services and assertive outreach services to meet the needs arising from decommissioning of in-patient services.

Discussion

This survey was limited because of a low response rate and its limited geographic coverage, making the findings difficult to generalise. It did not take into account services where more than one consultant worked in a community team. This could be overcome by a more systematic trust-by-trust survey, which would provide a more accurate picture of community services.

There was considerable variation in the level of mental health liaison provided by intellectual disability services. Similarly, there were differing levels of integration with the local authority Social Services depending on the geographic region. There was evidence of the use of care pathways, especially in the area of dementia, mental illness and challenging behaviour. Acute in-patient services and crisis teams were frequently used by community teams in the sample. The in-patient services were frequently provided by intellectual disability services rather than mainstream mental health services.

Community intellectual disability services are key in supporting people with intellectual disability in their homes and local communities. However, they need to be more outcomes-focused and commissioning should encourage this approach. Commissioners and providers need to work in partnership to create local community-based services that are personalised, effective and safe. More research is needed into the effective components of community intellectual disability service models and care pathways for adults with mental health, behavioural and forensic problems in reducing the use of in-patient services.

Appendix 1. Literature review

Table A1 International studies of models of mental health services for people with intellectual disability			
Study	Population (area)	What they did	What they found
Torrey (1993)	6 case studies of people with an ID and mental health condition	Discusses how to treat people with an ID and a mental health condition in the community	Professionals should focus on the clinical needs of patients and try to reduce administrative barriers.
Holt *et al* (2000)	Service providers across 5 countries (Austria, England, Greece, Ireland and Spain)	Carried out a literature review as well as collected data from questionnaires and interviews with service providers	Mental health needs of those with ID were not addressed on a national level, except in England and Ireland. However, there were still gaps in these countries' services. Normalisation has taken effect across all the countries. Policy tends to separate disability and mental health, rendering the full service needs of this group invisible.
Polgar *et al* (2000)	100 program leaders of the Thomas S class service (North Carolina, USA)	Conducted a survey about a coordinated care system for those with a dual diagnosis	Single entry point improved accessibility. Linkages of mental health and disability services allowed better coordination of health, housing, social and occupational services offered. Cooperation of program leaders led to increased service variety and interorganisation linkage.
Hackerman *et al* (2006)	210 patients at special needs clinic that provides comprehensive treatment for people with intellectual disability and a psychiatric illness (Baltimore, USA)	Reports on the clinical characteristic and service utilisation of patients using the clinic	Factors supporting a good service include professionals having expertise with patient's condition, good relationship with other disability and mental health services, and good understanding of targeted behaviours.
Mansell (2006)		Identifies problems of deinstitutionalisation and current community service models for people with intellectual disability	Changes required: improving quality of life of patients and allowing staff to provide more facilitative support, especially for patients with more complex needs.

Table A2 UK studies of models of mental health services for people with intellectual disability

Study	Population (area)	What they did	What they found
Cambridge *et al* (2005)	275 people with intellectual disabilty and 125 people with a mental health condition (Kent)	12-year, longitudinal study looking at the community care of patients who had previously been admitted to hospital	Found many services became fragmented. Supports community care modes of integrative services and a person-centred approach.
Hall *et al* (2006b)	37 participants: 19 in in-patient care, 18 in community care (London)	Assessment of an integrative mental health service model; participants were assessed across three time-points for outcomes such as symptoms, risk, needs met and level of functioning	Significant improvements in outcome measures were seen for participants. Supports mainstream services working across health and Social Service boundaries.
Chaplin *et al* (2008)		Description of Mental Health in Learning Disabilities (MHiLD) services in four South London boroughs	MHiLD provides specialist mental health care for 600–800 people with intellectual disability in the London area. MHiLD works across several interfaces including adult mental health services, community intellectual disability teams, the independent sector, Social Services and local authorities to provide optimal care.
Slevin *et al* (2008)		Literature review of community intellectual disability teams	Lack of evidence-based literature. The teams are not efficient enough to meet the mental health needs of patients.
Chaplin *et al* (2009)		Evaluates care given to people with intellectual disability and a mental health condition	Mainstream mental health services are not good enough for people with intellectual disability. Commissioners must work with staff/professionals to improve services.
Hemmings *et al* (2009)	49 multidisciplinary professionals: 29 psychiatrists, 12 nurses, 5 psychologists, 1 operational manager, 1 social worker, 1 occupational therapist (UK)	Used the Delphi method (a series of questionnaires), which allowed consensus on important components for community services for adults with psychosis and intellectual disability	Most important service provisions were a need for focused approach to the patient and their illness (e.g. monitoring mental state, monitoring medication, access to crisis plan, out-of-hours support, care coordinators, risk assessment/management, care programme approach) and the need to work within the wider context of the patient (make sure they are engaged with recreational activities, have appropriate housing, adequate advice/ support for patient and carers/families).
Fear *et al* (2012)	Interviews of patients, carers, commissioners and politicians (Gloucester)	Described a person-centred and non-discriminatory model of mental health service that allows services to be accessed via a single access point and for patients to be treated based on their needs rather than circumstances	No results but hope that model will lead to an improved service for those with intellectual disability.

Table A2 *cont'd*

Study	Population (area)	What they did	What they found
Hemmings & Al-Sheikh (2013)	14 professionals: 4 psychiatrists, 4 nurses, 3 psychologists, 2 social workers and 1 occupational therapist (UK)	Semi-structured interviews about important service components of community services for adults with intellectual disability and a mental health condition	Important components identified included clarity of purpose, training in assessment of dual diagnosis, person-centred services, holistic, multidisciplinary and evidence-based service and flexible delivery. Also, clearer care pathways and improved joint working with mainstream services. Interviewees also expressed a desire for increased resources for services but admitted that this might not be financially viable.
Bouras & Holt (2004)		Review of evidence base of mental health care for people with intellectual disability	Evidence base is inconsistent and inconclusive. Supports tertiary services as the way forward.

Table A3 Models of specialist services for aggression/challenging behaviour

Study	Population	What they did	What they found
Naylor & Clifton (1993)	–	Literature review of challenging behaviour in people with intellectual disability. Aims: • define challenging behaviour • identify therapeutic intervention • identify models of service • identify implications of developing a skilled workforce to deal with challenging behaviour	Definitions of challenging behaviour vary. People with a dual diagnosis are at risk of losing provisions from both intellectual disability and mental health services. Professional tension regarding therapeutic response and service models must be resolved in order to provide appropriate service.
Lowe *et al* (1996)	30 individuals with challenging behaviour and referred to a specialist service; 21 individuals with challenging behaviour but not referred to a specialist service	Compared outcomes for patients treated at two different specialist community services for people with intellectual disability and challenging behaviour over a 3-year period	Patients treated in service A had significantly reduced behavioural problems, improved mental health, gained adaptive behaviours and enhanced quality of life in comparison to service B. Service A differed in that the staff had more prior experience of working with ID. The team members had clear delineated roles and there was a single referral point. Service B was underfunded while service A had a ring-fenced budget.
Martin *et al* (2005)	27 patients with mild–moderate intellectual disability and a mental health condition	Randomised, controlled trial comparing assertive outreach treatment with standard community care	No significant differences between unmet needs, carer burden, functioning and quality of life. Borderline difference for quality of life favouring standard treatment.

Table A3 *cont'd*

Study	Population	What they did	What they found
McClean *et al* (2007)	5 individuals with mild to severe intellectual disability and long-standing challenging behaviour	Monitored five outcomes (behaviour, medication, quality of life, psychiatric symptoms and costs) for the individuals receiving positive behavioural support in their community over 2 years	Significant reductions in challenging behaviour and improved outcomes were seen in all patients over 2-year period. Challenging behaviour reduced to near zero levels, use of medication dropped by 66% and there was a significant improvement in quality of life for 3 in 5 patients.
Hemmings *et al* (2008)	21 staff who provide assertive community treatment (ACT) to patients with intellectual disability	Conducted in-depth structured interviews on staff agreement on statements made about ACT	Agreement that service should be delivered in the community and involve the patient's support network. Patients and carers should have involvement in service development, support roles and feedback.
Lehrer & Ott (2009)	38 patients referred to specialty clinic after challenging behaviour could not be resolved in community	Measured challenging behaviour by the Aberrant Behaviour Checklist at initial assessment and then at 6-month follow-up	Interdisciplinary evaluation and treatment resulted in reduction in challenging behaviour. Families also said the patients' quality of life improved and they became more involved in community.
Oliver *et al* (2005)	30 patients recruited over 25 months; inclusion criteria: moderate–mild intellectual disability, a serious mental health condition and challenging behaviour	Randomised, controlled trial comparing assertive outreach treatment to standard community care	No significant differences on outcomes such as functioning, carer burden and quality of life. In practice, there was a blurring of standard and assertive practice.
McKenzie et al (2009)	4 individuals with an intellectual disability and challenging behaviour	1-year community-based project in which psychology graduates supported patients with challenging behaviour in their own homes	On average challenging behaviour decreased over time and it was a positive experience for staff and patients. But the sample size was very small, so further research is needed.
Allen (1999)	14 patients who had experienced placement breakdown and admitted to hospital or institutional care and 33 patients who had been successfully maintained in the community. All patients were being treated by intensive support services.	Natural observational study over 6-year period monitoring personal characteristics, support service characteristics and type of specialist support received	No behavioural or psychiatric differences between groups. The group who experienced breakdown were less likely to receive intensive support services input and were more likely to come from services with a lack of internal organisation and optimal resource utilisation.

Appendix 2. Survey questions

1 Please indicate within which region your service is located.

- London North Central and North East
- London North West
- London South East
- London South West
- North East
- Yorkshire
- North West
- North West (Mersey)
- South East (Kent, Surrey, Sussex)
- South East (Oxford, Buckinghamshire, Berkshire)
- South West
- South West (Wessex)
- Trent
- Eastern
- West Midlands
- Other (please specify)

2 What model of community intellectual disability service do you offer? (Please tick all that apply.)

- Generic community intellectual disability team
- Neurodevelopmental disorders service (autism/ADHD)
- Stand-alone health intellectual disability team
- Specialist challenging behaviour service
- Other (please specify)

3 Is your service integrated with social care?

- Yes
- No

4 Please tick any other psychiatric services that you use. (Please tick all that apply.)

- Crisis teams
- Assertive outreach
- Acute in-patient services

- Rehabilitation services
- Early intervention
- Assessment service
- Increasing Access to Psychological Therapies (IAPT)
- Memory clinic

5 Please indicate which of these (if any) are also provided by your intellectual disability service (tick all that apply)

- Crisis teams
- Assertive outreach
- Acute in-patient services
- Rehabilitation services
- Early intervention
- Assessment service
- Improving Access to Psychological Therapies (IAPT)
- Memory clinic

6 Does your service offer a mental health liaison (that is support to generic mental health services) in cases of patients treated by such services?

- Yes
- No

7 In your area, do you work under or are you aware of any local care pathways for adults with an intellectual disability and mental health disorder?

- Yes
- No

8 If yes, please describe the pathway (or you can send reports or documents to IDproject@rcpsych.ac.uk)

9 Do you regularly implement any outcome measures in your daily practice?

- Yes
- No

10 If yes, what are they? (tick all that apply)

- ABC
- HoNOS-LD
- SF-36
- GAF
- PAS-ADD
- TAG
- CANDID
- Other (please specify)

11 Are you aware of any plans for commissioning new services for adults with an intellectual disability and mental health disorder in your local area?

- Yes
- No

12 Are you aware of any plans for decommissioning services for adults with an intellectual disability and mental health disorder in your area?

- Yes
- No

13 If yes, please give details (or you can send reports or documents to IDproject@rcpsych.ac.uk)

14 Who is the lead commissioner of intellectual disability in your area?

- CCG
- Local authority
- Joint commissioning
- NHS England
- Other

15 Which outcomes and/or service developments do you think are important for community mental health services for adults with an intellectual disability in your area?

16 We are interested in any research projects and service evaluations that are being carried out on models of care for mental health services for those with an intellectual disability. Have you carried out or been involved in any such research or evaluation? If yes, any reports or documents can be sent to IDproject@rcpsych.ac.uk and would be greatly appreciated.

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Local Government Association

directors of adass adult social services

NHS England

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition





Service model for commissioners of health and social care services

October 2015

Contents

Introduction	**4**
About this document	**5**
Who this service model is about	**8**
Good services for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition	**10**
Annex A – terminology	**30**
Annex B – common needs and common shifts in service response	**33**
Annex C – understanding the local population	**38**
Annex D – reference group membership	**39**

Introduction

Service model vision statement

Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition* have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life.

"The success in this lies not within systems and processes but within human connections, commitments, accountability and sustainable relationships that are non-adversarial."

Commissioner

The principles which underpin this service model build on what have been described before, including in Valuing People and Valuing People Now, all of which focus on rights, independence, choice and inclusion for people with a learning disability and/or autism.

Good practice guidance around the commissioning of services for people with a learning disability and/or autism who display behaviour that challenges, including the 1993 and 2007 Mansell reports, describe the need to develop high quality local services that understand and support people, and reduce the reliance on out-of-area placements. They focus on ensuring the best outcomes for people by working in partnership with individuals and families/carers and through adopting person-centred approaches – vital to delivering independence and control for people and ensuring that the person's wishes and aspirations for their own life are at the centre of their care and support arrangements.

There has been a renewed commitment to transforming the way in which care and support is delivered to people with a learning disability and/or autism who display behaviour that challenges. In line with the provisions of the Children and Families Act and the Care Act, which focus on outcomes, personalisation and wellbeing, this commitment focuses on strengthening support in the community by building on the provision of preventative support that will avoid crises and help support people to be active members of their communities, with all the benefits that brings.

This service model brings together the current good practice taking place in local areas, and that which has previously been described for this group of people. It recognises that improvements are typically underpinned by visionary leadership, a focus on human rights based approaches, workforce development, co-production and a preparedness to reflect and learn. It aims to support commissioners across health and social care to work together to commission the range of services and support required to meet the needs of this diverse group.

* Hereafter people with a learning disability and/or autism

About this document

Since the investigation into the abuse at Winterbourne View and other similar hospitals[1], there has been a cross-government commitment to transform care and support for people with a learning disability and/or autism who display behaviour that challenges, including behaviour that can lead to contact with the criminal justice system. This is focused on building up community capacity and reducing inappropriate hospital admissions.

Services will not look the same all over the country. Each local area is different: local populations have different needs, and their range of providers have different strengths and weaknesses. Each local area will therefore need to draw up its own model for how services should look in future, based on an agreed service model.

However, there will be some national consistency in what services should look like across local areas, based on established best practice. This document seeks to describe that national consistency, while giving commissioners the flexibility to design services that best fit the needs of their local population. It sets out to provide clarity on 'what good looks like' for health, social care and housing services for people with a learning disability and/or autism.

Who this service model is for

This service model is for all health and social care commissioners – not just learning disability commissioners; in particular, this includes mental health commissioners, Continuing Health Care (CHC) commissioners, public health and children's commissioners. It covers the full range of commissioning – strategic, operational and individual/micro commissioning.

Different types of commissioning



[1] 'Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism, or the equivalent organisations in Wales and Scotland for English commissioned patients.

Commissioners should ensure that plans impacting on people of all ages with a learning disability and/or autism align with related initiatives, and identify opportunities for joint working. This should include commissioners seeking to align these plans with the development of their Local Transformation Plans for Children and Young People's Health and Wellbeing, local action plans under the Mental Health Crisis Concordat and the 'local offer' for personal health budgets.

Scope of the service model

This service model focuses on services and packages of care and support funded by the NHS and local government, as well as NHS/local government interfaces with other services (e.g. education), but not those services funded by other public sector agencies themselves (e.g. schools).

This does not mean, however, that other public services and organisations do not also need to review and improve the way they support and provide services for children, young people and adults with a learning disability and/or autism. It is essential that links across all local system partners are established both to ensure a joined-up and effective approach to supporting people, with clearly identified care and support pathways, and to maximise opportunities for sharing knowledge, skills and support across agencies and systems. This is in line with existing NICE guidelines (see below) on challenging behaviour and learning disabilities which recommends the need for leadership teams across health, social care and education to develop care pathways for people including transitions between and within services.

How the service model was developed

A reference group[2] was set up to provide expert advice on the development of the model, bringing together a range of stakeholders. In addition, six 'fast-track' areas[3] used a draft version of the service model as they developed plans to transform services for people with a learning disability and/or autism over the summer of 2015 and provided feedback. Through a process of engagement, NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS), sought the views of clinicians, commissioners, providers, families and people with a learning disability and/or autism.

This service model is intended for a particular juncture in the transformation of services for people with a learning disability and/or autism. It builds on existing NICE guidance (such as that on challenging behaviour and learning disabilities and that on autism and will be superseded as good practice develops and in particular once NICE service model guidance is published in 2017.

We do not expect the services and support described here to be put in place over night, but we do expect all areas to implement this service model over the next three years.

[2] See Annex D for reference group membership.
[3] The 'fast-track' areas are Greater Manchester; Lancashire; Cumbria and the North East; Arden, Herefordshire and Worcestershire; Nottinghamshire; and Hertfordshire.

The transforming care programme

The service model forms part of a national plan to support commissioners across the country to formulate joint transformation plans. This in turn is part of a much broader programme of work led by the Department of Health, NHS England, the LGA, ADASS, the Care Quality Commission (CQC), and Health Education England (HEE) to transform services.

The national plan describes in further detail the mechanisms for achieving transformation, including the financial underpinnings and commissioning arrangements, which are key to delivering on the vision outlined in this service model. Other aspects of the wider transforming care programme will also support its delivery, including the development of effective assurance metrics; robust inspection/ regulation; and development of the workforce.

Who this service model is about

Who this is about[4]

This service model is about those people with a learning disability and/or autism who display behaviour that challenges, including behaviour which is attributable to a mental health condition[5].

This includes people of all ages and those with autism[6] (including Asperger syndrome) who do not also have a learning disability (as well as those who have both a learning disability and autism), and includes those people with a learning disability and/or autism whose behaviour can lead to contact with the criminal justice system.[7]

Services to meet diverse and complex needs

This is an extremely diverse group of people and the support they require will be highly individualised - tailored to their particular needs, strengths, interests and in some cases the risks they pose to others (all of which might change over time).

However, there are some common needs that services in any one local area need to ensure they have the capacity to address. There are also some common deficiencies in how services currently address those needs in the community, with the result that, too often, people may end up in hospital (including through diversion from the criminal justice system) at great human cost to themselves and their families/carers[8], and when those circumstances could have been avoided. There are therefore, also some common shifts that services will often need to make.

[4] For simplicity, henceforth when we refer to 'everyone' or people in this document, we are referring to this defined group of people (children, young people and adults) unless otherwise stated and when we refer to people with learning disabilities and/or autism, we are referring to people with learning disabilities and/ or autism who display behaviour that challenges, including those with a mental health condition.

[5] See Annex A for definitions: behaviour that challenges, learning disability and autism.

[6] Throughout this document we use the term 'autism' as an umbrella term for all Autistic Spectrum Conditions, including Asperger Syndrome.

[7] A small percentage of people with a learning disability and/or autism engage in behaviour that may lead to contact with the criminal justice system, and potentially diversion to a hospital setting. They are included as a distinct group within this service model because their specific needs have not always been recognised; the model presents an opportunity to develop the support and services they may require.

[8] In this document we use the term 'carer' to mean those people who provide unpaid support to someone. This is often a family member, but not always. We refer to people who provide paid support as 'paid support and care staff'.

The following groupings help to illustrate some common needs amongst the diversity of the population that this service model is about:

- Children, young people or adults with a learning disability and/or autism who have a mental health condition such as severe anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
- Children, young people or adults with an (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to severe mental ill health, some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.
- Children, young people or adults with a learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).
- Children, young people or adults with a learning disability and/or autism, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family backgrounds) who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.
- Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in hospital settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.

This is not an exhaustive list. These groupings cannot cover the complexities of every individual, nor all the causes of certain behaviours. Individuals do not 'slot neatly' into any single grouping – they overlap, people's needs change over time, and often a large part of the challenge for local services will be to understand what combination of factors lies behind an individual's behaviour.

These groupings are a means of demonstrating the range and complexity of the group described within the service model and some common themes and needs that will require consideration by commissioners. Annex B provides further detail on these common needs and the common shifts in service responses that are required.

Good services for people with a learning disability and/or autism

This section describes what good services and support look like for people with a learning disability and/or autism who display behaviour that challenges, including behaviours which may result in contact with the criminal justice system.

It is structured around **nine core principles** that are stated from the perspective of the reasonable expectations of someone who might use such services. Additional supplementary information for commissioners has been published alongside this to provide further detail on each aspect of the model outlined.

The human rights of people who use services are incontrovertible and must be upheld at all times; consequently there are a number of **'golden threads'** that run consistently through the nine principles described and which should therefore be reflected in local commissioning strategies:

- **Quality of life** – people should be treated with dignity and respect. Care and support should be personalised, enabling the person to achieve their hopes, goals and aspirations; it should be about maximising the person's quality of life regardless of the nature of their behaviours that challenge. There should be a focus on supporting people to live in their own homes within the community, supported by local services.
- **Keeping people safe** – people should be supported to take positive risks whilst ensuring that they are protected from potential harm, remembering that abuse and neglect can take place in a range of different environments and settings. There should be a culture of transparent and open reporting, ensuring lessons are learned and acted upon.
- **Choice and control** – people should have choice and control over their own health and care services; it is they who should make decisions about every aspect of their life. There is a need to 'shift the balance of power' away from more paternalistic services which are 'doing to' rather than 'working with' people, to a recognition that individuals, their families and carers are experts in their own lives and are able to make informed decisions about the support they receive. Any decisions about care and support should be in line with the Mental Capacity Act. People should be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interests involving them as much as possible and those who know them well.
- **Support and interventions** should always be provided in the least restrictive manner. Where an individual needs to be restrained in any way – either for their own protection or the protection of others, restrictive interventions should be for the shortest time possible and using the least restrictive means possible, in line with Positive and Proactive Care.

- **Equitable outcomes**, comparable with the general population, by addressing the determinants of health inequalities outlined in the Health Equalities Framework. The starting point should be for mainstream services, which are expected to be available to all individuals, to support people with a learning disability and/or autism, making reasonable adjustments where necessary, in line with Equality Act legislation, with access to specialist multi-disciplinary community based health and social care expertise as appropriate.

The vision described in this service model

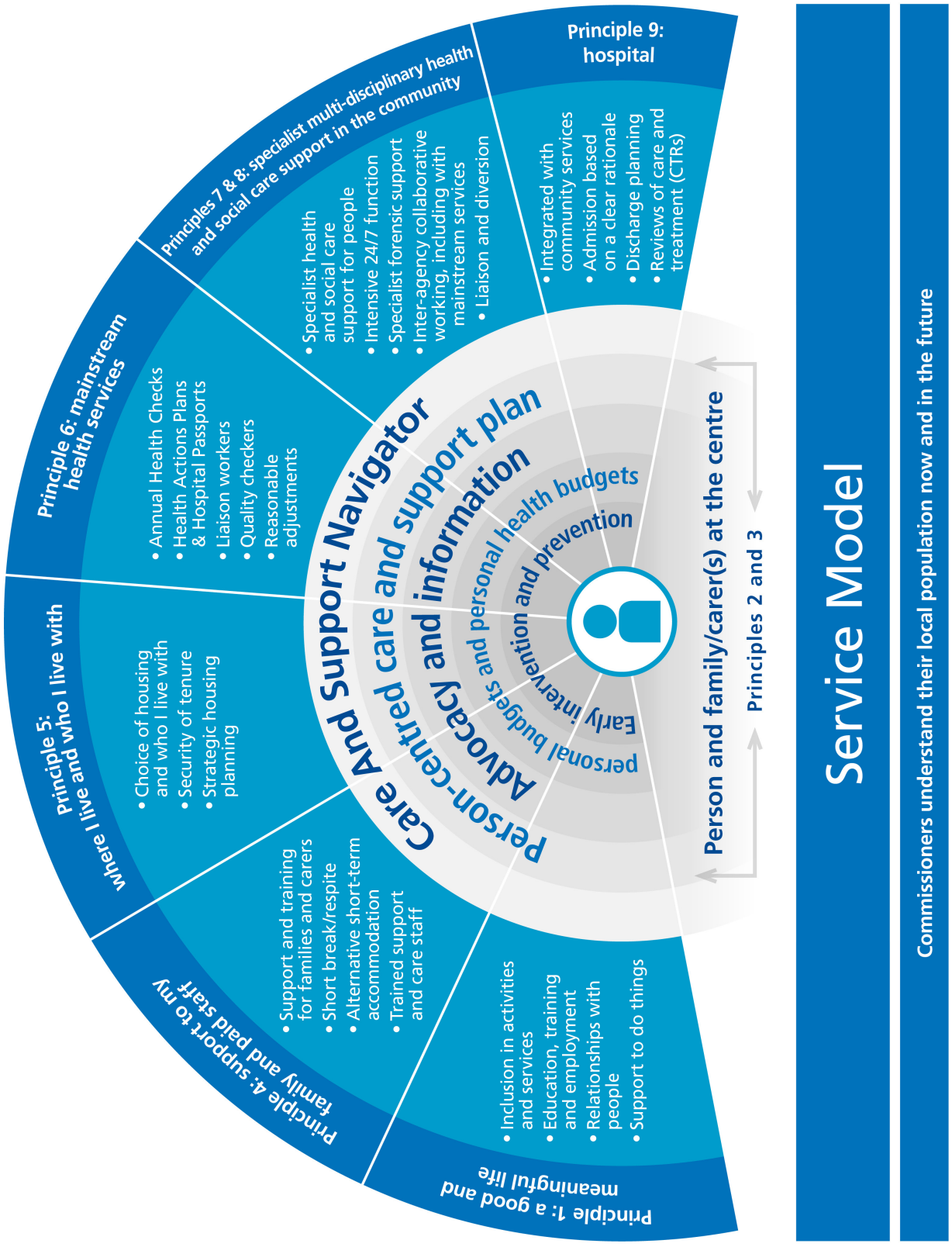
A whole-system response is the key to delivering high quality services and support for people. For this to be a reality, services need to demonstrate a strong commitment to a shared value base which places individuals and their quality of life at the heart of all they do. This value base should reflect the 'golden threads' and be evident on the basis of the capable environments[9] within which care and support is delivered. Capable environments are characterised by: positive social interactions, support for meaningful activity, opportunities for choice, encouragement of greater independence, support to establish and maintain relationships and mindful and skilled family/carers and paid support and care staff.

The service model describes a range of services and supports that should be in place within any local area. Depending on their needs and circumstances, people with a learning disability and/or autism and their families/carers should be able to draw upon the support described in the model in a way that is right for them. They should also be supported to navigate their way through an often complex and anxiety provoking system.

Just as people's situations and experiences vary (for example, some may have a long history of behaviour that challenges, whilst others may develop such behaviours as a result of transient physical or mental health problems), they will become known to different local services in different ways and at different points in their lives. What works and is needed for each individual will look different, and not all aspects of the service model will apply, or be required by everyone.

However, the starting point for everyone should be about **access to support that is based on individual need**, through establishing an understanding of the factors, both historic and current, that have contributed to the individual's behaviour. Care and support should then be delivered with the aim of improving the person's quality of life. In order for this to be successful, it will require **multi-disciplinary** and **multi-agency** working, as well as skilled informed responses from specialist health and social care services, in partnership with the person and those who provide day-to-day support.

[9] See: http://www.kcl.ac.uk/sspp/policy-institute/scwru/news/2014/newsfolder/McGill-et-al-Capable-environments.pdf


Service Model
Commissioners understand their local population now and in the future
Person and family/carer(s) at the centre
Principles 2 and 3
Care And Support Navigator
Person-centred care and support plan
Advocacy and information
personal budgets and personal health budgets
Early intervention and prevention
Principle 1: a good and meaningful life
• Inclusion in activities and services
• Education, training and employment
• Relationships with people
• Support to do things
Principle 4: support to my family and paid staff
• Support and training for families and carers
• Short break/respite
• Alternative short-term accommodation
• Trained support and care staff
Principle 5: Where I live and who I live with
• Choice of housing and who I live with
• Security of tenure
• Strategic housing planning
Principle 6: mainstream health services
• Annual Health Checks
• Health Actions Plans & Hospital Passports
• Liaison workers
• Quality checkers
• Reasonable adjustments
Principles 7 & 8: specialist multi-disciplinary health and social care support in the community
• Specialist health and social care support for people
• Intensive 24/7 function
• Specialist forensic support
• Inter-agency collaborative working, including with mainstream services
• Liaison and diversion
Principle 9: hospital
• Integrated with community services
• Admission based on a clear rationale
• Discharge planning
• Reviews of care and treatment (CTRs)

1. I have a good and meaningful everyday life.

> "When I move to my flat, the most important thing is friends."
> "It's all about relationships – with my friends, my family and my staff."
> **Individuals with a learning disability in a secure hospital**

1.1 Children, young people and adults with a learning disability and/or autism[10], should be included in **activities and services (such as early years services, education, employment, social and sports/leisure) that enable them to lead a good and meaningful everyday life**. They should have choice and control over the activities in which they participate, facilitated through person-centred care and support plans/ Education, Health and Care (EHC) plans and personal budgets/personal health budgets (see principles 2 and 3) – any restrictions imposed (Ministry of Justice/MAPPA)[11] will need to be considered but should not adversely affect the individual experiencing, where possible and under appropriate supervision, a fulfilling and meaningful life.

1.2 Everyone should have access to **education, training and employment (including supported internships)** which they can access within their local area. To enable this, support providers and specialist multi-disciplinary health and social care teams (see principle 7) should provide training and support to mainstream service staff and/or provide support to individuals and their families/carers that enables them to participate in mainstream services, and to access education and training within local schools and colleges. Commissioners should also seek to ensure that supported employment/ training services meet the needs of this group.

1.3 Everyone should have the opportunity to **develop and maintain good relationships** with people. Commissioners should be mindful of the importance of relationships to keep people safe and well, and should therefore seek to offer good support to families/ carers, friends and others (see principle 4). This should form a key part of people's person-centred care and support plans (see principle 2).

Key actions for health and social care commissioners:

- Strategic learning disability commissioners should work with those that commission and manage mainstream activities/services to find ways to make them accessible, in line with Equality Act duties.
- Operational commissioners will need to work with mainstream services to enable people with a learning disability and/or autism who display behaviour that challenges to be included.
- Local authorities should commission supported employment services that can meet the needs of this group.
- Commissioners should ensure that service specifications are based on person-centred outcomes.

[10] For simplicity, henceforth when we refer to 'everyone' or 'people' in this document, we are referring to this defined group of people (children, young people and adults) with a learning disability and/or autism. Unless otherwise stated.
[11] Multi agency public protection arrangements

2. My care and support is person-centred, planned, proactive and coordinated.

> "We know about person-centred planning. Now we want to see the person-centred doing."
>
> **Family carer**

2.1 Local health and care services should develop a **dynamic register** based on sophisticated risk stratification of their local populations. This will enable local services to anticipate and meet the needs of those people with a learning disability and/or autism who display behaviour that challenges, or who are at risk of developing behaviour that challenges, ensuring local services plan appropriately and provide early interventions, including preventative support.

2.2 Everyone should have a **single person centred care and support plan**, incorporating a range of other plans, including behaviour support plans where appropriate, as well as crisis and contingency plans, which they have been involved in drawing up and which they have a copy of. Plans should focus on what is important to the individual. For children and young people up to the age of 25 with a special educational need (SEN), this should take the form of an Education, Health and Care (EHC) plan.

2.3 Everyone should be offered a named **local care and support navigator or keyworker** to coordinate and ensure timely delivery of a wide range of services set out in the person centred care and support plan, working closely with the person and their families/carers where appropriate and ensuring a consistent point of contact.

Key actions for health and social care commissioners:

- Strategic learning disability commissioners should risk stratify their local population of people with a learning disability and/or autism. See Annex C.
- Micro-commissioners should ensure that the person they are supporting has a single person-centred care and support plan, not just those on the Care Programme Approach (CPA).
- Commissioners should ensure that everyone is offered a local care and support navigator or key worker.
- Commissioners should ensure a multi-disciplinary approach to EHC plans, not leaving this only to education.

Relevant guidance and standards:

- NHS England guidance on personalised care and support planning.
- Think Local Act Personal (TLAP) guidance on personalised care and support planning.
- National Institute for Health and Care Excellence (NICE) guidance on challenging behaviour and learning disabilities, section on understanding the risks of developing behaviour that challenges.
- Preparing for adulthood programme, including information and guidance on EHC plans.

3. I have choice and control over how my health and care needs are met.

> "My advocate spoke for me after I told her what I wanted to say. I didn't have the courage to speak myself [in review meeting]."
>
> **Individual with a learning disability**

3.1 Everyone should receive information about their care and support in formats that they can understand and should receive appropriate support to help them communicate, in keeping with the new Accessible Information Standard.

3.2 Individuals, and where appropriate families/carers, should be integral partners in care and support planning discussions (see principle 2). Even where people lack capacity to make specific decisions, they should be involved in care and support planning discussions wherever possible and any decisions taken on their behalf should be made in their best interests. These discussions and the final plan should be person-centred and focused on what is important to the individual. Increasingly, people should expect to be offered a **personal budget, personal health budget, or integrated personal budget** across health and social care, and should have access to information advice and support to help them understand the choices available to them, exercise these choices and to help them plan how to use and manage their budget. Many will already have a right by law to personal budgets or personal health budgets, but commissioners should be rapidly and ambitiously extending this offer beyond rights guaranteed in law.

3.3 At key points in their interaction with health, education and care services, people should have access to different types of **independent advocacy**. In addition to the legal right to advocacy, people should also be offered non-statutory advocacy, which should be available to them either at key transition points and/or for as long as they require at other times in their lives. This will include in preparation for and on leaving a specialist hospital. Both statutory and non-statutory advocacy should be delivered by services that are independent of the organisations providing the person's care and support.

Key actions for health and social care commissioners:

- Commissioners should be planning for, and delivering the offer of, personal budgets, personal health budgets and integrated personal budgets beyond rights guaranteed in law.
- By April 2016, every CCG will be expected to have a 'local offer' for how to expand the use of personal health budgets; this must include people with a learning disability.
- Commissioners should work with the local voluntary sector to consider what additional or different local services are needed to ensure that people with personal budgets have a range of services to choose from.

- Commissioners should be extending the offer of advocacy through investment in non-statutory advocacy services and should ensure statutory and non-statutory advocacy is available to people who are leaving a hospital setting.
- Commissioners should ensure that advocacy services are independent and provided separately from care and support providers

Relevant guidance and standards:

- NHS England's Accessible Information Standard.
- NHS planning guidance, section on Personal Health Budgets : Forward view into action: Planning for 2015/16.
- NHS England's Personal Health Budgets Right to Have guidance.
- Think Local Act Personal (TLAP) guide to personal health budgets for people with learning disabilities.

4. My family and paid support and care staff get the help they need to support me to live in the community.

> "It is paramount that families get support especially when their child has complex needs. Support rarely arrives until there is a crisis…by which time it's too late to remedy."
>
> **Family carer**

4.1 All families or carers who are providing care and support for people who display behaviour that challenges should be offered **practical and emotional support** and access to **early intervention programmes**, including evidence-based parent training programmes, and other skills training, in line with NICE guidance and which is targeted to meet their specific strengths, challenges and needs.

4.2 All families or carers who are providing care and support for people who display behaviour that challenges should be offered information about **carers' assessment and advocacy support** in their own right, **access to short breaks/respite** suitable for people whose behaviour challenges and which meets their own needs, and support to care for the person from specialist multi-disciplinary health and social care teams (see principle 7).

4.3 **Alternative short term accommodation** (available for a few weeks) should be available to people, as and when it is needed, to be used in times of crisis or potential crisis as a place where they can go for a short period, preventing an avoidable admission into a hospital setting. It might also provide a setting for assessment from teams providing intensive multi-disciplinary health and care support (see principle 7) where that assessment cannot be carried out in the individual's home.

4.4 Everyone who is getting a social care package should have access to paid support and care staff **trained and experienced** in supporting people who display behaviour that challenges, and those who may have come into contact with or are at risk of coming into contact with the criminal justice system. These staff should be able to deliver proactive and reactive strategies to reduce the risk of behaviour that challenges, in line with NICE guidelines.

4.5 Local authorities should use **Market Position Statements** with an explicit focus on people with a learning disability and/or autism. **They should identify a group of preferred providers**, which can demonstrate minimum quality standards and competencies. These providers should be seen as genuine partners of specialist multi-disciplinary health and social care teams (see principles 7 and 8.3) as part of multi-agency working. Commissioners, along with the providers, should develop competency frameworks, such as that provided by Health Education England. These competency frameworks need to include requirements for staff training, for example person-centred approaches, communication and Positive Behaviour Support (PBS), in line with the PBS competency framework.

Key actions for health and social care commissioners:

- Children's and strategic learning disability commissioners should ensure availability of early intervention programmes, including evidence-based parent training programmes.
- Children's and strategic learning disability commissioners should ensure availability of a range of support and training for families and carers.
- Children's and strategic learning disability commissioners should provide flexible and creative short break/respite options.
- Children's and strategic learning disability commissioners should work with their local providers to develop models of alternative short-term accommodation.
- Commissioners should develop a group of social care preferred providers that meet the needs of people with a learning disability and/or autism.
- Local authorities should develop Market Position Statements with an explicit focus on this group.

Relevant guidance and standards

- NICE guidance on challenging behaviour and learning disabilities, sections on parent-training programmes and proactive and reactive strategies.
- Positive Behaviour Support (PBS) competency framework.
- Health Education England's learning disability skills and competency framework.
- Department of Education guidance on short breaks for carers of disabled children.

5. I have a choice about where I live and who I live with.

"I don't want to lose my home again if I go back to hospital."

Individual with autism

"Help people to see what their housing options are and what it really means to them."

Feedback from a discussion forum on housing

5.1 People should be offered a **choice of housing, including small-scale supported living**. This choice may be circumscribed by the Ministry of Justice (MOJ) in some instances if the individual is on an offender pathway. Choice about housing should be offered early in any planning processes (e.g. in transition from childhood to adulthood, or in hospital discharge planning) and should be based on individual need and be an integral component of a person's person-centred care and support plan (see principle 2). Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective and at the outset of planning.

5.2 Everyone should be offered **settled accommodation**. This should include exploring home ownership, or ensuring security of tenure.

5.3 Commissioners need to work closely with housing strategy colleagues to ensure that the future needs of this group are understood, considered and planned for strategically and form part of **local housing strategies**.

Key actions for health and social care commissioners:

- Commissioners should co-produce local housing solutions leading to security of tenure, that enable people to live as independently as possible, rather than in institutionalised settings.
- CCGs could consider allowing individuals with a personal health budget to use some of their budget to contribute to housing costs if this meets a health need and is agreed as part of the individual's care and support plan.
- Strategic commissioners need to work with housing strategy colleagues to ensure strategic housing planning.

Relevant guidance and standards:

- Communities and local government guidance on Disabled Facilities Grants

6. I get good care and support from mainstream health services.

> "Professionals working with people with autism and not knowing that autism is a 'triad" of social impairments is a bit like finding a builder who does not know how to mix cement."
>
> **Feedback from people with lived experience**

6.1 Everyone with a learning disability over the age of 14, should be offered an **Annual Health Check**. This is particularly important for those with communication difficulties. Everyone should have **a Health Action Plan**, which identifies how any physical and mental health needs will be met, and this should form an integral component of a person's person-centred care and support plan (see principle 2). Where appropriate it should include a **'Hospital Passport'** to help mainstream NHS services make the reasonable adjustments required by law (including meeting the needs of people who display behaviour that challenges) and ensure equity of health outcomes for people.

6.2 Everyone should expect universal NHS services to employ clearly identified and readily accessible primary and secondary healthcare **'liaison' workers** who have specialist knowledge and specific skills in working with people with a learning disability and/or autism which enable them to advise those services on how to make effective adjustments.

6.3 Everyone should expect **'quality checker'** schemes to be in place ensuring that mainstream services serve them appropriately.

6.4 Everyone should expect mainstream mental health services to regularly audit how effective they are at meeting the needs of people with a learning disability and/or autism. The Green Light Toolkit should be used to both **evaluate services and to agree local actions** to deliver real improvements. In many instances this will require investment in mainstream mental health services (such as Child and Adult Mental Health (CAMHS) Services, Improving Access to Psychological Therapies (IAPT) and services that are helping to deliver against the Crisis Care Concordat). In other instances there will be new initiatives to support mainstream mental health services to make reasonable adjustments to their pathways of care and support, and to improve access to those services.

Key actions for health and social care commissioners:

- Health commissioners should ensure that people with a learning disability are offered Annual Health Checks.
- Health commissioners should ensure that everyone has the option of a Health Action Plan, and are promoting the use of Hospital Passports.
- Mental Health commissioners should ensure that the Green Light Toolkit audit is completed annually, and an action plan developed.
- Commissioners should ensure that practices and care and support pathways within mainstream primary and secondary NHS services are 'reasonably adjusted' to meet the needs of this group, in line with Equality Act duties, and are routinely monitoring equality of outcomes.

Relevant guidance and standards:

- Green Light toolkit: reasonable adjustments in mental health services.
- Improving Health and Lives (IHAL) resources on making reasonable adjustments for people who need mental health services and support.
- IHAL Working Together guidance for improving support for people with learning disabilities in hospital.
- NHS England Quality Checkers initiative.
- IAPT Positive Practice guidance for people with learning disabilities.
- 2015 Directions on Annual Health Checks.

7. I can access specialist health and social care support in the community.

> "It is important for them to stick with the person."
>
> **Family carer and a consultant psychiatrist**

7.1 Everyone should have access to **integrated, community-based, specialist multidisciplinary health and social care support for people with a learning disability and/or autism in their community** that is readily accessible, when needed, by children, young people and adults with a learning disability and/or autism, including those who may have come into contact with or are at risk of coming into contact with the criminal justice system (see principle 8). Key functions of this specialist support should include: support to enable people to access mainstream health and social care services, work with mainstream services to develop their ability to deliver individualised reasonable adjustments, support to commissioners in service development and quality monitoring, and the delivery of direct assessment and therapeutic support.

7.2 Specialist support might be provided by a range of services, and often across services (e.g. children's services, Child and Adult Mental Health Services (CAMHS), learning disability CAMHS teams and specialist community learning disability teams). Support should be built around the needs of the individual through a **'Collaborative Care' model, or by combined teams** (e.g. all age, learning disability and autism). Individuals should expect continuity of care and support through close collaboration between services/agencies, including between specialist and mainstream services. Access to and provision of support should be based on need.

7.3 Anyone who requires additional support to prevent or manage a crisis should have access to hands-on **intensive 24/7 multi-disciplinary health and social care support** at home, or in other appropriate community settings, including schools and short break/respite settings. This support should be delivered by members of highly-skilled and experienced multi-disciplinary/agency teams with specialist knowledge in managing behaviours that challenge. The interface between specialist routine multi-disciplinary support services (described above) and this type of intensive support service should be seamless.

Key actions for health and social care commissioners:

- Commissioners should ensure the availability of specialist integrated multi-disciplinary health and social care support in the community for people with a learning disability and/or autism, covering all ages.
- Commissioners should ensure this specialist health and social care support includes an intensive 24/7 support function.
- Commissioners should ensure inter-agency collaborative working, including between specialist and mainstream services.

Relevant guidance and standards:

- Mansell Report: Services for people with learning disabilities and challenging behaviour or mental health needs.
- Royal College of Psychiatrists: Challenging Behaviour a Unified Approach.

8. If I need it, I get support to stay out of trouble.[12]

> "There was too much focus on mental health reports and a lack of learning disability awareness."
>
> **Individual with a learning disability**

8.1 People who have come into contact with, or may be at risk of coming into contact with the criminal justice system, should have **access to the same services aimed at preventing or reducing anti-social or 'offending' behaviour**[13] **as the rest of the population**. They should expect services (including those provided by youth offending teams, liaison and diversion schemes, as well as troubled family schemes and programmes such as those for drug and alcohol misuse) to identify people with a learning disability and/or autism amongst the people they support, and to make reasonable adjustments so they can effectively support those people. This should be achieved through collaboration with specialist multi-disciplinary health and social care services for people with a learning disability and/or autism (see principle 7, and 8.3 below).

8.2 **Liaison and diversion schemes** should seek to support people through the youth or criminal justice system 'pathway' enabling people to exercise their rights and/or where appropriate, diverting people to appropriate support from health and social care services. Clear pathways for diversion to health and social care services should be established through local multi-agency protocols.

8.3 When required, people should have access to **specialist multidisciplinary health and social care support for people who have come into contact with or may be at risk of coming into contact with the criminal justice system** (i.e. offering a community forensic function for people with a learning disability and/or autism) including the expertise to manage risks posed to others in the community. The interventions offered by these services will depend on the needs of the individual and the level of risk they pose, from individual and group offence-specific interventions, to specialist assessment and established links with other services aimed at facilitating appropriate pathways away from the criminal justice system. It is likely that some people will be best served by mainstream forensic services able to work with people with a learning disability and/or autism, and some by specialist multi-disciplinary health and social care services for people with a learning disability and/or autism. In some areas, specialist community forensic learning disability and autism teams or hospital outreach teams work with small numbers of people who pose a more significant risk to others, usually spanning several localities.

[12] A small percentage of people with a learning disability and/or autism engage in behaviour that may lead to contact with the criminal justice system, and potentially diversion to a hospital setting. They are included as a distinct group within this service model because their specific needs have not always been recognised; the model presents an opportunity to develop the support and services they may require.

[13] The term 'offending' behaviour is used in this way to encompass those people whose behaviour has brought them into contact with the criminal justice system, even if they have not been convicted of an offence.

Actions for health and social care commissioners:

- Commissioners should ensure that mainstream services aimed at preventing or reducing anti-social or 'offending' behaviour are making reasonable adjustments to meet the needs of people with a learning disability and/or autism, in line with Equality Act duties, and are routinely monitoring equality of outcomes.
- Commissioners should ensure the availability of specialist health and social care support for people with a learning disability and/or autism who may be at risk of or have come into contact with the criminal justice system, offering a community forensic function for this group.

Relevant guidance and standards:

- NHS England - Liaison and Diversion Services.

9. If I am admitted for assessment and treatment in a hospital[14] setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to.

> "Being in hospital helped me understand my mental health needs and I am now living in my own home."
>
> "Sometimes I feel I need a safe place to go every now and again. I stay in hospital for a long time and I have to rebuild my life each time."
>
> **Two individuals with recent experience of being in hospital**

9.1 Everyone who is admitted to a hospital setting for assessment and treatment should expect this to be **integrated into their broader care and support pathway**, with hospitals working closely with community mental health, learning disability/autism and other services, including those providing intensive community and/or forensic support (see principles 7 and 8).

9.2 When people are admitted for assessment and treatment in a hospital setting they should expect support to focus on **proactively encouraging independence and recovery**. Services should seek to minimise patients' length of stay and any admissions should be supported by a clear rationale of planned assessment and treatment with measurable outcomes. Hospitals should not become de facto homes; discharge planning should start from the point of admission - or earlier for a planned admission. Care and treatment should be regularly reviewed, in line with NHS England Care and Treatment Review guidance and CPA requirements. Services should be as close to home as possible and provide care and treatment in the least restrictive setting.

9.3 People who present an immediate risk to those around them and/or to themselves may require admission to a hospital setting when their behaviour and/or mental state is such that assessment and/or treatment is temporarily required that cannot be provided safely and effectively in the community. They should have access to high quality assessment and treatment in **non-secure hospital services** with the clear goal of returning them to live in their home. Sometimes people will be detained under the Mental Health Act if the necessary conditions are met. People with a learning disability and/or autism should be assessed and treated in mainstream inpatient services where this is the most appropriate option. This is likely to be the case for people with a mild learning disability and/or autism who have a mental health problem of a type and severity that warrants inpatient care. Providers should make the reasonable adjustments to enable this (e.g. liaison nurses and collaborative working with learning

(cont.)

[14] 'Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism, or the equivalent organisations in Wales and Scotland for English commissioned patients

disability and/or autism specialists). This might require providers to designate particular wards as suitable for this purpose. People whose learning disability and/or autism is more significant and who require an adapted environment and/or intensive specialist treatment and care should be admitted to a specialist unit if they require inpatient care. These specialist beds should be increasingly co-located within mainstream hospital settings as part of integrated specialist inpatient services, rather than in isolated stand-alone units. With the right support at the right time in the community, use of inpatient services should be rare and only for clearly defined purposes.

9.4 Admission to **secure inpatient services** should only occur when a patient is assessed as posing a significant risk to others. Often they will be detained under Part III of the Mental Health Act ('patients concerned in criminal proceedings or under sentence') and in contact with the criminal justice system, with or without restrictions from the Ministry of Justice. Some patients, however, may be detained in secure settings under Part II of the Mental Health Act where they pose an equivalent level of risk to others and this risk cannot be managed safely in less secure settings. For example, those who have been diverted away from the criminal justice system as a result of criminal justice agencies not taking the case through the courts, or discontinuing proceedings once it is seen that the person is already in hospital. In line with the Mental Health Code of Practice, only patients who require a combination of enhanced physical, procedural and relational security should be placed in secure services.

9.5 Everyone, other than those following diversion or direction from the criminal justice system, should expect a **community (pre-admission) Care and Treatment Review (CTR)**. In urgent situations where there is not time to convene a CTR then there should be a 'Blue Light' meeting, in line with NHS England policy and guidance. Admissions should always be with a clear stated purpose and set of expected outcomes. In the event of an urgent admission, where a CTR has not been carried out, then this should take place within 10 working days of their admission. After six months they should expect a mandatory CTR. Additionally, at any stage in hospital, should there be concerns about care and treatment, the person themselves, their family, advocate, commissioner or clinical team have a 'right to request' a CTR.

9.6 For all inpatient provision (secure or not) children admitted to hospital should be placed in an environment suitable for their age and must have access to education. For adults, provision of single-sex accommodation is essential.

Actions for health and social care commissioners

- Health commissioners should ensure that hospital admissions are supported by a clear rationale of assessment and treatment, and desired outcomes, and that services are as close to home as possible.
- Micro-commissioners should be working with individuals, families/carers, clinicians and local community services to ensure that the discharge planning process starts from the point of admission, or before.

- Health commissioners should be ensuring the appropriate CTRs are taking place and are of a high quality, in line with NHS England policy.
- Commissioners should ensure that support for families and carers are part of any commissioning framework.

Relevant guidance and standards

- NHS England Care and Treatment Review (CTR) guidance.
- NICE guidance on challenging behaviour and learning disabilities.

Services to meet complex and diverse needs

When designing the service commissioners should also take into account their legal duties under the Equality Act 2010 and with regard to reducing health inequalities, their duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities. See further guidance for NHS commissioners on Equality and Health Inequalities legal duties.

Personal Information

Recording and sharing confidential personal information is a vital part of implementing the principles and procedures set out in this document. It should be done with the explicit informed consent of the person the information is about (or when appropriate someone with parental responsibility for them); or, if they lack capacity, an assessment is needed to ensure sharing their information is in their best interests within the framework set out by the Mental Capacity Act 2005 and its Code of Practice. It is particularly important in the context of people with a learning disability and/or autism to make sure that consent is freely given.

The above paragraph above applies to all recording and sharing of confidential personal information for the purposes set out in this and the related documents, including: registers, risk stratification tools, personal health budgets, care plans, communication passports, 'quality checkers' and quality assessment.

However, confidential personal information can be recorded and shared in the public interest to help a child or young person who is or may be at risk of harm, or anyone who is or may be at risk of offending or of suffering harm or loss from offending. In each case the information recorded or shared should be in proportion to the risk.

Clear and robust information sharing protocols or agreements will always be beneficial. However they do not form a legal basis for sharing in themselves. Moreover the absence of a protocol should never be an obstacle to information sharing. Staff should be supported by adequate training and procedures to ensure they share information appropriately and are able to make informed judgements about overriding confidentiality when required.

Annex A
Terminology

Learning disability[15]

Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning), and;
- which is apparent before adulthood is reached and has a lasting effect on development.

Each of these three criteria must be met before someone can be said to have a learning disability; Intelligence Quotient (IQ) alone should not be used to determine presence of a learning disability. In terms of intellectual functioning, learning disability is conventionally defined as an IQ score in the region of 70 or below. However, it is not appropriate to use a 'cut off' figure of 70, as the results of a recognised IQ test require skilled interpretation. There should also be significant difficulties in adaptive and/or social functioning, for example in relation to conceptual, social and practical skills (such as language, interpersonal skills and activities of daily living).

The level of support someone needs depends on individual factors, including the severity of their learning disability, which can range from someone with a mild or moderate learning disability to someone with a severe or profound learning disability. The extent and nature of a person's learning disability may be determined by the presence or not of a single major genetic or environmental cause or by multiple factors interacting with educational and social opportunities that facilitate learning and the development of functional and social skills.

Learning disability is different from a specific learning difficulty, such as dyslexia, or a mental health condition.

Autism[16]

Also referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC).

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them.

[15] Adapted from Valuing People, Department of Health, 2001. See: Valuing People – A New Strategy for Learning Disability for the 21st Century

[16] Adapted from Fulfilling and rewarding lives, Department of Health, 2010. See: Fulfilling and rewarding lives: the strategy for adults with autism in England

The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice);
- social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own);
- social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with.

Autism is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives, while others (including those who also have a learning disability) may need more support. It is estimated that around 50% of people with autism also have a learning disability.

Behaviour that challenges

> "Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion."[17]

Some people with a learning disability and/or autism display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and does not in itself imply any understanding as to the causes of the behaviour. The behaviour may be a way for someone to let people know what they want or how they feel, or to try and control what is going on around them, or be a response to physical or mental distress.

A variety of factors are likely to contribute towards the development and escalation of behaviour that challenges, these include (but are not limited to): biological and genetic factors, physical ill-health, impaired communication difficulties, mental ill-health, the impact of poverty and social disadvantage, quality of support and exposure to adversities. Some care and support environments may increase the likelihood of behaviour that challenges, including those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise, as well as environments where physical health needs and pain go unrecognised or are not managed.

[17] Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. (2007). See: Challenging Behaviour: A Unified Approach.

Behaviour that challenges can often result from the interaction between personal and environmental factors, and can include self-injury or physical aggression, severe agitation and extreme withdrawal, as well as behaviours that can result in contact with the criminal justice system – in some cases leading to someone being arrested, charged and convicted of an offence.

Some people may have a long and persistent history of behaviour that challenges, perhaps starting in childhood. In others, it may be highly episodic – arising only under specific circumstances of stress or when the individual has a physical or mental health condition. In others still, it can be traced to a specific life event, such as a bereavement. This means that even if someone does not display behaviour that challenges today, they may do so in the future.

Annex B
Common needs and common shifts in service responses

Children, young people or adults with a learning disability and/or autism who have a mental health condition, such as severe anxiety, depression or a psychotic illness, and those people with personality disorders, which may result in them displaying behaviour that challenges.

Now

Too often, mental health conditions may not be picked up or appropriately treated at an early stage in the community.

Difficulties accessing appropriate treatment for mental health conditions sometimes mean that people's conditions, once recognised, are so severe or acute that the person needs admission to hospital.

Specialist care and support is too often provided only in reaction to a crisis. The care and support being provided by multiple agencies is typically poorly coordinated and not joined up.

People often feel they have little or no control or choice over the nature of their care and support and are often excluded from mainstream services/activities.

In the future

There is better and earlier identification and treatment of mental health conditions in the community, including through reasonable adjustments to mainstream health services.

Care and support is more proactive, planned and coordinated; there is multi-agency person-centred planning to meet mental health needs resulting in a person-centred care and support plan; planning takes place in partnership with individuals and families/carers who have more choice and control.

People have the support of a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their plan.

Care and support is focused on promoting mental health and wellbeing. People have access to activities and service within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

Where a person needs to be admitted to hospital for a mental health condition, it will be for no longer than is necessary and based on a clear treatment plan; it will be form part of an integrated care and support pathway of mental health support that spans hospital and community.

Children, young people or adults with an (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to severe mental ill-health, some of whom will have a specific neurodevelopmental syndrome with often complex life-long health needs and where there may be an increased likelihood of displaying behaviour that challenges.

Now

Too often poorly constructed care and support packages fail to fully or adequately meet people's needs.

People may be exposed to living environments that contribute to the development or maintenance of behaviours that challenge. Often the impact of physical health conditions are not fully recognised.

At important points of life transitions, care and support is often poorly coordinated. Foreseeable difficulties are not anticipated and ongoing needs are not fully understood or met immediately following transition.

Specialist care and support may not be readily available to people who are not presenting in acute crisis and there is poor coordination between agencies delivering care and support.

A failure to recognise and meet the person's needs often contributes to families/carers or paid support and care staff struggling to support the individual. This can lead to people being admitted to hospital.

People often struggle to access mainstream activities/services.

In the future

Care and support is highly personalised; there is multi-agency person-centred planning and a proactive approach to the identification/treatment of physical and mental health problems.

Individuals and families/carers are fully involved in the development of their person-centred care and support plans and have more choice and control over what their housing, care and support looks like, including through increased use of personal budgets/personal health budgets.

People have the support of a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their plan.

Highly skilled and resilient families/carers and paid support and care staff are able to deliver proactive and reactive strategies for managing behaviour that is challenging, and services are actively supporting and enhancing the knowledge and skills of families/carers and paid support and care staff.

People, and those who support them, will be able to readily access advice and support from specialist multi-disciplinary health and/or social care teams. Specialist support will be provided more intensively and flexibly at times of crisis.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

Children, young people or adults with a learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive, aggressive or sexually inappropriate behaviour)

Now

Often, evidence-based interventions that, if delivered at an early age would minimise or reduce the development of challenging or risky behaviours, are not available.

Staff working in social care services may struggle to cope with the person's behaviour or effectively support the person.

Involvement with the criminal justice system (which then struggles to recognise and meet people's needs) can lead to people being admitted to hospital.

Specialist care and support may not be readily available to people who are not presenting in acute crisis.

There is often poor coordination between agencies delivering care and support.

People often struggle to access mainstream activities/services.

In the future

Care and support is more proactive, planned and coordinated; there is multi-agency person-centred planning resulting in a person-centred care and support plan.

Services/agencies are working together to deliver evidence-based interventions, from an early age, and people and families/carers are supported by a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their person-centred care and support plan.

People, and those who support them, are able to readily access advice and support from specialist multi-disciplinary health / social care teams and specialist community-based forensic services and are supported to manage risks to others in the community.

There is multi-agency and collaborative working. Liaison and diversion schemes, where appropriate, divert people away from the criminal justice system to appropriate specialist health and social care services or provide support throughout the criminal justice pathway in collaboration with these health and social care partners.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

Children, young people or adults with a learning disability and/or autism, often with lower level support needs, from disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family background), who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.

Now

Too often, people may have displayed behaviour that challenged as a child or young adult, but their learning disability, autism or mental health condition was not diagnosed (possibly masked by the multiple nature of the child/family's difficulties).

People may be unknown to/not eligible for support from specialist community teams for people with a learning disability (or equivalent), and yet mainstream services struggle to provide the right support.

The person may commit an offence before being diverted to secure hospital settings (which may be where their learning disability and/or autism is first diagnosed or the point at which they are first known to health and social care services).

The individual may be excluded from programmes to address 'offending 'behaviours or struggle to participate. Services that are not familiar with the combination of learning disability and/or autism with 'offending' behaviour may struggle to meet their needs and to assess and manage risk effectively.

Care and support is too often provided in reaction to a crisis and is fragmented, with the individual having little choice or control.

In the future

Services that are aimed at preventing or reducing anti-social/or 'offending' behaviours are able to meet the needs of people with a learning disability and/or autism, including through support from specialist multi-disciplinary health / social care teams and specialist community-based forensic services.

Adapted programmes are available and local services are competent to deliver them.

Local multi-agency working means that a person's health and social care needs are identified earlier and addressed within ordinary community services/settings.

People, and those who support them, are able to readily access advice and support from specialist multi-disciplinary health / social care teams and specialist community-based forensic services and are supported to manage risk to others in the community.

Care and support is more proactive, planned and coordinated, and the individual has more choice and control over what this looks like.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in inpatient settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.

Now

Too many people have been in hospital for very many years (in some cases decades).

Care and support is often delivered to people in this situation in a way that isolates them from friends and family; affords them little or no control over their care and support; is not individualised; and is impersonal.

They will often be excluded from mainstream services/activities.

In the future

People are not effectively 'living' in hospitals.

People are resettled in the community; they have highly personalised packages of care and support, through careful planning with the individual, their family/carers and an independent advocate.

People are supported by an independent advocate to help in the transition from a hospital setting.

Care and support is proactive, planned and coordinated, and the individual has more choice and control over what this looks like, including through increased use of personal budgets/ personal health budgets.

People have the support of a local care and support navigator (or keyworker) who is responsible for coordinating and ensuring delivery of their person-centred care and support plan.

People have access to activities and services within the community (taking into account, where relevant, risks posed to others); they have opportunities to learn new skills and have new experiences, and are supported to develop and maintain relationships.

Annex C
Understanding the local population

Commissioners need to have an understanding of different types of need (see Annex B) in order to ensure the availability of the right sorts of support and services in their area. They will need to establish in one place, who their local people are through increasingly sophisticated risk stratification of their local population.

This needs to be included within the Joint Strategic Needs Assessment's ensuring they are an integral part of the whole system assessments of the current and future health and social care needs of the local community and are informing commissioning decisions. The risk stratification will inform local evidence-based priorities for commissioning which will improve the public's health and reduce inequalities.

The starting point should be a focus on those who are most at risk of inappropriate responses by services.

Commissioners should identify and provide enhanced vigilance and service coordination for people who are displaying behaviours which may result in significant harm to themselves/ others/ the environment, and/or are at risk of abuse/exploitation.

This should include (for children, young people and adults):

- anyone currently in a hospital setting;
- anyone referred for or accessing specialised services for challenging behaviour (e.g. intensive support services, specialist short breaks, special schools, residential care and supported living);
- anyone subject to the provisions of the Mental Health Act or subject to Deprivation of Liberty safeguards;
- anyone with a previous hospital stay (for example, within the last 5 years);
- anyone with involvement with the youth or criminal justice system (for example, within the last 12 months);
- those children in 52 week educational placements;
- those in receipt of NHS Continuing Healthcare (CHC) funding;
- those in receipt of services from youth offending teams (YOT).

This will enable commissioners to start to quantify their populations and establish capacity to meet need.

Commissioners will need to work across commissioning and organisations to improve transparency and accountability across the whole system, being clear about how resources are being used in each area and providing evidence to support collaborative decision making.

Annex D
Service model reference group membership

The reference group was co-chaired by Professor Tony Holland (CBE), Department of Psychiatry, University of Cambridge, and Scott Watkin, from national charity SeeAbility and former national learning disability co-director for learning disabilities for the Department of Health.

The reference group was set up to provide expert advice and to bring together perspectives from a range of stakeholders.

Individuals represented:

Dominic Tumelty	Association of Directors of Children's Services (ADCS)
Steve James	Avenues Group
Sam Sly	Centre for Welfare Reform
Viv Cooper	The Challenging Behaviour Foundation
Mark Humble	Darlington Borough Council
Stuart Miller	Department for Education (DfE)
Helen Toker-Lester	Devon Clinical Commissioning Group (CCG)
Daniel Dalton	Hertfordshire Partnership University NHS Foundation Trust
Sue Turner	Improving Health and Lives (IHAL)
Susan Harrison	London Borough of Camden
William Wormell	Ministry of Justice (MOJ)
Mark Lever	The National Autistic Society
Rob Greig	National Development Team for Inclusion (NDTi)
Karen Flood	National Forum of People with a Learning Disability

Vicki Raphael	National Valuing Families Forum
Shaun Clee	NHS Confederation
Michael Mellors	National Institute for Health Care and Excellence (NICE)
Gill Bell	Northumberland Tyne and Wear NHS Foundation Trust
Nick Hindley	Oxford Health, NHS Foundation Trust
Ashok Roy	Royal College of Psychiatry
Jean Riley	People hub
Alison Giraud-Saunders	Policy into Practice
Gyles Glover	Public Health England
Jan Tregelles	Royal Mencap Society
Rhodri Hannan	Sheffield Health and Social Care NHS Foundation Trust
Angela Hassiotis, Susan Harrson	University College London (UCL)
Peter Langdon, Glynis Murphy	University of Kent
Richard Hastings	Independent academic
Karen Dodd	Learning Disability Professional Senate

Transforming Care national delivery partners represented: NHS England, Local Government Association, Association of Directors of Adult Social Services, Department of Health, Care Quality Commission and Health Education England.

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

October 2015

Association of Directors of Adult Social Services (ADASS)
Local Government Association (LGA)
NHS England

NICE National Institute for Health and Care Excellence

NICE quality standard

Learning disability: behaviour that challenges

Quality standard

Published: 8 October 2015
www.nice.org.uk/guidance/qs101

Contents

Quality statements 7
Information about this quality standard for people with a learning disability 8
Quality statement 1: Lead commissioner 10
Quality statement 10
Rationale 10
Quality measures 10
What the quality statement means for different audiences 11
Source guidance 11
Definitions of terms used in this quality statement 11
Quality statement 2: Annual health check 13
Quality statement 13
Rationale 13
Quality measures 13
What the quality statement means for different audiences 14
Source guidance 14
Definitions of terms used in this quality statement 14
Equality and diversity considerations 16
Quality statement 3: Initial assessment of behaviour that challenges 17
Quality statement 17
Rationale 17
Quality measures 17
What the quality statement means for different audiences 18
Source guidance 19
Definitions of terms used in this quality statement 19
Equality and diversity considerations 20
Quality statement 4: Named lead practitioner 21
Quality statement 21

Rationale 21
Quality measures 21
What the quality statement means for different audiences 23
Source guidance 24
Definitions of terms used in this quality statement 24
Equality and diversity considerations 25
Quality statement 5: Involving families and carers 26
Quality statement 26
Rationale 26
Quality measures 26
What the quality statement means for different audiences 28
Source guidance 28
Definitions of terms used in this quality statement 29
Quality statement 6: Parent-training programmes 31
Quality statement 31
Rationale 31
Quality measures 31
What the quality statement means for different audiences 32
Source guidance 32
Definitions of terms used in this quality statement 33
Quality statement 7: Personalised daily activities 34
Quality statement 34
Rationale 34
Quality measures 34
What the quality statement means for different audiences 35
Source guidance 36
Definitions of terms used in this quality statement 36
Equality and diversity considerations 37

Quality statement 8: Services in the community 38
Quality statement 38
Rationale 38
Quality measures 38
What the quality statement means for different audiences 40
Source guidance 41
Definitions of terms used in this quality statement 41
Equality and diversity considerations 42
Quality statement 9: Housing 43
Quality statement 43
Rationale 43
Quality measures 43
What the quality statement means for different audiences 44
Source guidance 45
Definitions of terms used in this quality statement 45
Equality and diversity considerations 47
Quality statement 10: Review of restrictive interventions 48
Quality statement 48
Rationale 48
Quality measures 48
What the quality statement means for different audiences 49
Source guidance 50
Definitions of terms used in this quality statement 50
Equality and diversity considerations 51
Quality statement 11: Use of medication 52
Quality statement 52
Rationale 52
Quality measures 52

What the quality statement means for different audiences 53
Source guidance 54
Definitions of terms used in this quality statement 54
Equality and diversity considerations 55
Quality statement 12: Review of medication 56
Quality statement 56
Rationale 56
Quality measures 56
What the quality statement means for different audiences 57
Source guidance 58
Definitions of terms used in this quality statement 58
Equality and diversity considerations 59
Update information 60
About this quality standard 61
Improving outcomes 62
Resource impact 62
Diversity, equality and language 63

This standard is based on NG11 and NG93.

This standard should be read in conjunction with QS59, QS51, QS27, QS26, QS14, QS154, QS187, QS142 and QS194.

Quality statements

Statement 1 Local authorities and clinical commissioning groups jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability. **[new 2019]**

Statement 2 People with a learning disability have an annual health check from their GP. **[2015, amended 2019]**

Statement 3 People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour. **[2015]**

Statement 4 People with a learning disability and behaviour that challenges have a named lead practitioner. **[2015, updated 2019]**

Statement 5 Families and carers of people with a learning disability and behaviour that challenges are involved by services in developing the person's care and support plan, which includes how to prevent or respond to a crisis. **[new 2019]**

Statement 6 Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme. **[2015]**

Statement 7 People with a learning disability and behaviour that challenges take part in personalised daily activities. **[2015]**

Statement 8 People with a learning disability and behaviour that challenges have access to specialist behavioural support in the community. **[new 2019]**

Statement 9 Adults with a learning disability and behaviour that challenges are supported to choose where and how they live. **[new 2019]**

Statement 10 People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used. **[2015]**

Statement 11 People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions. **[2015]**

Statement 12 People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months. **[2015]**

Information about this quality standard for people with a learning disability

NICE has produced information for the public and EasyRead versions about this quality standard and its source guidance. See:

- information for the public and the EasyRead version on support for people with a learning disability and behaviour that challenges
- information for the public and the EasyRead version on health and social care services for people with a learning disability and behaviour that challenges.

NICE has developed guidance and a quality standard on people's experiences using adult social care services, adult NHS services and adult mental health services (see the NICE Pathways on people's experience in adult social care services, patient experience in adult NHS services and service user experience in adult mental health services).

Other quality standards that should be considered when commissioning or providing services for people with a learning disability and behaviour that challenges include:

- Learning disability: care and support of people growing older. NICE quality standard 187
- Learning disability: identifying and managing mental health problems. NICE quality standard 142
- Autism. NICE quality standard 51

A full list of NICE quality standards is available from the quality standards topic library.

Quality statement 1: Lead commissioner

Quality statement

Local authorities and clinical commissioning groups jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability. **[new 2019]**

Rationale

Having a lead commissioner who is experienced in working with children, young people and adults with a learning disability, including those with behaviour that challenges, will help to make sure that services meet their needs. In the longer term, the lead commissioner can bring together commissioning across health, social care and education for children, young people and adults. This will simplify the system, make better use of resources and clarify responsibilities. It might also improve the experience and outcomes of people with a learning disability, for example by reducing crises and the need for more intensive support.

Quality measures

Structure

a) Evidence of local arrangements for local authorities and clinical commissioning groups to jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability.

Data source: Local data collection, for example from joint working protocols.

b) Evidence that the lead commissioner role specifies that they have in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services.

Data source: Local data collection, for example job descriptions.

What the quality statement means for different audiences

Commissioners (local authorities and clinical commissioning groups) jointly choose a lead commissioner to oversee strategic commissioning of services for people with a learning disability. They choose a lead commissioner who has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services.

People of all ages with a learning disability use services for health, social care and education that are organised by one person who has worked with people with a learning disability and behaviour that challenges before, called the 'lead commissioner'. The lead commissioner is in charge of making sure that these different services work together to meet the needs of people with a learning disability.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.1.1

Definitions of terms used in this quality statement

Lead person to oversee strategic commissioning

A commissioner who plans and oversees joined-up commissioning arrangements for health, social care and education services for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges. They have in-depth knowledge and experience of working with people with a learning disability and behaviour that challenges, including knowledge of local services. They ensure that:

- resources are pooled across services and with neighbouring authorities to develop local and regional services
- service planning and delivery are based on assessments of current and future service needs

- services are planned and delivered in a way that is co-produced with people using services and their families, carers and independent advocates (see the definition of co-production in the Think Local, Act Personal care and support jargon buster)
- organisations take joint responsibility for managing risk when developing and delivering care and support
- services liaise regularly with the named worker, keeping them informed and involved in decision making.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendations 1.1.1 to 1.1.3, 1.1.6, 1.1.7, 1.1.9 and 1.2.11]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Quality statement 2: Annual health check

Quality statement

People with a learning disability have an annual health check from their GP. **[2015, amended 2019]**

Rationale

Annual health checks in people with a learning disability are likely to lead to identification and management of underlying physical health problems at an early stage. Unrecognised physical illness in people with a learning disability may lead to pain and discomfort, which, in turn, may be an important factor in triggering and maintaining behaviour that challenges. Therefore, early identification of physical health problems in people with a learning disability may reduce behaviour that challenges, leading to a reduction in costs associated with assessing and managing such behaviour.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability have an annual health check from their GP.

Data source: Local data collection.

Process

Proportion of people with a learning disability who have an annual health check from their GP.

Numerator – the number in the denominator who had an annual health check from their GP in the past 12 months.

Denominator – the number of people with a learning disability in contact with a GP service.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (primary care providers) ensure that people with a learning disability have an annual health check from their GP.

Healthcare professionals (GPs) carry out an annual health check for people with a learning disability.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services in which GPs provide an annual health check for people with a learning disability.

People with a learning disability have a thorough health check from their GP every year. This should include checking their physical health and any medicines they are taking. The checks should help to plan the person's healthcare over the next year and make sure that any physical health problems are treated.

Source guidance

- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.2.1
- Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.2.23

Definitions of terms used in this quality statement

An annual health check

An NHS initiative for adults and young people aged 14 and over with a learning disability to

provide additional health support and help to identify health conditions that could otherwise go undetected.

The enhanced scheme for providing annual health checks for GPs specifies details of the checks required, including that they should be undertaken by an appropriately trained provider and based on a protocol that as a minimum covers:

- A review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems.
- A collaborative review of physical and mental health with referral through the usual practice routes if health problems are identified. This includes conditions such as epilepsy and dysphagia.
- A specific syndrome check.
- A check on the accuracy of prescribed medications.
- A review of whether vaccinations and immunisations are up to date, for instance seasonal influenza, pneumonia or hepatitis B.
- A review of coordination arrangements with secondary care.
- A review of transition arrangements if appropriate.
- A discussion of likely reasonable adjustments should secondary care be needed.
- A review of communication needs, including how the person might communicate pain or distress.
- A review of family carer needs.
- Offering support to the person to manage their own health and make decisions about their health and healthcare, including through providing information in a format they can understand and any support they need to communicate.

[NICE's guideline on care and support of people growing older with learning disabilities, terms used in this guideline, NICE's guideline on challenging behaviour and learning disabilities, recommendation 1.2.1, NHS England's Learning Disability Annual Health Check electronic clinical template and Public Health England's People with learning disabilities: health checks audit tool]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 3: Initial assessment of behaviour that challenges

Quality statement

People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour. **[2015]**

Rationale

Early and timely assessment of behaviour that challenges can identify and seek to address the factors that lead to the behaviour and help to understand why the person is behaving in that way. In turn, this should help to reduce escalation of the behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Data source: Local data collection.

Process

Proportion of people with a learning disability and behaviour that challenges who have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Numerator – the number in the denominator who have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Denominator – the number of people with a learning disability presenting with behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (health and social care providers) ensure that systems are in place for people with a learning disability and behaviour that challenges to have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Health and social care practitioners ensure that people with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Commissioners (clinical commissioning groups, NHS England and local authorities) ensure that they commission services that provide initial assessments for people with a learning disability and behaviour that challenges to identify possible triggers, environmental factors and function of the behaviour.

People who have a learning disability have an assessment when there are signs of behaviour that challenges. The assessment includes the following:

- a description of the behaviour
- how often it occurs and for how long
- how it affects the person
- what events or situations make the behaviour happen
- what purpose the behaviour has for the person.

This helps to identify what may be causing the behaviour and any changes that might stop or reduce it.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.5.4

Definitions of terms used in this quality statement

Initial assessment

An initial assessment should include:

- a description of the behaviour and its function (including its severity, frequency, duration, purpose for the person and effect on the person and others); the description should be provided by the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- an explanation of the personal and environmental factors involved in triggering or maintaining the behaviour; the explanation should be provided by the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- any involvement of the service, staff, family members or carers in triggering or maintaining the behaviour.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, recommendation 1.5.4]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 4: Named lead practitioner

Quality statement

People with a learning disability and behaviour that challenges have a named lead practitioner. **[2015, updated 2019]**

Rationale

Children, young people and adults with a learning disability, and their families and carers, can find it difficult to get support from the right services at the right time. Having a named lead practitioner to coordinate support can help with this and make sure that services work together. The person and their family or carer should be given a choice of lead practitioner that takes into account any personal needs, such as cultural or religious needs. The lead practitioner can also get to know the person and their family or carer, and involve them in decision making, which can improve understanding of the care and support the person needs. The lead practitioner can also improve outcomes for people with a learning disability by consistently making sure their care and support needs are met, and allowing them to feel empowered and involved in their care.

Quality measures

Structure

a) Evidence of local arrangements to ensure that named lead practitioners are responsible for coordinating care and support of people with a learning disability and behaviour that challenges.

Data source: Local data collection, such as records from community learning disability teams or GP practices.

b) Evidence of local arrangements to ensure that lead practitioners have access to all agencies involved in supporting people with a learning disability and behaviour that

challenges.

Data source: Local data collection, such as review of service level agreements.

Process

Proportion of people with a learning disability and behaviour that challenges who have a named lead practitioner.

Numerator – the number in the denominator who have a named lead practitioner.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection, such as records from community learning disability teams or GP practices.

Outcomes

a) Proportion of people with a learning disability and behaviour that challenges who feel satisfied with services.

Numerator – the number in the denominator who feel satisfied with services.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, using surveys, focus groups and other methods of gathering the views of people using services, such as those used in the Challenging Behaviour Foundation and Mencap's valuing the views of children with a learning disability.

b) Proportion of people with a learning disability and behaviour that challenges and their families and carers who feel satisfied with involvement in decision making.

Numerator – the number in the denominator who feel satisfied with services.

Denominator – the number of people with a learning disability and behaviour that

challenges and their families and carers.

Data source: Local data collection, for example, using surveys, focus groups and other methods of gathering the views of people using services and their families, such as those used in the Challenging Behaviour Foundation and Mencap's valuing the views of children with a learning disability.

What the quality statement means for different audiences

Service providers (such as social care providers, community mental health teams, community learning disability teams and disabled children's teams) ensure that there is a named lead practitioner for each child, young person and adult with a learning disability and behaviour that challenges. Service providers are in regular contact with the lead practitioner, keeping them informed and involved in decision making.

Health and social care practitioners (such as social workers in a disabled children's team or community learning disability team, community learning disability nurses or allied health professionals) with appropriate skills and knowledge act as the named lead practitioner for a child, young person or adult with a learning disability and behaviour that challenges. They get to know the person and coordinate support to meet their long-term needs. They work in partnership with the person, and their family or carers, to arrange regular meetings to discuss the person's care and support, and invite people in the person's support network to the meetings, if this is what the person wants, or when decisions are made in a person's best interests (if the person is over 16, and in line with the Mental Capacity Act 2005). They identify gaps in support and service provision and report these to the lead commissioner. They develop and review the care and support plan with the person with a learning disability and behaviour that challenges, and their family or carers.

Commissioners (such as local authorities, clinical commissioning groups and lead commissioners) ensure that services assign a named lead practitioner, for example, a social worker (in a disabled children's team or community learning disability team) or community learning disability nurse, for a child, young person or adult with a learning disability and behaviour that challenges. They are in regular contact with the lead practitioner, making sure that no decisions are made without involving them and the person with a learning disability and behaviour that challenges.

People of all ages with a learning disability and behaviour that challenges have one person, called the 'lead practitioner', who they can talk to about their support. The lead practitioner is a person who understands learning disability and behaviour that challenges. They might be a social worker or a nurse. The lead practitioner meets regularly with the person, gets to know them and makes sure they get the support they need.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.2.10

Definitions of terms used in this quality statement

Named lead practitioner

A named practitioner with appropriate skills and knowledge, such as a social worker in a disabled children's team or community learning disability team, or community learning disability nurse, who gets to know the person and coordinates support to meet their long-term needs. Their responsibilities include working in partnership with the person to:

- arrange regular meetings to discuss the person's care and support, and invite people in their support network, including the family, carers, independent advocates and practitioners from all services that support them
- recognise and use the expertise brought by all members of the person's support network (not only those who are paid)
- develop and review the person's care and support plans with community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendations 1.2.10, 1.2.12 to 1.2.14 and 1.2.16]

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

Lead practitioners may find it particularly difficult to communicate effectively with children, young people and adults who have severe or profound learning disability. They may need to call on additional support to help them communicate with the person. This could include involving speech and language therapists, or working with family members or social care providers who know the person well to find ways of improving communication. Lead practitioners may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and aids to help people to communicate well.

Quality statement 5: Involving families and carers

Quality statement

Families and carers of people with a learning disability and behaviour that challenges are involved in developing the person's care and support plan, which includes how to prevent or respond to a crisis. **[new 2019]**

Rationale

Families and carers of children, young people and adults with a learning disability can find it hard to get information and support to help them understand behaviour that challenges, and to know the signs to look out for, what to do in a crisis and where to find services and support. Involving families in developing a care and support plan (if this is what the person wants), listening to their ideas, and providing information and support will increase their confidence and skills. This means that people with a learning disability are more likely to stay with their family, if they want to, and behaviour that challenges is less likely to occur or worsen.

Quality measures

Structure

Evidence of local arrangements to ensure that community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers work in partnership with the families and carers of people with a learning disability and behaviour that challenges to develop a care and support plan that includes how to prevent or respond to a crisis.

Data source: Local data collection, for example, from service level agreements and policy documents.

Process

Proportion of care and support plans for people with a learning disability and behaviour that challenges where families and carers were involved in developing them.

Numerator – the number in the denominator where families and carers were involved in developing them.

Denominator – the number of care and support plans for people with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, local audit of care and support plans or education, health and care plans.

Outcomes

a) Proportion of adults with a learning disability who live in their own home or with their family.

Numerator – the number in the denominator who live in their own home or with their family.

Denominator – the number of adults with a learning disability.

Data source:NHS Digital's data set 1G - Proportion of adults with a learning disability who live in their own home or with their family. This data set is part of measures from the adult social care outcomes framework, England – 2017-18.

b) Proportion of children and young people with a learning disability who live with their family.

Numerator – the number in the denominator who live with their family.

Denominator – the number of children and young people with a learning disability.

Data source: Local data collection, for example, from children's social care services data sets.

What the quality statement means for different audiences

Service providers (such as community learning disability teams or relevant children's services [for example, disabled children's teams or schools], community support providers, community mental health teams, social care providers, supported housing and residential care providers, and inpatient teams) ensure that staff have the time and resources to meet the families and carers of children, young people and adults with a learning disability and behaviour that challenges to discuss a care and support plan that sets out how to prevent or respond to a crisis.

Health, social care and education practitioners (such as social workers, care managers, advocates, community learning disability nurses, allied health professionals and education staff) meet the families and carers of children, young people and adults with a learning disability and behaviour that challenges, independent advocates and the named lead practitioner to discuss and develop a care and support plan together that sets out how to prevent or respond to a crisis.

Commissioners (such as NHS England, local authorities and lead commissioners) ensure that they monitor whether services meet and involve the families and carers of children, young people and adults with a learning disability and behaviour that challenges, independent advocates and the named lead practitioner in developing a care and support plan that sets out how to prevent or respond to a crisis.

Families and carers of people with a learning disability and behaviour that challenges are involved in developing a care and support plan. The plan includes tips on how to prevent a crisis and what families and carers should do if a crisis happens. The plan also includes practical information to help them in their role as carers.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.2.14

Definitions of terms used in this quality statement

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Care and support plan

A person-centred plan that:

- meets the person's needs and preferences
- works to support and maximise the person's mental capacity
- takes into account people's fluctuating mental capacity and needs
- adopts a 'whole life' approach that covers what they want to achieve in both the short and long term, and supports smooth transitions
- takes a positive approach to managing risk
- sets out what to do to prevent or respond to a crisis, including early intervention and management of a crisis. The plan includes key local emergency contact numbers and simple, practical interventions. It might also cover rapid involvement of additional services and provision of extra resources, such as short break services.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendation 1.2.14 and expert opinion]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Quality statement 6: Parent-training programmes

Quality statement

Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme. **[2015]**

Rationale

Early interventions for parents or carers support them to better understand and manage behaviour that challenges. This can help prevent the behaviour from developing into a long-term problem that is distressing for the person with a learning disability and leads to a greater burden of care for families and the wider service system. Parent-training programmes include training to promote the communication and social skills of children with a learning disability. They are designed to help parents and carers to understand, respond to and support children more effectively, with the aim of reducing and managing behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements to ensure that parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme for behaviour that challenges.

Data source: Local data collection.

Process

Proportion of parents or carers of children aged under 12 years with a learning disability and behaviour that challenges who are offered a parent-training programme for behaviour

that challenges.

Numerator – the number in the denominator whose parents or carers are offered a parent-training programme for behaviour that challenges.

Denominator – the number of children aged under 12 years with a learning disability and behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (secondary care and social care providers) ensure that parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme for behaviour that challenges.

Health and social care practitioners ensure that parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme for behaviour that challenges.

Commissioners (clinical commissioning groups, NHS England and local authorities) ensure that they commission services that offer parent-training programmes for behaviour that challenges to parents or carers of children aged under 12 years who have a learning disability and behaviour that challenges.

Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a training programme to help them better understand and support the child. They learn how to help children improve their communication and social skills, which can help to reduce behaviour that challenges.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendations 1.6.1 and 1.7.1

Definitions of terms used in this quality statement

Parent-training programme

Parent-training programmes:

- are delivered in groups of 10 to 15 parents or carers
- focus on developing communication and social functioning in the child with a learning disability
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow a treatment manual
- are accessible (for example, take place outside normal working hours or in community-based settings with childcare facilities)
- use practical materials to ensure consistent implementation of the programme.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, recommendation 1.7.2]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Quality statement 7: Personalised daily activities

Quality statement

People with a learning disability and behaviour that challenges take part in personalised daily activities. **[2015]**

Rationale

People with a learning disability and behaviour that challenges often have limited opportunity to engage in meaningful occupation or activity, or may take part in activities that are not meaningful to them. Very high rates of behaviour that challenges have been reported in institutions that typically offer relatively limited activities. Ensuring that people with a learning disability have planned, personalised daily activities will help to reduce rates of behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and behaviour that challenges take part in personalised daily activities.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges with a personalised daily activity schedule.

Numerator – the number in the denominator with a personalised daily activity schedule.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection.

b) Proportion of people taking part in personalised daily activities.

Numerator – the number in the denominator who take part in personalised daily activities.

Denominator – the number of people with a learning disability and behaviour that challenges with a personalised daily activity schedule.

Data source: Local data collection.

Outcome

Service user experience of personalised daily activities.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as health and social care providers, providers of residential care and providers in educational settings) ensure that systems are in place for people with a learning disability and behaviour that challenges to take part in personalised daily activities.

Health and social care practitioners (including staff in residential settings and educational settings) ensure that people with a learning disability and behaviour that challenges take part in personalised daily activities.

Commissioners (NHS England, clinical commissioning groups and local authorities) ensure that they commission services that plan personalised daily activities for people with a learning disability and behaviour that challenges.

People with a learning disability and behaviour that challenges take part in activities

planned for each day. The activities should be interesting for the person and should be recorded in a daily activity schedule. This should form part of the behaviour support plan that sets out how they will be supported. The activity schedule should be developed with the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.6.1

Definitions of terms used in this quality statement

Daily activity schedule

The daily activity schedule should be developed and agreed with the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers. The planned activities should be of interest to the person and be meaningful to them. The activities should be recorded in the daily activity schedule and form part of the behaviour support plan.

Behaviour support plan

A behaviour support plan should be developed and agreed with the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers. The behaviour support plan is based on a shared understanding about the function of the behaviour and should:

- identify proactive strategies designed to improve the person's quality of life and remove the conditions likely to promote behaviour that challenges
- identify adaptations to a person's environment and routine, and strategies to help them develop another behaviour that fulfils the same function by developing a new skill (for example, improved communication, emotional regulation or social interaction)

- identify preventive strategies to calm the person when they begin to show early signs of distress
- identify reactive strategies to manage any behaviours that are not preventable
- incorporate risk management and take into account the effect of the behaviour support plan on the level of risk
- be compatible with the abilities and resources of the person's family members, carers or staff, including managing risk, and be able to be implemented within these resources
- identify training for family members, carers or staff to improve their understanding of behaviour that challenges shown by people with a learning disability.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, recommendation 1.6.1]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 8: Services in the community

Quality statement

People with a learning disability and behaviour that challenges have access to specialist behavioural support in the community. **[new 2019]**

Rationale

A lack of specialist support in the community can affect quality of life for children, young people and adults with a learning disability and behaviour that challenges, and their families and carers. It can lead to problems after discharge from specialist inpatient care, such as assessment and treatment units or secure services. Insufficient community support can also delay or prevent discharges and transition from residential placements. Ensuring that specialist support is available locally for early intervention can help families and carers to look after the person at home, and reduce the incidence of crises and the need for intensive services and out-of-area and residential placements.

Quality measures

Structure

a) Evidence of local arrangements for specialist behavioural support to be available in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system).

Data source: Local data collection, for example from service specifications.

b) Evidence that local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support for people with a learning disability and behaviour that challenges, have been set.

Data source: Local data collection, for example from service specifications.

c) Evidence that professionals working in specialist behavioural support are trained in helping people with a learning disability and their families and carers to understand and change behaviour that challenges.

Data source: Local data collection, for example, local service specifications.

Process

Proportion of people with a learning disability and behaviour that challenges accessing specialist behavioural support who receive support in the community.

Numerator – the number in the denominator who receive support in the community.

Denominator – the number of people with a learning disability and behaviour that challenges accessing specialist behavioural support.

Data source: Local data collection, for example from patient records and surveys on the experience of people with a learning disability and behaviour that challenges accessing specialist behavioural support, and their families and carers.

Outcomes

a) Proportion of adults with a learning disability who live in their own home or with their family.

Numerator – the number in the denominator who live in their own home or with their family.

Denominator – the number of adults with a learning disability.

Data source:NHS Digital's data set 1G - Proportion of adults with a learning disability who live in their own home or with their family. This data set is part of measures from the adult social care outcomes framework, England – 2017-18.

b) Proportion of children and young people with a learning disability who live with their family.

Numerator – the number in the denominator who live with their family.

Denominator – the number of children and young people with a learning disability.

Data source: Local data collection, for example, from children's social care services data sets.

c) Rates of inpatient admissions for people with a learning disability.

Data source:NHS Digital's learning disability services statistics includes inpatient data on learning disabilities and autism from the assuring transformation and the mental health service data set.

d) Rates of restrictive intervention use for people with a learning disability.

Data source: Local data collection, for example audit of records from schools and inpatient settings.

What the quality statement means for different audiences

Service providers (such as community learning disability teams, specialist intensive support teams, schools, short break services, social care providers and community support providers) ensure that practitioners working in the community are trained to help children, young people and adults with a learning disability and behaviour that challenges and their families and carers understand why the behaviour occurs and how to prevent or change the behaviour if it is causing problems for them, before it gets worse. They ensure that services are available in the community. If a child, young person or adult develops, or is at risk of developing, offending behaviour, they should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible.

Health, social care and education practitioners (such as clinical psychologists, behaviour therapists, psychiatrists, learning disability nurses, community learning disability professionals, education staff, specialist intensive support workers and social workers) assess the needs and risk of children, young people and adults with a learning disability and behaviour that challenges in a community setting. They help the person and their family and carers, as well as other practitioners, to get support in line with this assessment. This support should help them to understand their behaviour, improve their quality of life, and reduce the behaviour that challenges before it gets worse, if it is

causing problems for them. If a child, young person or adult develops, or is at risk of developing, offending behaviour, they refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible.

Commissioners (such as local authorities and clinical commissioning groups) have a lead commissioner to act on their behalf to commission specialist behavioural support in the community for children, young people and adults with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system). The lead commissioner should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges.

People with a learning disability and behaviour that challenges can access specialist behavioural support in the community when they need it to help them understand their behaviour, if it is causing problems for them, and to stop it from getting worse. Families can have specialist learning disability support in the community instead of residential placements away from home, which will reduce the need for such placements.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendations 1.3.1 and 1.4.7

Definitions of terms used in this quality statement

Specialist behavioural support

Support provided by practitioners who have training in helping children, young people and adults with a learning disability and their families and carers to understand and change their behaviour if it is causing problems for them or other people. This includes assessing behaviour that challenges to understand why the behaviour occurs and the function of the behaviour, and developing a behaviour support plan that identifies strategies to prevent or change the behaviour and improve quality of life.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and

delivery, terms used in this guideline and NICE's guideline on challenging behaviour and learning disabilities, recommendations 1.5.1, 1.5.6 and 1.6.1]

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

Children, young people and adults with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with severe or profound learning disability may have particularly complex needs. Practitioners working with people with a learning disability may need to call on additional support to help them communicate with the person. This could include involving speech and language therapists or working with family members to find ways of improving communication. Practitioners may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and communication aids to help people to communicate well.

Quality statement 9: Housing

Quality statement

Adults with a learning disability and behaviour that challenges are supported to choose where and how they live. **[new 2019]**

Rationale

People with a learning disability and behaviour that challenges face barriers to choosing where they live and who they live with, such as lack of available support and housing arrangements to live independently. They may want to live alone with support, with a small number of people in shared housing or with their family. Supporting people with a learning disability to make decisions about how they want to live and to be part of their community will enable them to have more control and independence and improve their quality of life.

Quality measures

Structure

Evidence that a range of different housing and care options are available that meet the needs of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, from land registries and Care Quality Commission registrations.

Process

a) Proportion of adults with a learning disability and behaviour that challenges who are supported to communicate their housing preferences and any specific support needs or risks.

Numerator – the number in the denominator who are supported to communicate their housing preferences and any specific support needs or risks.

Denominator – the number of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example local audit of patient records.

b) Proportion of adults with a learning disability and behaviour that challenges who live somewhere that meets their needs.

Numerator – the number in the denominator who live somewhere that meets their needs.

Denominator – the number of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example local audit of patient records.

Outcome

Proportion of adults with a learning disability and behaviour that challenges who feel satisfied with the level of involvement in decision making about housing.

Numerator – the number in the denominator who feel satisfied with the level of involvement in decision making about housing.

Denominator – the number of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example using surveys, focus groups and other methods of gathering the views of people using services, such as those used in the Challenging Behaviour Foundation and Mencap's valuing the views of children with a learning disability.

What the quality statement means for different audiences

Service providers (such as social care providers, community mental health teams, community support providers, community learning disability teams, residential services, supported living services and housing providers) provide a range of different housing and

care options that meet the needs of adults with a learning disability and behaviour that challenges. They ensure that practitioners working with adults with a learning disability and behaviour that challenges have the time and resources to discuss individual housing preferences and support needs with the person, and their family or carers if needed. They ensure that practitioners have training in how to communicate with people with a learning disability, and support and include them in the discussion.

Health and social care practitioners (such as social workers, community learning disability nurses and lead practitioners) support adults with a learning disability and behaviour that challenges to communicate their individual housing preferences and support needs, with their families or carers if needed, and support them to live where they choose.

Commissioners (such as local authorities, clinical commissioning groups, NHS England and lead commissioners) ensure that they monitor whether services working with adults with a learning disability and behaviour that challenges support them to communicate their individual housing preferences and support needs. They discuss housing with housing providers to ensure that adults with a learning disability and behaviour that challenges are being considered in housing plans.

Adults with a learning disability and behaviour that challenges are helped to choose where and how they live, and given the support they need to live as they would like to.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendations 1.2.5 and 1.5.4

Definitions of terms used in this quality statement

Adults

People aged 18 years or older.

Supported to choose where and how they live

Support that takes into account their preferences, and any specific support needs or risks, including the effect of environmental factors, that:

- is person-centred, reflecting their individual needs and choices, and maximising their control
- helps them take an active part in all aspects of daily life that they choose, based on what they can do and what they want to do
- takes into account the severity of their learning disability, their developmental stage, any communication difficulties or physical or mental health problems, and their life history
- respects their cultural, religious and sexual identity
- helps them before problems occur or as soon as they emerge, not just when crisis has been reached
- encourages people to speak out if they have any worries
- promotes continuity of relationships.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendations 1.2.5 and 1.5.4]

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

People with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with severe or profound learning disability may have particularly complex needs. Practitioners working with people with a learning disability may need to call on additional support to help them communicate with the person. This could include involving speech and language therapists or working with family members to find ways of improving communication. They may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and communication aids to help people to communicate well.

Quality statement 10: Review of restrictive interventions

Quality statement

People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used. **[2015]**

Rationale

Restrictive interventions should be used as a last resort and decisions to use them should be based on the principle of using the least restrictive intervention necessary. Documented risk assessment and review of restrictive interventions helps to ensure learning. This will reduce the use of future restrictive practices, identify and mitigate any risks associated with their use and ensure safety, dignity and respect for people with a learning disability and behaviour that challenges. A documented review will also help to ensure that people with a learning disability and behaviour that challenges and their families or carers understand why and when restrictive interventions could be used.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges who receive a restrictive intervention.

Numerator – the number in the denominator who receive a restrictive intervention.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection.

b) Proportion of people with a learning disability and behaviour that challenges who have a documented review every time a restrictive intervention is used.

Numerator – the number in the denominator who have a documented review every time a restrictive intervention is used.

Denominator – the number of people with a learning disability and behaviour that challenges who receive a restrictive intervention.

Data source: Local data collection.

Outcome

Rates of restrictive interventions.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as secondary care services, social care providers and providers of residential care) ensure that systems are in place for people with a learning disability and behaviour that challenges to have a documented review every time a restrictive intervention is used.

Health and social care practitioners (including staff in residential settings) ensure that people with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

Commissioners (such as clinical commissioning groups, NHS England and local

authorities) ensure that they commission services that carry out a documented review with people with a learning disability and behaviour that challenges every time a restrictive intervention is used.

Peoplewith a learning disability and behaviour that challenges who are stopped from moving around (for example, by being held or given an injection of medication) should have a review of how this was carried out and whether it was needed or could have been avoided. A review should help the person understand when and why this approach is used. A review should also make sure that the approach used restricts the person as little as possible.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendations 1.9.3 and 1.9.6

Definitions of terms used in this quality statement

Restrictive intervention

Interventions that may infringe a person's human rights and freedom of movement, including locking doors, preventing a person from entering certain areas of the living space, seclusion, manual and mechanical restraint, rapid tranquillisation and long-term sedation.

[NICE's guideline on challenging behaviour and learning disabilities]

Documented review of restrictive intervention

Use of a restrictive intervention should be accompanied by a documented review that includes the following:

- review of the delivery and outcome of the restrictive intervention, whether it was needed and how it could be avoided (and if so, what action will be taken)

- assessment of the safety, efficacy, frequency of use, duration and continued need for reactive strategies
- involvement of everyone who cares for the person with a learning disability, including their family members and carers, and the person themselves, if possible.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, recommendations 1.9.3 and 1.9.6]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 11: Use of medication

Quality statement

People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions. **[2015]**

Rationale

Antipsychotics are the most frequently used drugs for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. They should be used only if no or limited benefit has been derived from a psychosocial intervention, and treatment for any coexisting mental or physical health problem has not led to a reduction in behaviour that challenges. Psychosocial interventions are the most commonly reported forms of intervention used for people with a learning disability and behaviour that challenges and should be the first-line intervention to address any identified triggers for the behaviour.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges prescribed antipsychotic medication as part of treatment that includes psychosocial interventions.

Numerator – the number in the denominator who are receiving psychosocial interventions.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

Data source: Local data collection.

b) Proportion of people with a learning disability and behaviour that challenges prescribed antipsychotic medication with a recorded rationale for the prescribing decision.

Numerator – the number in the denominator with a recorded rationale for the prescribing decision.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

Data source: Local data collection.

Outcome

Prescribing rates of antipsychotics in people with a learning disability and behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (secondary care services) ensure that systems are in place for people with a learning disability and behaviour that challenges to only be prescribed antipsychotic medication as part of treatment that includes psychosocial interventions.

Healthcare professionals only prescribe antipsychotic medication for people with a learning disability and behaviour that challenges as part of treatment that includes psychosocial interventions.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that only prescribe antipsychotic medication for people with a learning disability and behaviour that challenges as part of treatment that includes

psychosocial interventions.

People with a learning disability and behaviour that challenges only have antipsychotic medication if they are also having psychological therapy or other therapies as part of their care. This should help to ensure that medication is only used if other therapies, or treatments for any physical health problems, have not changed or reduced the behaviour that challenges, or if there is a serious risk of the person harming themselves or others (for example, because of violence, aggression or self-harm).

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.8.2

Definitions of terms used in this quality statement

Psychosocial interventions

Psychosocial interventions include a broad range of therapeutic approaches designed to support the person. They are generally non-pharmacological and aim to identify underlying factors for behaviour, reduce the person's distress and increase their skills. Approaches include communication interventions, applied behaviour analysis, positive behaviour support and cognitive behavioural therapy.

[Adapted from NICE's full guideline on challenging behaviour and learning disabilities, section 11]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 12: Review of medication

Quality statement

People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months. **[2015]**

Rationale

Antipsychotics are the most frequently used drugs for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. The use of antipsychotics should be limited and regular review should ensure that there is an appropriate rationale for prescribing. A full multidisciplinary review will also help to reduce prolonged use of antipsychotics and thereby potential side effects.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges who have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment.

Numerator – the number in the denominator who have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

Data source: Local data collection.

b) Proportion of people with a learning disability and behaviour that challenges who have a multidisciplinary review of their antipsychotic medication at least every 6 months after the first 12 weeks of treatment.

Numerator – the number in the denominator who have a multidisciplinary review of their antipsychotic medication at least every 6 months after the first 12 weeks of treatment.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the last 12 months.

Data source: Local data collection.

Outcome

Prescribing rates of antipsychotics in people with a learning disability and behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (secondary care services) ensure that systems are in place for people with a learning disability and behaviour that challenges to have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

Health and social care practitioners ensure that people with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication

12 weeks after starting treatment and then at least every 6 months.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that provide people with a learning disability and behaviour that challenges with a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

Peoplewith a learning disability and behaviour that challenges who take antipsychotic medication have their medication checked 12 weeks after they start taking it and then at least every 6 months. Their medication should be checked by a team that includes doctors, nurses and care staff. The check should include how well the medication is working (including whether it is causing any side effects) and whether the person should keep taking it. This should be explained to the person and their family or carers.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendations 1.8.4, 1.8.5 and 1.8.6

Definitions of terms used in this quality statement

Multidisciplinary review

A review of prescribed antipsychotic medication by a team that includes doctors, nurses and care staff that includes the following:

- a record of the extent of the response, how the behaviour has changed and any side effects or adverse events
- identification of any physical abnormalities
- the rationale for continuing the medication, if this is being done, and an explanation of this for the person with a learning disability and behaviour that challenges and everyone involved in their care, including their family members and carers.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, section 1.8]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Update information

July 2019: This quality standard was updated. Four new statements were added to the 2015 version, one statement from 2015 was updated and one was amended.

Statements are marked as:

- **[new 2019]** if the statement covers a new area for quality improvement
- **[2015, updated 2019]** if the statement covers an area for quality improvement included in the 2015 quality standard and has been updated
- **[2015, amended 2019]** if the statement has been amended
- **[2015]** if the statement remains unchanged.

Statement 2 (statement 1 in the 2015 version) has been amended to align with a statement on annual health checks in NICE's quality standard on learning disability: care and support of people growing older. It is marked as **[2015, amended 2019]**.

Statement 4 (statement 3 in the 2015 version) has been updated and is marked as **[2015, updated 2019]**.

A definition of behaviour that challenges has been added to the 2015 statements, in line with NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery.

The 2015 quality standard for learning disabilities: challenging behaviour is available as a pdf.

Minor changes since publication

June 2020: The source guidance for statement 6 was updated to include recommendation 1.6.1 from NICE's guideline on challenging behaviour and learning disabilities.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

The statements in this quality standard have been developed with 2 different quality standards advisory committees. See quality standard advisory committees on the website for details of standing committee 3 members who advised on the 2019 statements in this quality standard. Information about the standing members who advised on the 2015 statements, along with the topic experts invited to join the standing members, is available on the quality standard's webpage.

This quality standard has been included in the NICE Pathway on learning disabilities and behaviour that challenges, which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh

government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- promotion of independence, choice and control over daily life
- experience of people with a learning disability and behaviour that challenges using social care services
- experience of people with a learning disability and behaviour that challenges using healthcare services
- experience of services working together
- use of restrictive practices
- health and social care-related quality of life for people with a learning disability and behaviour that challenges
- health and social care-related quality of life for carers of people with a learning disability and behaviour that challenges.

It is also expected to support delivery of the following national frameworks:

- Adult social care outcomes framework
- NHS outcomes framework
- Public health outcomes framework for England
- Quality framework for public health.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource

impact products for the source guidance to help estimate local costs:

- resource impact template and report for the NICE guideline on learning disabilities and behaviour that challenges: service design and delivery
- costing statement for the NICE guideline on challenging behaviour and learning disabilities.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

ISBN: 978-1-4731-1467-8

Endorsing organisation

This quality standard has been endorsed by Department of Health and Social Care, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- The Challenging Behaviour Foundation
- Royal College of Nursing (RCN)

- Skills for Care
- Royal College of Paediatrics and Child Health
- Foundation for People with Learning Disabilities
- British Institute of Learning Disabilities
- British Psychological Society (BPS)

QNLD QUALITY NETWORK FOR INPATIENT LEARNING DISABILITY SERVICES CCQI

AIMS ACCREDITATION FOR INPATIENT MENTAL HEALTH SERVICES CCQI

RC PSYCH ROYAL COLLEGE OF PSYCHIATRISTS



Standards for adult inpatient learning disability services

Third edition: July 2016

Editors: Renata Souza, Lucy Palmer, Yvonne Amar and Eryna Tarant

A manual of standards written primarily for:
Adult inpatient services for people with learning disabilities

Also of interest to:
People with learning disabilities
Family and friends of people with learning disabilities
Commissioners
Policy makers
Researchers

Third edition: July 2016
Publication number: CCQI235

This document contains the third edition of the standards for adult inpatient learning disability services. This is the first edition published under the name Quality Network for Inpatient Learning Disability Services (QNLD). This reflects the change in the structure of the programme following the introduction of a quality network cycle in 2009. These standards will be used for both quality improvement and accreditation processes (AIMS-LD) within the network.

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Contents

Foreword 3
Introduction 4
1. Admission and assessment 7
Access and referral 8
First hour of admission 8
First 4 hours of admission 8
Completing the admission process 10
2. Care planning and treatment 11
Reviews and care planning 12
Leave from the ward/unit 12
Care and treatment 12
Physical healthcare 14
3. Safety, discharge, capacity and consent 16
Risk and safeguarding 17
Discharge planning and transfer of care 18
Interface with other services 18
Capacity and consent 19
4. Patient and carer experience 20
Patient involvement 21
Carer engagement and support 21
Treating patients with compassion, dignity and respect 21
Provision of information to patients and carers 21
Patient confidentiality 22
5. Environment and facilities 23
Ward/unit environment 24
6. Leadership, workforce and governance 26
Leadership and culture 27
Team working 27
Staffing levels and skill mix 27
Staff recruitment and induction 27
Appraisal, supervision and support 28
Staff wellbeing 28
Staff training and development 28

Clinical outcome measurement....29
Audit and service evaluation....29
The ward/unit learns from incidents....29
Acknowledgements....30
Key to references....31

Foreword

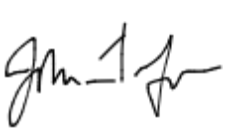
People with learning disabilities often face barriers in accessing health care, especially when staff lack the appropriate specialist knowledge, communication skills and learning disability awareness.

For those people who have a learning disability and a mental health problem, accessing good quality care can be even more difficult. Left untreated, these problems can become worse and have a devastating impact on a person's health and wellbeing. People with learning disabilities deserve good quality, timely and evidence-based mental health care, delivered by competent and compassionate staff and provided in a safe and therapeutic environment.

With changes afoot to the provision of mental health services for people with learning disability, never has it been more important to ensure that the care provided is of the highest standard. Staff should ensure that patients receive consistent and thorough assessment and care plans, centred on the person's needs, risks and strengths. Transitions between services should be handled smoothly and systematically, with attention being given to ensuring the patient's individual needs are well communicated between services and acted upon.

This set of standards sets out to describe how inpatient mental health units for people with learning disability can deliver good quality assessment, care, treatment and discharge planning. It is hoped that by following these standards and taking part in the Quality Network for Learning Disability mental health services (QNLD), services can build on the good work they are already doing and make improvements where these are needed. Once ready to do so, services can become officially accredited by the Royal College of Psychiatrists. This process might seem challenging but the QNLD project team are here to provide support throughout the process. By taking part in the network, staff and patients will be able share ideas, innovations and best practice suggestions with each other, achieving more together than they could alone.

We hope that members of QNLD will find these standards helpful. If staff would like advice on how to meet a particular standard, or have any feedback on the standards themselves, please contact the project team here at the College who will be happy to help you.



Dr John Devapriam
Chair, QNLD Advisory Group and Accreditation Committee

Introduction

What is the Quality Network for Inpatient Learning Disability Services (QNLD)?

QNLD is a standards-based quality network that facilitates the sharing of good practice, provides a system of standards-based external peer-review and provides accreditation. It engages staff and service users in a comprehensive process of review, through which good practice and high quality care are recognised. Services are supported to identify areas for improvement and set achievable targets for change.

Accreditation is offered to services that are fully prepared. It is recommend that a minimum of one year's membership is completed before services transfer to accreditation.

How have the QNLD standards been developed?

The standards for the Quality Network for Inpatient Learning Disability Services (QNLD) are developed from key documents and expert consensus as well as drawing from previous editions of the standards and the Standards for Inpatient Mental Health Services (Royal College of Psychiatrists, 2015) that have been recently published.

The full set of standards are aspirational and it is unlikely that any ward would meet all of them. To support their use in the accreditation process, each standard has been categorised as follows:

- **Type 1:** criteria relating to patient safety, rights, dignity, the law and fundamentals of care, including the provision of evidence-based care and treatment;

- **Type 2:** criteria that a service would be expected to meet.

Membership pathway

QNLD Year I

In year one members complete a limited self-review, and the peer-review visit is focused on quality improvement, rather than a rigorous assessment of performance against the standards. The peer-review team meets with the members of the host team to discuss practice covered in two sections of the standards selected by the hosts. During these meetings, good practice is shared, and the results of the self-review of these sections of the standards are validated. The day also involves a tour of the host service and an open discussion on an area of practice that the host unit would like to improve upon.

QNLD Year II

Stage two is a more comprehensive process of both self- and peer-review and feedback is collected from patients, carers and staff. The peer-review visit covers all sections of the standards and meetings with different groups (senior clinicians, front line staff, patients and carers) take place. This process is intended to help members fully understand what is required once they progress to accreditation, and to identify any deficits in practice that might be barriers to accreditation. A summary of the results from the self-review will inform discussions at the visit by the peer-review team. The same review format is used in the accreditation stage.

Accreditation

When services move to the accreditation stage, data from the self- and peer-review are compiled into a summary report of the unit's strengths and areas for improvement. Once this has been verified by the review and the host team, it will be taken to the next meeting of the *Accreditation Committee (AC)*, where they will consider the data and recommend an accreditation status for the unit.

The review cycle



*Stage 5 is only applicable to wards/units participating in the accreditation stage.

There are three categories of accreditation status:

Level 1: "accredited"

The unit would *at the point of peer-review*:

- meet all Type 1 standards;
- meet at least 80% of Type 2 standards, with no significant gaps in any particular section of the standards;

Accreditation at Level 1 is valid for up to three years, subject to satisfactory completion of interim self-review.

Level 2: "accreditation deferred"

The unit would *at the point of peer-review*:

- fail to meet one or more Type 1 standards but demonstrate the capacity to meet these within a short time;
- fail to meet a substantial number of Type 2 standards but demonstrate the capacity to meet the majority within a short time.

Level 3: "not accredited"

The unit would *at the point of peer-review*:

- fail to meet one or more Type 1 standards and not demonstrate the capacity to meet these within a short time;
- fail to meet a substantial number of Type 2 standards and not demonstrate the capacity to meet these within a short time.

1. Admission and assessment

Access and referral			
1.1	1	Accessible information is made available, in paper and/or electronic format, to patients, carers and healthcare practitioners on: • A simple description of the ward/unit and its purpose; • Admission criteria; • Clinical pathways describing access, discharge, timescales and treatment pathways; • Main interventions and treatments available; • Contact details for the ward/unit and hospital.	Core (1.1)
First hour of admission			
1.2	1	Staff make people feel welcome when they arrive on the unit.	GPP
1.3	1	On admission to the ward/unit, or when the patient is well enough, staff members show the patient around.	Core (3.3)
1.4	1	Staff members are easily identifiable (for example, by wearing appropriate identification).	Core (3.4)
First 4 hours of admission			
1.5	2	The patient is given an age appropriate 'welcome pack' or introductory information that contains the following: • A clear description of the aims of the ward/unit; • The current programme and modes of treatment; • The ward/unit team membership; • Personal safety on the ward/unit; • The code of conduct on the ward/unit; • Ward/unit facilities and the layout of the ward/unit; • What practical items can and cannot be brought in; • Clear guidance on the smoking policy in smoke-free hospitals and how to access smoking breaks off the hospital grounds; • Resources to meet spiritual, cultural and gender needs. *Guidance: The information is provided in an accessible format.*	Core (4.1)
1.6	1	Staff members explain the purpose of the admission to the patient.	Core (4.3)
1.7	1	The patient's carer or next of kin is contacted by a staff member (with patient consent) to notify them of the admission and to give them the ward/unit contact details.	Core (4.4)
1.8	1	Detained patients are given accessible information on their rights under the Mental Health Act (or equivalent) and this is documented in their notes.	Core (4.5)
1.9	1	Patients are given accessible information on: • Their rights regarding consent to care and treatment; • How to access advocacy services (including independent mental capacity advocate and independent mental health advocate); • How to access a second opinion; • How to access interpreting services; • How to raise concerns, complaints and compliments; • How to access their own health records.	Core (4.6)
1.10	1	Where a patient is being admitted directly from the community, the admitting nurse checks that the referring agency gives clear details on and management plans for: • The security of the patient's home; • Arrangements for dependents (children, people they are caring for); • Arrangements for pets.	Core (4.7)

1.11	1	Patients have a comprehensive assessment which is started within 4 hours and completed within 1 week. This involves the multi-disciplinary team and includes patients': • Mental health and medication; • Psychosocial needs; • Strengths and weaknesses, which must include an adaptive functioning assessment and an assessment of sensory needs; • Personal preferences including coping strategies and challenges, traits and routines.	Core (4.8)
1.12	1	Patients have a comprehensive physical health review. This is started within 4 hours of admission, completed within 1 week, and reviewed on discharge. It includes: FIRST 4 HOURS • Details of past medical history; • Current medication, including side effects and compliance (information is sought from the patient history and collateral information within the first 4 hours. Further details can be sought from medical reconciliation after this); • Physical observations including blood pressure, heart rate and respiratory rate. FIRST 24 HOURS • Physical examination; • Height, weight; • Blood tests (can use recent blood tests if appropriate); • ECG. FIRST 1 WEEK • Details of past family medical history; • A review of physical health symptoms; • Lifestyle factors e.g. sleeping patterns, diet, smoking, exercise, sexual activity, drug and alcohol use. *Guidance: Staff should also check the status of the patient's annual health check.*	Core (4.9)
1.13	1	Patients are offered a staff member of the same gender as them, and/or a chaperone of the same gender, for physical examinations.	Core (4.10)
1.14	1	Patients are informed of the outcome of their physical health assessment and this is recorded in their notes. *Guidance: With patient consent, this can be shared with their carer.*	Core (4.11)
1.15	1	Patients have a risk assessment that is shared with relevant agencies (with consideration of confidentiality) and includes a comprehensive assessment of: • Risk to self; • Risk to others; • Risk from others.	Core (4.12)
1.16	1	The team discusses the purpose and outcome of the risk assessment with each patient and a management plan is formulated jointly.	Core (4.13)

Completing the admission process			
1.17	1	All patients have a documented diagnosis and clinical formulation. *Guidance: The formulation includes the presenting problem and predisposing, precipitating, perpetuating and protective factors as appropriate.*	Core (5.1)
1.18	2	The community team (including the social worker) and the GP are informed about the patient's admission within five working days.	GPP

2. Care planning and treatment

Reviews and care planning			
2.1	1	There is a documented admission meeting within one week of the patient's admission. *Guidance: This could take the form of a ward round meeting or a Care Programme Approach meeting (or equivalent), should include the community team where possible and the patient is invited to attend.*	Core (6.4)
2.2	1	Actions from reviews are fed back to the patient (and carer, with the patient's consent) and this is documented.	Core (6.7)
2.3	1	Risk assessments and management plans are updated according to clinical need or at a minimum frequency.	Core (6.8)
2.4	1	Every patient has a written care plan, reflecting their individual needs. *Guidance: This clearly outlines:* • *Agreed intervention strategies for physical and mental health;* • *Measurable goals and outcomes;* • *Strategies for self-management;* • *Any advance directives or stated wishes that the patient has made;* • *Crisis and contingency plans;* • *Review dates and discharge framework.*	Core (6.9)
2.5	1	Care plans are developed collaboratively with the patient. *Guidance: Patients' preferences are taken into account around the selection of medication, therapies and activities, and are acted upon as far as possible.*	Core (6.2, 8.1.2)
2.6	1	The patient and their carer (with patient consent) are offered a copy of the care plan and the opportunity to review this.	Core (6.12)
2.7	1	The team reviews and updates care plans according to clinical need or at a minimum frequency.	Core (6.11)
Leave from the ward/unit			
2.8	1	The team develops a leave plan jointly with the patient that includes: • A risk assessment and risk management plan that includes an explanation of what to do if problems arise on leave; • Conditions of the leave, escorted, accompanied, unescorted; • Contact details of the ward/unit. *Guidance: If there are concerns about a patient's cognition, the risk assessment includes consideration of whether the patient may be driving/using heavy machinery etc. and there is a plan in place to manage this.*	Core (7.1)
2.9	1	Staff members feel safe when escorting patients on leave.	Core (7.2)
2.10	1	Patients are sent on leave into the care of carers only with carer agreement and timely contact with them beforehand.	Core (7.3)
2.11	1	The team follows a protocol for managing situations where patients are absent without leave.	Core (7.4)
Care and treatment			
Therapies and activities			
2.12	1	Patients are offered evidence based pharmacological and psychological interventions and any exceptions are documented in the case notes. *Guidance: The number, type and frequency of psychological interventions offered are informed by the evidence base.*	Core (8.1.1)

2.13	1	Activities are provided 7 days a week and out of hours. *Guidance: Activities which are provided during working hours, Monday–Friday, are timetabled.*	Core (8.1.6)
2.14	2	Every patient has a personalised timetable of meaningful activities to promote social inclusion, which the team encourages them to engage with. *Guidance: This includes activities such as education, employment, volunteering and other occupations such as leisure activities and caring for dependants.*	Core (8.1.7)
2.15	1	Every patient is engaged in active conversation at least twice a day by a staff member. *Guidance: This is an opportunity for patients to discuss any issues or difficulties they are experiencing.*	Core (8.1.8)
2.16	2	Each patient receives a pre-arranged session at least once a week with their key worker (or equivalent) to discuss progress, care plans and concerns. *Guidance: Include family or carers where appropriate.*	Core (8.1.9)
2.17	1	Patients and carers are offered accessible information about challenging behaviour, autism, sensory needs, physical health needs and the patient's mental illness. *Guidance: Verbal information could be provided in a 1:1 meeting with a staff member, a ward round or in a psycho-education group.*	Core (8.1.10)
2.18	2	There is a regular minuted community meeting that is attended by patients and staff members. *Guidance: This is an opportunity for patients to share experiences, to highlight issues on the ward/unit and to review the quality and provision of activities with staff members. The meeting should be facilitated by a professional who has an understanding of group dynamics. Actions should be followed up at each meeting. The frequency is agreed with the patient group.*	Core (8.1.11)
2.19	2	Patients have access to relevant faith-specific support, preferably through someone with an understanding of mental health issues.	Core (8.1.12)
2.20	1	Patients are able to leave the ward/unit to access safe outdoor space every day.	Core (8.1.13)
2.21	2	The team provides information, signposting and encouragement to patients to access local organisations for peer support and social engagement such as: • Voluntary organisations; • Community centres; • Local religious/cultural groups; • Peer support networks; • Recovery colleges.	Core (8.1.14)
2.22	1	All staff members who deliver therapies and activities are appropriately trained and supervised.	Core (8.1.15)
2.23	1	The patient and the team can obtain a second opinion if there is doubt, uncertainty or disagreement about the diagnosis or treatment.	Core (8.1.16)

Medication			
2.24	1	The indication(s) and rationale for prescribing psychotropic drugs is clearly stated, including whether the prescribing is off-label, polypharmacy or high dose.	Fac
2.25	1	Consent-to-treatment procedures (or best interest decision-making processes) should be followed and documented.	Fac
2.26	1	Patients and their carers (with patient consent) are helped to understand the functions, expected outcomes, limitations and side effects of their medications and to self-manage as far as possible. *Guidance: Best interest processes are followed if the patient does not have the capacity to consent.*	Core (8.2.2)
2.27	1	Patients have their medications reviewed at least weekly. Medication reviews include an assessment of therapeutic response, safety, side effects and adherence to medication regime. *Guidance: Side effect monitoring tools can be used to support reviews.*	Core (8.2.3)
2.28	1	Review and evaluation of the need for continuation or discontinuation of the psychotropic drug should be undertaken on a regular basis (preferably every 3 months or less, at a minimum every 6 months) or whenever there is a request from patients, carers or other professionals.	Fac
2.29	1	When patients experience side effects from their medication, this is engaged with and there is a clear care plan in place for managing this.	Core (8.2.4)
2.30	1	The team follows a policy when prescribing PRN (i.e. as required) medication.	Core (8.2.5)
2.31	1	All staff members who administer medications have been assessed as competent to do so. Assessment is repeated on a yearly basis using a competency-based tool.	Core (8.2.6)
2.32	2	Patients have access to a specialised pharmacist and/or pharmacy technician to discuss medications.	Core (8.2.8)
2.33	1	The safe use of high risk medication is audited, at least annually and at a service level. *Guidance: This includes medications such as lithium, high dose antipsychotic drugs, antipsychotics in combination, benzodiazepines.*	Core (8.2.10)
Physical healthcare			
Physical healthcare, personal hygiene and substance misuse			
2.34	1	Patients have follow-up investigations and treatment when concerns about their physical health are identified during their admission. *Guidance: This is undertaken promptly and a named individual is responsible for follow-up. Advice may be sought from primary or secondary physical healthcare services.*	Core (9.1.1)
2.35	1	The team gives targeted lifestyle advice and provides health promotion activities for patients. This includes: • Smoking cessation advice; • Healthy eating advice; • Physical exercise advice and opportunities to exercise.	Core (9.1.2)

2.36	1	The team understands and follows an agreed protocol for the management of an acute physical health emergency. *Guidance: This includes guidance about when to call 999 and when to contact the duty doctor.*	Core (9.1.3)
Managing the physical health of patients on mood stabilisers or antipsychotics			
2.37	1	The physical health of long-stay patients who are prescribed mood stabilisers or antipsychotics are reviewed at the start of treatment (baseline), at 3 months and then annually unless a physical health abnormality arises. The clinician monitors the following information about the patient: • A personal/family history (at baseline and annual review); Lifestyle review (at every review); • Weight (every week for the first 6 weeks); • Waist circumference (at baseline and annual review); • Blood pressure (at every review); • Fasting plasma glucose/ HbA1c (glycated haemoglobin) (at every review); • Lipid profile (at every review).	Core (9.2.1)

3. Safety, discharge, capacity and consent

Risk and safeguarding			
3.1	1	The team receives training, consistent with their roles, on risk assessment and risk management. This is refreshed in accordance with local guidelines. This includes, but is not limited to, training on: • Safeguarding vulnerable adults and children; • Assessing and managing suicide risk and self-harm; • Prevention and management of aggression and violence; • Recognising and responding to the signs of abuse or neglect.	Core (10.1)
3.2	1	Patients are told about the level of observation that they are under, how it is instigated, the review process and how their own patient perspectives are taken into account.	Core (10.2)
3.3	1	If a patient is identified as at risk of absconding, the team completes a plan, which includes clear instructions for alerting and communicating with carers, people at risk and the relevant authorities.	Core (10.3)
3.4	1	The team effectively manages violence and aggression on the ward/unit. *Guidance:* • *Staff members do not deliberately restrain patients in a way that affects their airway, breathing or circulation;* • *Restrictive intervention always represents the least restrictive option to meet the immediate need;* • *Individualised support plans, incorporating behaviour support plans, are implemented for all patients who are known to be at risk of being exposed to restrictive interventions;* • *The team does not use seclusion or segregation other than for patients detained under the Mental Health Act (or equivalent) or unless in an emergency as a last resort;** • *The team works to reduce the amount of restrictive practice used;* • *Providers report on the use of restrictive interventions to service commissioners, who monitor and act in the event of concerns.* **If an emergency situation arises involving an informal patient and, as a last resort, seclusion is necessary to prevent harm to others, then an assessment for an emergency application for detention under the Act should be undertaken immediately.*	Core (10.4)
3.5	1	All staff involved in administering or prescribing rapid tranquillisation, or monitoring service users to whom parenteral rapid tranquillisation has been administered, have received training in immediate life support.	LD (5.48)
3.6	1	After any episode of control and restraint, or compulsory treatment including rapid tranquillisation, the team spends time with the patient reflecting on why this was necessary. The patient's views are sought and they are offered the opportunity to document this in their care record along with any disagreement with healthcare professionals.	Core (10.5)
3.7	1	After any episode of control and restraint, or compulsory treatment including rapid tranquillisation, the team makes sure that other patients on the ward/unit who are distressed by these events are offered support and time to discuss their experiences.	Core (10.6)
3.8	1	The team audits the use of restrictive practice, including face-down restraint. *Guidance: Audit data are used to compare the service to national benchmarks where possible.*	Core (10.7)

3.9	1	Staff members follow inter-agency protocols for the safeguarding of vulnerable adults and children. This includes escalating concerns if an inadequate response is received to a safeguarding referral.	Core (10.9)
Discharge planning and transfer of care			
3.10	2	Discharge planning is initiated at the first multi-disciplinary team review and a provisional discharge date is set.	Core (11.1)
3.11	1	Patients and their carer (with patient consent) are invited to a discharge meeting and are involved in decisions about discharge plans.	Core (11.2)
3.12	1	A letter setting out a clear discharge plan, which the patient takes home with them, is sent to the GP and any other relevant parties before or on the day of discharge. The plan includes details of: • Care in the community/aftercare arrangements; • Crisis and contingency arrangements including details of who to contact; • Medication; • Details of when, where and who will follow up with the patient.	Core (11.3)
3.13	1	The team follows a protocol to manage informal patients who discharge themselves against medical advice. This includes: • Recording the patient's capacity to understand the risks of self-discharge; • Putting a crisis plan in place; • Contacting relevant agencies to notify them of the discharge.	Core (11.4)
3.14	2	The inpatient team invites a community team representative to attend and contribute to ward rounds and discharge planning.	Core (11.5)
3.15	1	The team makes sure that patients who are discharged from hospital to the care of the community team have arrangements in place to be followed up within one week of discharge, or within 48 hours of discharge if they are at risk. *Guidance: This may be in coordination with the Home Treatment/Crisis Resolution Team.*	Core (11.6)
3.16	1	When patients are transferred between wards/units there is a handover which ensures that the new team have an up to date care plan and risk assessment.	Core (11.7)
3.17	2	Where there are delayed transfers/discharges: • The team can easily raise concerns about delays to senior management; • Local information systems produce accurate and reliable data about delays; • Action is taken to address any identified problems.	Core (11.8)
Interface with other services			
3.18	1	There are coherent care pathways in place to support patients in accessing other mental health services. *Guidance: This might include inviting the mental health service to attend ward rounds and take part in joint care planning.*	Core (12.1, 12.3)
3.19	1	The team follows a joint working protocol with primary health care teams. *Guidance: This includes the team informing the patient's GP of any significant changes in the patient's mental health or medication, or of their referral to other teams. It also includes teams following shared prescribing protocols with the GP and accessing summary care records.*	Core (12.2)

3.20	1	The team supports patients to access organisations which offer: • Housing support; • Support with finances, benefits and debt management. *Guidance: Housing advice and/or support is given to patients prior to discharge.*	Core (12.4)
3.21	2	There are protocols for joint working between learning disabilities and social care services.	LD (13.14)
Capacity and consent			
3.22	1	Capacity assessments are performed in accordance with current legislation.	Core (13.1)
3.23	1	Patients have an assessment of their capacity to consent to admission, care and treatment prior to admission and then within 24 hours of admission.	Core (13.2)
3.24	1	When patients lack capacity to consent to interventions, decisions are made in their best interests.	Core (13.3)
3.25	1	There are systems in place to ensure that the ward/unit takes account of any advance directives and statements that the patient has made.	Core (13.4)

4. Patient and carer experience

Patient involvement			
4.1	1	Patients and their carers are given the opportunity to feed back about their experiences of using the service, and their feedback is used to improve the service. *Guidance: This might include patient and carer surveys or focus groups.*	Core (14.1)
4.2	2	Patient representatives attend and contribute to local and service level meetings and committees.	Core (14.2)
Carer engagement and support			
Note: Carer involvement in the patient's care and treatment is subject to the patient giving consent and/or carer involvement being in the best interests of the patient.			
4.3	1	Carers are involved in discussions about the patient's care, treatment and discharge planning.	Core (15.1)
4.4	1	Carers are advised on how to access a statutory carers' assessment, provided by an appropriate agency.	Core (15.2)
4.5	2	Staff approach carers within 24 hours of the patient's admission to discuss concerns, family history and their own needs.	Core (15.3)
4.6	2	The team provides each carer with a carer's information pack. *Guidance: This includes the names and contact details of key staff members on the unit. It also includes other local sources of advice and support such as local carers' groups, carers' workshops and relevant charities.*	Core (15.4)
4.7	2	Carers have access to a carer support network or group. This could be provided by the ward/unit or the team could signpost carers to an existing network. *Guidance: This could be a group/network which meets face-to-face or communicates electronically.*	Core (15.5)
4.8	1	The team follows a protocol for responding to carers when the patient does not consent to their involvement.	Core (15.6)
4.9	2	The ward/unit has a staff member designated as the carer lead or champion.	Core (15.7)
Treating patients with compassion, dignity and respect			
4.10	1	Patients are treated with compassion, dignity and respect.	Core (16.1)
4.11	2	Patients feel listened to and understood in consultations with staff members.	Core (16.2)
Provision of information to patients and carers			
4.12	1	Information provided to patients is available in an accessible format. *Guidance: Information can be provided in languages other than English and in formats that are easy to use for people with sight/hearing/ cognitive difficulties and learning disabilities. For example; easy read, audio and video materials, using symbols and pictures, using plain English, communication passports and signers. In verbal and written communication, staff should avoid using jargon. Information is culturally relevant.*	Core (17.1)

4.13	1	There are processes in place to facilitate the understanding of information given to patients throughout their stay. Guidance: *Staff regularly check patients' understanding of information provided.*	GPP
4.14	1	The ward/unit has access to professional interpreters and the patient's relatives are not used in this role unless there are exceptional circumstances. *Guidance: Exceptional circumstances might include crisis situations where it is not possible to get an interpreter at short notice.*	Core (17.2)
Patient confidentiality			
4.15	1	Confidentiality and its limits are explained to the patient and carer on admission, in an accessible format. *Guidance: For carers this includes confidentiality in relation to third party information.*	Core (18.1)
4.16	1	All patient information is kept in accordance with current legislation. *Guidance: Staff members ensure that no confidential data is visible beyond the team by locking cabinets and offices, using swipe cards and having password protected computer access.*	Core (18.2)
4.17	1	The patient's consent to the sharing of clinical information outside the clinical team is recorded. If this is not obtained the reasons for this are recorded.	Core (18.3)

5. Environment and facilities

Ward/unit environment			
5.1	2	The ward has clear signage.	Core (19.1)
5.2	1	Male and female patients (self-defined by the patient) have separate bedrooms, toilets and washing facilities.	Core (19.2)
5.3	2	All patients have single bedrooms.	Core (19.3)
5.4	2	Patients are able to personalise their bedroom spaces.	Core (19.4)
5.5	2	The ward/unit has at least one bathroom/shower room for every three patients.	Core (19.5)
5.6	2	Laundry facilities are available to all patients.	Core (19.7)
5.7	1	Patients are supported to access materials and facilities that are associated with specific cultural or spiritual practices, e.g. covered copies of faith books, access to a multi-faith room.	Core (19.8)
5.8	2	All patients can access a range of current culturally-specific resources for entertainment, which reflect the ward/unit's population. *Guidance: This may include recent magazines, daily newspapers, board games, a TV and DVD player with DVDs, computers, charge points for mobile phones and electronic devices and internet access (where risk assessment allows this).*	Core (19.9)
5.9	1	The environment complies with current legislation on disabled access. *Guidance: Relevant assistive technology equipment, such as hoists and handrails, are provided to meet individual needs and to maximise independence.*	Core (19.11)
5.10	1	Patients can wash and use the toilet in private.	Core (19.12)
5.11	1	Staff members respect the patient's personal space, e.g. by knocking and waiting before entering their bedroom.	Core (19.13)
5.12	1	Patients can make and receive telephone calls in private (subject to risk).	Core (19.14)
5.13	1	Staff members follow a policy on managing patients' use of cameras, mobile phones and other electronic equipment, to support the privacy and dignity of all patients on the ward/unit.	Core (19.15)
5.14	1	There is a visiting policy which includes procedures to follow for specific groups including: • Children; • Unwanted visitors (i.e. those who pose a threat to patients, or to staff members).	Core (19.16)
5.15	1	Staff members follow a protocol when conducting searches of patients and their personal property.	Core (19.17)
5.16	1	An audit of environmental risk is conducted annually and a risk management strategy is agreed. *Guidance: This includes an audit of ligature points.*	Core (19.18)
5.17	1	There are clear lines of sight to enable staff members to view patients. Measures are taken to address blind spots and ensure sightlines are not impeded, e.g. by using mirrors.	Core (19.19)
5.18	1	Staff, patients and visitors are able to raise alarms at any stage, i.e. using panic buttons, strip alarms, or personal alarms.	Core (19.22, 19.23)

5.19	1	A collective response to alarm calls is rehearsed at least 6 monthly.	Core (19.24)
5.20	1	All rooms are kept clean. *Guidance: All staff members are encouraged to help with this.*	Core (19.25)
5.21	2	Staff members and patients can control heating, ventilation and light. *Guidance: For example patients are able ventilate their rooms through the use of windows and have access to light switches and can request adjustments to control heating.*	Core (19.26)
5.22	1	Emergency medical resuscitation equipment (crash bag), as required by Trust/organisation guidelines, is available within 3 minutes.	Core (19.28)
5.23	1	The crash bag is maintained and checked weekly, and after each use.	Core (19.29)
5.24	2	The ward/unit has a designated room for physical examination and minor medical procedures.	Core (19.30)
5.25	1	In wards/units where seclusion is used, there is a designated room that meets the following requirements: • It allows clear observation; • It is well insulated and ventilated; • It has direct access to toilet/washing facilities; • It is safe and secure – it does not contain anything that could be potentially harmful; • It includes a means of two-way communication with the team; • It has a clock that patients can see.	Core (19.31)
5.26	2	The ward/unit has at least one quiet room other than patient bedrooms for patients to relax in.	Core (19.32)
5.27	2	There is a designated space for patients to receive visits from children, with appropriate facilities such as toys, books. *Guidance: The children should only visit if they are the offspring of or have a close relationship with the patient and it is in the child's best interest to visit.*	Core (19.33)
5.28	2	There is a designated area or room (de-escalation space) that the team may consider using, with the patient's agreement, specifically for the purpose of reducing arousal and/or agitation.	Core (19.34)
5.29	2	There are lounge areas that may become single-sex areas as required.	Core (19.35)
5.30	2	There are facilities for patients to make their own hot and cold drinks and snacks.	Core (19.37)
5.31	1	Patients are provided with meals which offer choice, address nutritional/balanced diet and specific dietary requirements and which are also sufficient in quantity. Meals are varied and reflect the individual's cultural and religious needs.	Core (19.38)
5.32	2	Staff members ask patients for feedback about the food and this is acted upon.	Core (19.39)
5.33	2	Where smoking is permitted, there is a safe allocated area for this purpose.	Core (19.40)
5.34	2	Patients are consulted about changes to the ward/unit environment.	Core (19.42)

6. Leadership, workforce and governance

Leadership and culture			
6.1	1	Staff members and patients feel confident to contribute to and safely challenge decisions. *Guidance: This includes decisions about care, treatment and how the ward/unit operates.*	Core (20.6)
6.2	1	Staff members feel able to raise any concerns they may have about standards of care.	Core (20.7)
Team working			
6.3	1	When the team meets for handover, adequate time is allocated to discuss patients' needs, risks and management plans.	Core (21.1)
Staffing levels and skill mix			
6.4	1	The multidisciplinary team includes or has dedicated sessional time from: • Psychiatrists • Registered Nurses • Healthcare Assistants • Registered Psychologists • Occupational Therapists • Speech and Language Therapists • Social Workers	GPP
6.5	1	The ward/unit has a mechanism for responding to low staffing levels, when they fall below minimum agreed levels, including: • A method for the team to report concerns about staffing levels; • Access to additional staff members; • An agreed contingency plan, such as the minor and temporary reduction of non-essential services.	Core (22.2)
6.6	2	The ward/unit is staffed by permanent staff members, and bank and agency staff members are used only in exceptional circumstances, e.g. in response to additional clinical need.	Core (22.3)
6.7	2	If the ward/unit uses bank and agency staff members, the service manager monitors their use on a monthly basis. An overdependence on bank and agency staff members results in action being taken.	Core (22.4)
6.8	1	There is an identified duty doctor available at all times to attend the ward/unit, including out of hours. The doctor can: • Attend the ward/unit within 30 minutes in the event of a psychiatric emergency; • Attend the ward/unit within 1 hour during normal working hours; • Attend the ward/unit within 4 hours when out of hours.	Core (22.5)
Staff recruitment and induction			
6.9	2	Patient or carer representatives are involved in interviewing potential staff members during the recruitment process.	Core (23.1)
6.10	1	New staff members, including bank and agency staff, receive an induction based on an agreed list of core competencies. *Guidance: This should include arrangements for shadowing colleagues on the team; jointly working with a more experienced colleague; being observed and receiving enhanced supervision until core competencies have been assessed as met.*	Core (23.3)

Appraisal, supervision and support			
6.11	1	All staff members receive an annual appraisal and personal development planning (or equivalent). *Guidance: This contains clear objectives and identifies development needs.*	Core (24.1)
6.12	1	All clinical staff members receive clinical supervision at least monthly, or as otherwise specified by their professional body. *Guidance: Supervision should be profession-specific as per professional guidelines and provided by someone with appropriate clinical experience and qualifications.*	Core (24.2)
6.13	2	Staff members in training and newly qualified staff members receive weekly supervision.	Core (24.3)
Staff wellbeing			
6.14	1	The ward/unit actively supports staff health and well-being. *Guidance: For example, providing access to support services, monitoring staff sickness and burnout, assessing and improving morale, monitoring turnover, reviewing feedback from exit reports and taking action where needed.*	Core (25.1)
6.15	1	Staff members are able to take breaks during their shift that comply with the European Working Time Directive.	Core (25.2)
6.16	2	Staff members have access to reflective practice groups.	Core (25.3)
Staff training and development			
6.17	1	Clinical staff members have received formal training to perform as a competent practitioner, or, if still in training, are practising under the supervision of a senior qualified clinician.	Core (26.2)
6.18		Staff members receive training consistent with their role, which is recorded in their personal development plan and is refreshed in accordance with local guidelines. This training includes:	Core (26.3)
6.19	1	The use of legal frameworks, such as the Mental Health Act (or equivalent) and the Mental Capacity Act (or equivalent);	Core (26.3a)
6.20	1	Physical health assessment; *Guidance: This could include training in understanding physical health problems, physical observations and when to refer the patient for specialist input.*	Core (26.3b)
6.21	1	Recognising and communicating with patients with cognitive impairment, learning disabilities or developmental disabilities	Core (26.3c)
6.22	1	Statutory and mandatory training; *Guidance: Includes equality and diversity, information governance.*	Core (26.3d)
6.23	2	Carer awareness, family inclusive practice and social systems, including carers' rights in relation to confidentiality.	Core (26.3f)
6.24	2	Patients and carers are involved in delivering training to staff members.	Core (26.4)

6.25	1	All staff have received awareness training in how to communicate effectively with people within the context of a person centred approach. *Guidance: This should include:* • *The person's preferred means of communicating;* • *Use of different communication methods and visual aids;* • *Tone of voice, non-verbal communication and appropriate language;* • *Active listening techniques;* • *Recognising when people might be distressed, or suggestible/acquiescing;* • *The link between communication and challenging behaviour;* • *Checking the patient's comprehension of the information being given to them.*	LD (5.44)
Clinical outcome measurement			
6.26	2	Clinical outcome monitoring includes reviewing patient progress against patient-defined goals in collaboration with the patient.	Core (28.2)
Audit and service evaluation			
6.27	2	A range of local and multi-centre clinical audits is conducted which include the use of evidence based treatments, as a minimum.	Core (29.1)
6.28	2	When staff members undertake audits they: • Have some say in what audit topics are chosen; • Agree and implement action plans in response to audit reports; • Disseminate information (audit findings, action plan); • Complete the audit cycle.	Core (29.3)
The ward/unit learns from incidents			
6.29	1	Systems are in place to enable staff members to quickly and effectively report incidents and managers encourage staff members to do this.	Core (30.1)
6.30	1	Staff members share information about any serious untoward incidents involving a patient with the patient themself and their carer, in line with the Statutory Duty of Candour.	Core (30.2)
6.31	1	Staff members, patients and carers who are affected by a serious incident are offered a debrief and post incident support.	Core (30.3)
6.32	1	Lessons learned from incidents are shared with the team and disseminated to the wider organisation.	Core (30.4)
6.33	2	Key clinical/service measures and reports are shared between the team and the organisation's board, e.g. findings from serious incident investigations and examples of innovative practice.	Core (30.5)

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[1] For the full list of advisory group members please visit www.rcpsych.ac.uk/QNLD.

Key to references

These standards were derived from the following documents:

Core	Royal College of Psychiatrists (2015) Standards for Inpatient Mental Health Services.
Fac	Royal College of psychiatrists (2016) Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviour that challenge: practice guidelines. Faculty of Psychiatric of Intellectual Disability. Faculty Report.
GPP	'Good Practice Principle': established by expert consensus (see acknowledgements page for details of those who contributed).
LD	Royal College of Psychiatrists (2012). Accreditation for Acute Inpatient Mental Health Services (AIMS): Standards for Adult Inpatient Learning Disability Units – Assessment and Treatment Units (2nd Edition).

For more details on the source documents please email LD@rcpsych.ac.uk.

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COLLEGE CENTRE FOR QUALITY IMPROVEMENT

NICE National Institute for Health and Care Excellence

NICE guideline

Transition between inpatient mental health settings and community or care home settings

NICE guideline
Published: 30 August 2016
www.nice.org.uk/guidance/ng53

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

Overview 5
Who is it for? 5
Recommendations 6
1.1 Overarching principles 6
1.2 Before hospital admission 8
1.3 Hospital admission 10
1.4 Support for families, parents and carers throughout admission 16
1.5 Hospital discharge 18
1.6 Follow-up support 23
Terms used in this guideline 27
Carers 27
Coping strategies 27
Discharge letter 27
Discharge summary 27
Observation 27
Psychoeducation 19
Recovery 28
Therapeutic relationships 28
Implementation: getting started 29
Challenges for implementation 29
Context 33
Finding more information and committee details 35
Recommendations for research 36
1 Care and support for people with dementia 36
2 People with complex needs other than dementia 36
3 Children and young people in transition between settings 37

Update information 39

This guideline is the basis of QS159.

Overview

This guideline covers the period before, during and after a person is admitted to, and discharged from, a mental health hospital. It aims to help people who use mental health services, and their families and carers, to have a better experience of transition by improving the way it's planned and carried out.

The Care Quality Commission uses NICE guidelines as evidence to inform the inspection process.

Who is it for?

- Providers of care and support in inpatient and community mental health and social care services
- Front-line practitioners and managers in inpatient and community mental health and social care services
- Commissioners of mental health services
- People who use inpatient and community mental health services, their families and carers

Recommendations

Although most of the recommendations in this guideline cover both planned and unplanned admissions, some (like those on pre-admission planning) are only applicable to planned admissions. If an admission is unplanned, then these recommendations should be applied at the soonest possible point after admission, if appropriate to the person's individual circumstances. Use this guideline alongside NICE guidance on mental health services.

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 Overarching principles

1.1.1 Ensure the aim of care and support of people in transition is person-centred and focused on recovery.

1.1.2 Work with people as active partners in their own care and transition planning. For more information, see the section on relationships and communication in the NICE guideline on service user experience in adult mental health.

1.1.3 Support people in transition in the least restrictive setting available (in line with the Mental Health Act Code of Practice).

1.1.4 Record the needs and wishes of the person at each stage of transition planning and review.

1.1.5 Identify the person's support networks. Work with the person to explore ways in which the people who support them can be involved throughout

their admission and discharge.

1.1.6 Enable the person to maintain links with their home community by:

- supporting them to maintain relationships with family and friends, for example, by finding ways to help with transport
- helping them to stay in touch with social and recreational contacts
- helping them to keep links with employment, education and their local community.

  This is particularly important if people are admitted to mental health units outside the area in which they live.

1.1.7 Mental health services should work with primary care, local authorities and third sector organisations to ensure that people with mental health problems in transition have equal access to services. This should be based on need and irrespective of:

- gender
- sexual orientation
- socioeconomic status
- age
- disability
- cultural, ethnic and religious background
- whether or not they are receiving support through the Care Programme Approach
- whether or not they are subject to mental health legislation.

1.1.8 Give people in transition comprehensive information about treatments and services for their mental health problems at the time they need it. If required, provide information:

- in large-print, braille or Easy Read format

- by audio or video
- in translation.

For more information, see the section on care and support across all points on the care pathway in the NICE guideline on service user experience in adult mental health.

1.2 Before hospital admission

Planning and assessment

1.2.1 Mental health practitioners supporting transition should respond quickly to requests for assessment of mental health from:

- people with mental health problems
- family members
- carers
- primary care practitioners (including GPs)
- specialist community teams (for example, learning disability teams)
- staff such as hostel, housing and community support workers.

Assessments for people in crisis should be prioritised.

1.2.2 If admission is being planned for a treatment episode involve:

- the person who is being admitted
- their family members, parents or carers
- community accommodation and support providers.

1.2.3 When planning treatment for people being admitted, take account of the expertise and knowledge of the person's family members, parents or carers.

1.2.4 Allow more time and expert input to support people with complex, multiple or specific support needs to make transitions to and from services, if necessary. This may include:

- children and young people
- people with dementia, cognitive or sensory impairment
- people on the autistic spectrum
- people with learning disabilities and other additional needs
- people placed outside the area in which they live.

1.2.5 For planned admissions, offer people an opportunity to visit the inpatient unit before they are admitted. This is particularly important for:

- children and young people
- people with dementia, cognitive or sensory impairment
- people on the autistic spectrum
- people with learning disabilities and other additional needs
- people placed outside the area in which they live.

1.2.6 If it is not possible for the person to visit the inpatient unit that they will be admitted to in advance, consider using accessible online and printed information to support discussion about their admission.

1.2.7 During admission planning, record a full history or update that:

- covers the person's cognitive, physical and mental health needs
- includes details of their current medication
- identifies the services involved in their care.

For more information, see the section on medicines reconciliation in the NICE guideline on medicines optimisation.

1.2.8 If more than 1 team is involved in a person's transition to, within and from

a service, ensure there is ongoing communication between the inpatient team and other relevant teams that include:

- community health or social care providers, such as:
  - the community mental health team
  - the learning disability team
  - teams that work with older people
- child and adolescent mental health services (CAMHS)
- housing support teams
- general hospital or psychiatric liaison teams.

Crisis plans

1.2.9 Support people who have had more than 1 admission to develop a crisis plan as part of their care planning process. This should include:

- relapse indicators and plans
- who to contact in a crisis
- coping strategies
- preferences for treatment and specific interventions
- advance decisions.

For more information, see the section on community care in the NICE guideline on service user experience in adult mental health.

1.3 Hospital admission

General principles

1.3.1 Start building therapeutic relationships as early as possible to:

- lessen the person's sense of being coerced
- encourage the person to engage with treatment and recovery programmes and collaborative decision-making
- create a safe, contained environment
- reduce the risk of suicide, which is high during the first 7 days after admission.

  This is particularly important for people who have been admitted in crisis.

1.3.2 Practitioners involved in admission should refer to crisis plans and advance statements when arranging care.

1.3.3 Advance decisions must be followed in line with the Mental Capacity Act 2005. For more information on advance decisions as part of advanced care planning, see the NICE guideline on decision-making and mental capacity.

1.3.4 At admission, offer all people access to advocacy services that take into account their:

- language and communication needs
- cultural and social needs
- protected characteristics (see the GOV.UK page about discrimination).

1.3.5 Health and social care practitioners admitting someone with cognitive difficulties should try to ensure the person understands why they have been admitted.

1.3.6 During admission, discuss with the person:

- any strategies for coping that they use
- how they can continue to use, adapt and develop positive coping strategies on the ward.

1.3.7 Start discharge planning at admission or as early as possible when in crisis (for more information, see section 1.5).

1.3.8 For recommendations on assessing and treating people who have been detained under the Mental Health Act, see the section on assessment and treatment in the NICE guideline on service user experience in adult mental health.

1.3.9 For recommendations on crisis, including crisis admissions, see the section on assessment and referral in a crisis in the NICE guideline on service user experience in adult mental health.

Out-of-area admissions

1.3.10 If the person is being admitted outside the area in which they live, identify:

- a named practitioner from the person's home area who has been supporting the person
- a named practitioner from the ward they are being admitted to.

1.3.11 The named practitioners from the person's home area and the ward should work together to ensure that the person's current placement lasts no longer than required. This should include reviewing the person's care plan, current placement, recovery goals and discharge plan at least every 3 months, or more frequently according to the person's needs. This could be done in person or by audio or videoconference.

1.3.12 For people admitted to hospital outside the area in which they live, take into account the higher risk of suicide after discharge at all stages of the planning process (see the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness). This should include:

- assessing the risk
- discussing with the person how services can help them to stay safe
- discussing with the person's family members, parents or carers how they can help the person to stay safe.

Legal status of person being admitted

1.3.13 The senior health professional responsible for the admission should tell the person being admitted about their legal status at the point of admission. They should:

- use clear language
- discuss rights and restrictions with the person
- provide written and verbal information
- make the discussion relevant to the ward the person is being admitted to
- explain whether they are under observation and what this means (see observations and restrictions).

1.3.14 A senior health professional should ensure that discussions take place with the person being admitted to check that:

- they have understood the information they were given at admission
- they know they have a right to appeal, and that information and advocacy can be provided to support them to do so if they wish
- they understand that any changes to their legal status and treatment plans will be discussed as they occur.

Observations and restrictions

1.3.15 The admitting nurse or person responsible should tell the person what level of observation they are under and:

- explain what being under observation means
- explain clearly the reasons why the person is under observation and when, or under what circumstances, this will be reviewed
- explain how they will be observed and how often
- explain how observation will support their recovery and treatment

- discuss with the person how their preferences will be respected and how their rights to privacy and dignity will be protected
- offer the person an opportunity to ask questions.

1.3.16 Ensure that restrictions, including restrictions on access to personal possessions:

- are relevant and reasonable in relation to the person concerned
- take into consideration the safety of the person and others on the ward
- are explained clearly to ensure the person understands:
  - why the restrictions are in place
  - under what circumstances they would be changed.

Addressing personal concerns

1.3.17 To support the person's transition to the ward the admitting nurse or person responsible should make the following items available if the person needs them:

- a toothbrush
- hygiene products
- nightwear.

  This is particularly important for people who have been admitted in crisis.

1.3.18 Give the person verbal and written information about ward facilities and routines (see the section on hospital care in the NICE guideline on service user experience in adult mental health).

1.3.19 At admission, a senior healthcare professional should discuss all medication and care needs with the person being admitted. This should include:

- physical healthcare needs

- pregnancy, breastfeeding or the need for emergency contraception
- advice about immediate addiction issues, treatment and support
- mental health treatment.

1.3.20 The admitting nurse or person responsible should discuss with the person how to manage domestic and caring arrangements and liaise with the appropriate agencies. This may include:

- people they have a responsibility to care for, such as:
  - children
  - frail or ill relatives
- domestic arrangements, in particular:
  - home security
  - tenancy
  - benefits
  - home care service
  - pets.

1.3.21 On admission, ensure people (particularly children and young people) know who they can talk to if they are frightened or need support. For more information, see the section on hospital care in the NICE guideline on service user experience in adult mental health.

1.3.22 Identify whether the person has any additional need for support, for example, with daily living activities. Work with carers and community-based services, such as specialist services for people with learning or physical disabilities, to provide support and continuity while the person is in hospital.

1.4 Support for families, parents and carers throughout admission

1.4.1 Identify a named practitioner who will make sure that the person's family members, parents or carers receive support and timely information (see the section on sharing information with families, parents and carers).

1.4.2 Practitioners should start to build relationships with the person's family members, parents or carers during admission. This should be done:

- in an empathetic, reassuring and non-judgemental way
- acknowledging that admission to hospital can be particularly traumatic for families and carers, particularly if it is the person's first admission.

1.4.3 Arrange for parents to have protected time at an early point in the process of admitting their child to discuss the process with the relevant practitioners.

1.4.4 Try to accommodate parents' or carers' working patterns and other responsibilities so that they can attend meetings (if the person they care for wants this). This should include:

- care planning meetings
- discharge planning meetings
- other meetings concerning the care of the person.

Sharing information with families, parents and carers

1.4.5 Respect the rights and needs of carers alongside the person's right to confidentiality. Review the person's consent to share information with family members, carers and other services during the inpatient stay. For more information, see the subsection on involving families and carers in the NICE guideline on service user experience in adult mental health.

1.4.6 Throughout admission, give families, parents or carers clear, accessible information about:

- the purpose of the admission
- the person's condition (either general, or specific if the person agrees to this)
- the treatment, care and support that the person is receiving
- the inpatient unit, including:
  - the ward and the wider hospital environment
  - the practicalities of being in hospital
  - resources that are available, including accommodation for families
  - visiting arrangements
- preparing for discharge.

1.4.7 Give families, parents and carers information about support services in their area that can address emotional, practical and other needs (this is particularly important if this is the person's first admission).

1.4.8 Give young carers (under 18) of people in transition relevant information that they are able to understand.

Carers' assessments

1.4.9 Practitioners involved in admission and discharge should always take account of carers' needs, especially if the carer is likely to be a vital part of the person's support after discharge.

1.4.10 Identify carers (including young carers) who have recognisable needs. If the carer wishes it, make a referral to the carer's local authority for a carer's assessment (in line with the Care Act 2014). Ensure a carer's assessment has been offered, or started, before the person is discharged from hospital.

See the NICE guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers.

1.5 Hospital discharge

1.5.1 Health and social care practitioners in the hospital and community should plan discharge with the person and their family, carers or advocate. They should ensure that it is collaborative, person-centred and suitably-paced, so the person does not feel their discharge is sudden or premature. For more information, see discharge and transfer of care in the NICE guideline on service user experience in adult mental health.

Maintaining links with the community

1.5.2 Work with the person throughout their hospital stay to help them:

- keep links with their life outside the hospital (see recommendation 1.1.6)
- restart any activities before they are discharged.

  This is particularly important for people who need a long-term inpatient stay, are placed out-of-area, or who will have restricted access to the community.

1.5.3 Before discharge offer:

- phased leave (the person can have trial periods out of hospital before discharge)
- phased return to employment or education (the person can gradually build up hours spent in employment or education).

  This is particularly important for people who have been in hospital for an extended period and people who have had restricted access to the community.

1.5.4 Before discharging a person who is in education or training, arrange a planning meeting between them and a named person from the education setting to plan their return to learning.

Education – for people under 18

1.5.5 Children and young people under 18 must have continued access to education and learning throughout their hospital stay, in line with the

Education Act 1996.

1.5.6 Before the child or young person goes back into community-based education or training:

- identify a named worker from the education or training setting to be responsible for the transition
- arrange a meeting between the named worker and the child or young person to plan their return.

Accommodation

1.5.7 Before discharging people with mental health needs, discuss their housing arrangements to ensure they are suitable for them and plan accommodation accordingly. This should take into account any specific accommodation and observation requirements associated with risk of suicide.

1.5.8 Give people with serious mental health issues who have recently been homeless, or are at risk of homelessness, intensive, structured support (in line with the Homelessness Reduction Act 2017) to find and keep accommodation. This should:

- be started before discharge
- continue after discharge for as long as the person needs support to stay in secure accommodation
- focus on joint problem-solving, housing and mental health issues.

Helping the person to prepare for discharge

1.5.9 Before discharge, offer a series of individualised psychoeducation sessions for people with psychotic illnesses to promote learning and awareness. Sessions should:

- start while the person is in hospital

- continue after discharge so the person can test new approaches in the community
- cover:
  - symptoms and their causes
  - what might cause the person to relapse, and how that can be prevented
  - psychological treatment
  - coping strategies to help the person if they become distressed
  - risk factors
  - how the person can be helped to look after themselves
- be conducted by the same practitioner throughout if possible.

1.5.10 Consider psychoeducation sessions for all people with other diagnoses as part of planning discharge and avoiding readmission.

1.5.11 During discharge planning, consider group psychoeducation support for carers. This should include signposting to information on the specific condition of the person they care for.

1.5.12 Consider a staged, group-based psychological intervention for adults with bipolar disorder who have had at least 1 hospital admission and are being discharged from hospital. This should include:

- evaluation by a psychiatrist within 2 weeks of discharge
- 3 sequential sets of group sessions led by trained practitioners that focus on, respectively:
  - people's current mental health and recent experiences in hospital
  - psychoeducation or cognitive behavioural therapy
  - early warning signs and coping strategies.

Peer support

1.5.13 For people being discharged from hospital, consider a group-based, peer-delivered self-management training programme as part of recovery planning. Sessions should:

- continue for up to 12 weeks
- be delivered in groups of up to 12 members
- provide an opportunity for social support
- cover:
  - self-help, early warning signs and coping strategies
  - independent living skills
  - making choices and setting goals.

1.5.14 Consider providing peer support to people with more than 1 previous hospital admission. People giving peer support should:

- have experience of using mental health services
- be formally recruited, trained and supervised.

Care planning to support discharge

1.5.15 Ensure that there is a designated person responsible for writing the care plan in collaboration with the person being discharged (and their carers if the person agrees).

1.5.16 Write the care plan in clear language. Avoid jargon and explain difficult terms.

1.5.17 Ensure the care plan is based on the principles of recovery and describes the support arrangements for the person after they are discharged.

1.5.18 If a person is being discharged to a care home, involve care home managers and practitioners in care planning and discharge planning.

1.5.19 Ensure frequent, comprehensive review of the person's care plan and progress toward discharge.

1.5.20 Send a copy of the care plan to everyone involved in providing support to the person at discharge and afterwards. It should include:

- possible relapse signs
- recovery goals
- who to contact
- where to go in a crisis
- budgeting and benefits
- handling personal budgets (if applicable)
- social networks
- educational, work-related and social activities
- details of medication (see the recommendations on medicines-related communication systems in the NICE guideline on medicines optimisation)
- details of treatment and support plan
- physical health needs including health promotion and information about contraception
- date of review of the care plan.

Preparing for discharge

1.5.21 Mental health practitioners should carry out a thorough assessment of the person's personal, social, safety and practical needs to support discharge. The assessment should include risk of suicide (see recommendations 1.6.6–1.6.8). It should:

- relate directly to the setting the person is being discharged to
- fully involve the person

- be shared with carers (if the person agrees)
- explore the possibility of using a personal health or social care budget and ensure the person understands about charges for social care
- cover aftercare support, in line with section 117 of the Mental Health Act 1983
- cover aspects of the person's life including:
  - daytime activities such as employment, education and leisure
  - food, transport, budgeting and benefits
  - pre-existing family and social issues and stressors that may have triggered the person's admission
  - ways in which the person can manage their own condition
  - suitability of accommodation.

1.5.22 Recognise that carers' circumstances may have changed since admission, and take any changes into account when planning discharge.

1.5.23 Before the person is discharged:

- let carers know about plans for discharge
- discuss with carers the person's progress during their hospital stay and how ready they are for discharge
- ensure that carers know the likely date of discharge well in advance.

1.6 Follow-up support

1.6.1 Discuss follow-up support with the person before discharge. Arrange support according to their mental and physical health needs. This could include:

- contact details, for example of:
  - a community psychiatric nurse or social worker
  - the out-of-hours service
- support and plans for the first week
- practical help if needed
- employment support.

1.6.2 Consider booking a follow-up appointment with the GP to take place within 2 weeks of the person's discharge. Give the person a written record of the appointment details.

1.6.3 At discharge, the hospital psychiatrist should ensure that:

- Within 24 hours, a discharge letter is emailed to the person's GP. A copy should be given to the person and, if appropriate, the community team and other specialist services.
- Within 24 hours, a copy of the person's latest care plan is sent to everyone involved in their care (see recommendation 1.5.20).
- Within a week, a discharge summary is sent to the GP and others involved in developing the care plan, subject to the person's agreement. This should include information about why the person was admitted and how their condition has changed during the hospital stay.

1.6.4 If the person has a learning disability, dementia or is on the autistic spectrum, the hospital team should lead communication about discharge planning with the other services that support the person in the community. This could include:

- older people's services
- learning disability services
- the home care service.

1.6.5 If a person is being discharged to a care home, hospital and care home

practitioners should exchange information about the person. An example might be a hospital practitioner accompanying a person with cognitive impairment when they return to the care home to help their transition (see also sharing information about a resident's medicines in the NICE guideline on managing medicines in care homes).

1.6.6 In collaboration with the person, identify any risk of suicide and incorporate into care planning.

1.6.7 Follow up a person who has been discharged within 7 days.

1.6.8 Follow up a person who has been discharged within 48 hours if a risk of suicide has been identified.

1.6.9 Consider contacting adults admitted for self-harm, who are not receiving treatment in the community after discharge, and providing advice on:

- services in the community that may be able to offer support or reassurance
- how to get in touch with them if they want to.

Community treatment orders

1.6.10 Decide whether a community treatment order (CTO) or guardianship order is needed (see the Mental Health Act Code of Practice), based on:

- the benefit to the person (for example, it may be helpful for people who have had repeated admissions)
- the purpose (for example, to support the person to follow their treatment plan)
- the conditions and legal basis.

1.6.11 Ensure that the person who will be subject to the order has the opportunity to discuss why it is being imposed. Explain:

- the specific benefit for the person
- how to access advocacy (including their entitlement to an Independent Mental Health Advocate), and what this means

- what restrictions the order involves
- when it will be reviewed
- what will happen if the person does not comply with the order, and that this may not automatically lead to readmission.

1.6.12 Ensure that the conditions, purpose, legal basis and intended benefit of the order are explained to families, carers and others providing support.

Terms used in this guideline

Carers

A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally or through a voluntary organisation.

Coping strategies

Coping strategies are the methods a person uses to deal with stressful situations. The term is used in this guideline to refer to ways that people recognise changes and cope with their mental illness or related symptoms. Some coping strategies can have negative consequences for a person using them or for the people around them.

Discharge letter

A short document that includes the details of a person's current prescription, the reasons for any changes in medicines and their immediate medication treatment plan.

Discharge summary

A summary of what happened during a person's admission and hospital stay from a medical perspective. It must include the diagnosis, outcomes of investigations, changes to treatment and the medicines started or stopped, or dosage changes and reasons why.

Observation

An intervention in which a healthcare professional observes and maintains contact with a person using mental health services to ensure that person's safety and the safety of others. There are different levels of observation depending on how vulnerable to harm the person is considered to be.

Psychoeducation

Education sessions for people affected by mental illness and their families and carers. Psychoeducation uses shared learning to empower people to cope better. Sessions can cover areas such as recognising symptoms and triggers, preventing relapses and developing coping strategies. Carers learn how best to support the person. Sessions should start while the person is in hospital and run beyond discharge so the person can test approaches in their home setting.

Recovery

There is no single definition of recovery for people with mental health problems, but the guiding principle is the belief that it is possible for someone to regain a meaningful life, despite serious mental illness. In this guideline it is used to refer to someone achieving the best quality of life they can, while living and coping with their symptoms. It is an ongoing process whereby the person is supported to build up resilience and set goals to minimise the impact of mental health problems on their everyday life.

Therapeutic relationships

Relationships based on mutual trust, kindness and respect, focusing on the person's recovery goals.

For other social care terms, see the Think Local, Act Personal Care and Support Jargon Buster.

Implementation: getting started

This section highlights 3 areas of the transition between inpatient mental health settings and community and care home settings guideline that could have a big impact on practice and be challenging to implement, along with the reasons why change needs to happen in these areas. We identified these with the help of stakeholders and guideline committee members. For more information, see developing NICE guidelines: the manual. The manual also gives information on resources to help with implementation.

Challenges for implementation

The challenge: Delivering services that are person-centred and focus on recovery

See recommendations 1.1.1 to 1.1.4 and 1.5.1.

All practitioners have a role to play in ensuring care and support is provided in a therapeutic environment that is responsive to people's individual needs and choices while being focused on recovery. Creating the right culture needs skilled practitioners who work with people as active partners and have a good understanding of what makes a successful transition. People will benefit because they will experience care and support that is tailored to their needs and supports their recovery.

Transitions for people using acute mental health services can be complex. They often involve more than 1 agency and setting. Workload pressures in hospitals and community settings can lead to competing demands. A poor transition that is not person-centred can be stressful for people using mental health services and their families and carers. This can result in an unsatisfactory experience for all concerned and may impede recovery.

What can commissioners, managers and practitioners do to help?

- Embed principles of person-centred and recovery-focused care in all training, supervision and continuing professional development for practitioners involved in transitions. Publications from the Improving recovery through organisational change programme may be helpful; in particular those on supporting recovery in mental health services: quality and outcomes, making recovery a reality in forensic settings, peer support workers: a practical guide to implementation and recovery: a carer's perspective.
- Ensure that mental health and social care practitioners inexperienced in working with people from diverse backgrounds are able to seek advice, training and supervision from colleagues who do have this experience (in line with the section on community care in the NICE guideline on service user experience in adult mental health).
- Ensure that health and social care practitioners have opportunities to learn about the emotional and practical impact of transitions, change and loss. This should include discussion of the particular risks and challenges of transitions.
- Offer training opportunities to all professionals involved in assessments for admission under the Mental Health Act 2007. This includes police, community psychiatric nurses, approved mental health professionals, psychiatrists, GPs, ambulance staff, general hospital staff and psychiatric liaison staff. Training opportunities may include:
  - training delivered by people who use services
  - on-the-job learning
  - training done alongside other involved professionals.

The challenge: Ensuring effective communication between teams, and with people using services and their families and carers

See recommendations 1.1.5 and 1.1.8, 1.2.8, 1.3.10 to 1.3.14 and 1.4.1 to 1.4.8.

Good communication is important – both between health and social care practitioners working in multidisciplinary teams and between practitioners and people using mental health services (and their families, parents or carers). Good communication leads to better coordinated care and a better experience for the person.

Practitioners need to work together, across physical and professional boundaries, to ensure that people experience good transition. People need help to stay in touch with their life outside the hospital, including relationships, employment, education and their local community. But this can be particularly hard if they live some distance from the hospital, or if a number of agencies are involved.

What can commissioners and managers do to help?

- Ensure that effective systems are in place to help practitioners communicate effectively.

What can health and social care practitioners do to help?

- Ensure that information about people is shared with colleagues if appropriate (in line with information-sharing protocols).
- If people are placed outside the area in which they live, ensure that good communications are maintained, both between practitioners in different services and between practitioners and people using services (and their families and carers).
- Ensure that there is good communication between service providers and people using mental health services (and, if appropriate, their families and carers).
- Offer information on treatment and services to people at the point they need it.
- Think carefully about what information people need and how to make sure they have understood it. This could be checked during a conversation with the person when they are feeling less unwell.

The challenge: Co-producing comprehensive care plans that meet people's changing needs

See recommendations 1.1.2 and 1.1.4, 1.2.2 to 1.2.3, 1.3.15 and 1.6.10 to 1.6.11.

Co-producing care plans with people helps them to feel more in control and be active partners in their own care and recovery. Care plans should draw on all forms of documented treatment intentions and preferences relating to the person (including crisis plans, discharge and recovery plans, and Care Programme Approach documentation). Lack of coordination between plans can result in frustration and stress if people are asked for

information repeatedly. Plans should be reviewed regularly. Planning early for each stage of admission and discharge can ensure better continuity of care and a better experience for the person as they move between services.

Requiring practitioners to explain to people and their carers why a restriction (involuntary admission, observation or community treatment order) has been applied is likely to lead to improved communication with people and their carers. It will also support more reflective practice.

Identifying the person's family or carers early on means they can be more involved in the person's care and support from an earlier stage. It can also aid practitioners' understanding of the person and their needs.

Building in the flexibility to pace a transition according to a person's cognitive and communication needs may mean that changes are needed to the way things are usually done.

What can commissioners and managers do to help?

- Ensure that health and social care practitioners involved in transitions to and from mental health hospitals have the skills to:
  - carry out needs assessments
  - develop care and discharge plans in collaboration with the person.

What can health and social care practitioners do to help?

- Ensure that all planning is person-centred and involves the person as an active partner in their care.
- Start all plans at the earliest possible opportunity.
- Focus planning on enabling people to have a seamless transition into and out of hospital.
- Recognise that care plans are 'living documents' that should be regularly reviewed and take account of changed circumstances.

Context

Poor transition between inpatient mental health settings and community or care home settings has negative effects on people using services and their families and carers. A key issue affecting transitions between inpatient mental health settings and the community is a lack of integrated and collaborative working between mental health and social care services, and between practitioners based in hospitals and those in the community. Both can result in inadequate and fragmented support for people using mental health services.

People who use inpatient mental health services and their families and carers have reported a number of problem areas:

- delayed assessment and admission, so that the person is not treated until they are in crisis
- inadequate planning for – and support after – discharge, resulting in readmissions
- the person and their family or carers not being involved in planning admission, treatment and discharge
- people being discharged having no help to manage the mental health symptoms and other problems that contributed to their admission
- failure to give people the information, advocacy and support they need
- failure to arrange support to help the person reintegrate into the life they want to lead in the community (for example, returning to employment, education and social activities).

The consequences of a poor transition can be very serious for the person and their family or carers. For example, the University of Manchester's National Confidential Inquiry into Suicide and Homicide by People with Mental Illness found that, between 2003 and 2013 in England, 2,368 mental health patients died by suicide in the first 3 months after being discharged from hospital (compared with 1,295 inpatient deaths in the same period).

Older people are sometimes discharged to care homes when they might have been able to return to their own homes if extra support, such as home care, had been arranged in advance.

The impact of poor discharge planning on young people who are not supported to reintegrate into education and training can have long-lasting consequences for their life chances.

People placed in inpatient facilities away from their home communities are particularly vulnerable to delayed discharges, because case management is difficult at a distance. Delayed discharge is an unnecessary expense to the NHS, but also has consequences for patients, who may become dependent on inpatient care, lose coping skills that they will need after discharge, and find that personal relationships are damaged, and housing or jobs lost.

This guideline is about everyone who uses mental health inpatient facilities, including children, young people and adults, and people who have other health issues and care needs. It primarily covers transitions – admissions and discharges – and makes recommendations about how they might be handled in order to maximise the benefits of the treatment being offered, and continuity of care. It includes people who are admitted from, or discharged to, care homes and other community settings. The guideline also covers the preparation for discharge that takes place during the inpatient stay.

Finding more information and committee details

You can see everything NICE says on this topic in the NICE Pathway on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on service transition.

For full details of the evidence and the guideline committee's discussions, see the full guideline and appendices. 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 our guidelines into practice, see resources to help you put NICE guidance into practice.

Recommendations for research

The guideline committee has made the following recommendations for research.

1 Care and support for people with dementia

What is the effect of specific interventions to support people with dementia during transition between inpatient mental health settings and community or care home settings?

Why this is important

The review did not identify any studies about transition for people with dementia from or to inpatient mental health settings. This is one of the groups identified in the equality impact assessment that need special consideration.

Mental health disorders may be under-diagnosed in people with dementia due to 'diagnostic overshadowing', in which a person's symptoms may be wrongly attributed to dementia. If they are admitted to a psychiatric ward, being able to support them to communicate and function in a new environment, and to return to the community, may help ensure that they do not stay on inpatient wards longer than necessary. It is also important to consider how to achieve continuity of care if the person's usual residence is, or will be, a care home.

Effectiveness studies are needed to evaluate different approaches and interventions to support people with dementia during transition between inpatient mental health settings and community or care home settings. Qualitative studies exploring views and experiences of people with dementia and their families and carers would also be welcome.

2 People with complex needs other than dementia

What is the effect of specific interventions to support people with complex needs because of multiple diagnoses and resistance to treatment during transition between inpatient mental health settings and community or care home settings? (This includes people with physical or learning disabilities, people with personality disorder, people with complex psychosis, people with long-term severe mental illness and people on the autistic

spectrum.)

Why this is important

As the population ages and people live longer, the number of people with severe and complex mental and physical care needs is increasing. They may need ongoing intensive support from rehabilitation and other mental health services to live in the community after discharge. Although they are a relatively small group, expenditure on care for people in this group accounts for around 25% of the total mental health budget.

Studies are needed to evaluate different approaches and interventions to support people with complex needs during transition. Qualitative studies exploring views and experiences of people with complex needs and their families are also needed. These should include the views of staff from the receiving care home.

3 Children and young people in transition between settings

What is the effect of specific interventions to support children and young people during transition between inpatient mental health settings and community or care home settings? Is there any particular benefit for black, Asian and minority ethnic communities?

Why this is important

Young people admitted to inpatient mental health settings may have a range of associated difficulties, and may be more likely than adults to be admitted to out-of-area or specialist units.

The committee highlighted particular gaps in the evidence about children and young people during transitions. These included gaps in evidence on:

- child protection and safeguarding
- voluntary compared with involuntary admission
- understanding by children and young people of their status

- how looked-after children are best supported through transitions and reintegration into the school system after hospital discharge
- self-directed support or peer support for children and young people and their parents.

Effectiveness studies are needed to evaluate the different approaches and interventions to support children and young people through safe and timely transitions. These need to be supplemented with views and experiences studies.

Update information

Minor changes since publication

February 2021: We clarified that the guideline should be used alongside NICE guidance on mental health services. We linked to the NICE guideline on decision-making and mental capacity in recommendation 1.3.3 and to the Homelessness Act 2017 in recommendation 1.5.8.

11 September 2020: We linked to the NICE guideline on supporting adult carers in recommendation 1.4.10.

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NICE National Institute for Health and Care Excellence

NICE guideline

Mental health problems in people with learning disabilities: prevention, assessment and management

NICE guideline
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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

Overview 5

Who is it for? 5

Recommendations 6

1.1 Using this guideline with other NICE guidelines 6

1.2 Organisation and delivery of care and support 7

1.3 Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment 10

1.4 Support and interventions for family members and carers 12

1.5 Social and physical environment interventions 13

1.6 Annual health check 14

1.7 Identification and referral 15

1.8 Assessment 16

1.9 Psychological interventions 23

1.10 Pharmacological interventions 25

1.11 Occupational interventions 27

Terms used in this guideline 29

Recommendations for research 32

1 Develop case identification tools for common mental health problems 32

2 Psychological interventions for children and young people with internalising disorders 33

3 Psychological interventions for depression and anxiety disorders in adults with mild to moderate learning disabilities 34

4 Pharmacological interventions for anxiety disorders in people with learning disabilities who have autism 34

5 Psychosocial interventions for people with more severe learning disabilities 36

6 The experiences of people with learning disabilities and mental health problems in services 36

Putting this guideline into practice 38

Context 40

Finding more information and committee details 42

Update information 43

This guideline is the basis of QS142.

Overview

This guideline covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It aims to improve assessment and support for mental health conditions, and help people with learning disabilities and their families and carers to be involved in their care.

Who is it for?

- Healthcare professionals
- Social care practitioners
- Care workers
- Education staff
- Commissioners and service providers
- People with learning disabilities and their families and carers

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we used words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Using this guideline with other NICE guidelines

Improving the experience of care

1.1.1 Use this guideline with:

- the NICE guidelines on service user experience in adult mental health and patient experience in adult NHS services, to improve the experience of care for adults with learning disabilities and mental health problems
- recommendations for improving the experience of care for children and young people in the NICE guidelines on specific mental health problems
- the NICE guideline on challenging behaviour and learning disabilities if relevant.

Interventions for mental health problems in people with learning disabilities

1.1.2 Use this guideline with the NICE guidelines on specific mental health problems and other NICE guidelines on mental health services. Take into account:

- differences in the presentation of mental health problems

- communication needs (see recommendation 1.3.1)
- decision-making capacity (see recommendation 1.3.2)
- the degree of learning disabilities
- the treatment setting (for example, primary or secondary care services, mental health or learning disabilities services, in the community or the person's home)
- interventions specifically for people with learning disabilities (see the section on social and physical environment interventions and the sections on psychological, pharmacological and occupational interventions).

1.2 Organisation and delivery of care and support

Organising effective care

1.2.1 A designated leadership team of healthcare professionals, educational staff, social care practitioners and health and local authority commissioners should develop and implement service delivery systems in partnership with people with learning disabilities and mental health problems and (as appropriate) their family members, carers, self-advocates or care workers.

1.2.2 The designated leadership team should ensure that care is:

- person-centred and integrated within a care programme
- negotiable, workable and understandable for people with learning disabilities and mental health problems, their family members, carers or care workers, and staff
- accessible and acceptable to people using the services
- responsive to the needs and abilities of people with learning disabilities, and that reasonable adjustments (in line with the Equality Act 2010) are made if needed
- regularly audited to assess effectiveness, accessibility and acceptability.

1.2.3 The designated leadership team should ensure that care pathways:

- cover all health, social care, support and education services, and define the roles and responsibilities of each service
- have designated staff who are responsible for coordinating:
  - how people are involved with a care pathway
  - transition between services within and across different care pathways
- maintain consistency of care
- have protocols for sharing information:
  - with the person with learning disabilities and a mental health problem and their family members, carers or care workers (as appropriate)
  - with other staff (including GPs) involved in the person's care
- are focused on outcomes (including measures of quality, service user experience and harm)
- establish clear links (including access and entry points) to other care pathways (including those for physical health problems).

1.2.4 The designated leadership team should ensure that young people with learning disabilities and mental health problems have in place plans that address their health, social, educational and recreational needs (including Education, Health and Care Plans), as part of their transition to adult services and adulthood. This planning should start when young people are aged 14 and follow the NICE guideline on transition from children's to adults' services.

1.2.5 The designated leadership team, together with health and social care providers, should ensure that care pathways:

- provide access to all NICE-recommended interventions for mental health problems
- clearly state the responsibilities of specialist learning disabilities and specialist mental health services to ensure people's needs are met.

1.2.6 For people with learning disabilities who need acute inpatient treatment for a serious mental illness, provide treatment:

- within a locally available service where possible and
- with staff who are skilled and knowledgeable in the care and treatment of mental health problems in people with learning disabilities.

Staff coordination and communication

1.2.7 Staff working with people with learning disabilities and mental health problems should ensure they are fully informed about:

- the nature and degree of the learning disabilities
- the nature and severity of the mental health problem, and any physical health problems (including sensory impairments).

1.2.8 All people with learning disabilities and a serious mental illness should have a key worker who:

- coordinates all aspects of care, including safeguarding concerns and risk management
- helps services communicate with the person and their family members, carers or care workers (as appropriate) clearly and promptly, in a format and language suited to the person's needs and preferences
- monitors the implementation of the care plan and its outcomes.

Staff training and supervision

1.2.9 Health, social care and education services should train all staff who may come into contact with people with learning disabilities to be aware:

- that people with learning disabilities are at increased risk of mental health problems

- that mental health problems may develop and present in different ways from people without learning disabilities, and the usual signs or symptoms may not be observable or reported
- that people with learning disabilities can develop mental health problems for the same reasons as people without learning disabilities (for example, because of financial worries, bereavement or relationship difficulties)
- that mental health problems are commonly overlooked in people with learning disabilities
- where to refer people with learning disabilities and suspected mental health problems.

1.2.10 Health and social care services should ensure that staff who deliver interventions for people with learning disabilities and mental health problems are competent, and that they:

- receive regular high-quality supervision
- deliver interventions based on relevant manuals, if available
- evaluate adherence to interventions
- take part in the monitoring of their practice (for example, by using video and audio recording, external audit and scrutiny).

1.2.11 Health and social care staff who deliver interventions for people with learning disabilities and mental health problems should consider using routine sessional outcome measures, including service-user-reported experience measures.

1.3 Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment

Communication

1.3.1 Take into account the person's communication needs and level of

understanding throughout assessments, treatment and care for a mental health problem, and:

- speak to the person directly rather than talking about or over them
- use clear, straightforward and unambiguous language
- assess whether communication aids, an advocate or someone familiar with the person's communication methods are needed
- make adjustments to accommodate sensory impairments (including sight and hearing impairments)
- explain the content and purpose of every meeting or session
- use concrete examples, visual imagery, practical demonstrations and role play to explain concepts
- communicate at a pace that is comfortable for the person, and arrange longer or additional meetings or treatment sessions if needed
- use different methods and formats for communication (written, signing, visual, verbal, or a combination of these), depending on the person's preferences (see NHS England's Accessible Information Standard for guidance on ensuring people with learning disabilities receive information in formats they can understand)
- regularly check the person's understanding
- summarise and explain the conclusions of every meeting or session
- check that the person has communicated what they wanted.

Consent, capacity and decision-making

1.3.2 Assess the person's capacity to make decisions throughout assessment, care and treatment for the mental health problem on a decision-by-decision basis, in accordance with the Mental Capacity Act and supporting codes of practice (see NICE's information on making decisions about your care). Help people make decisions by ensuring that their communication needs are met (see recommendation 1.3.1) and (if

appropriate) involving a family member, carer, care worker or other individual familiar with the person's communication abilities.

1.3.3 Staff delivering care to people with learning disabilities and mental health problems should:

- discuss the assessment process and treatment options with the person and provide information in a format and language suited to their needs, including:
  - potential benefits
  - potential side effects or disadvantages
  - the purpose of treatment
  - outcome measures
- ensure that the person understands the purpose, plan and content of any meeting or intervention before it starts, and regularly throughout
- address any queries or concerns that the person may have at any stage
- allow enough time for the person to make an informed choice if they have decision-making capacity, and if they do not then provide enough time for their family members, carers or care workers to contribute fully.

Involving family members, carers and care workers

1.3.4 Encourage and support family members, carers and care workers (as appropriate) to be actively involved throughout the assessment, care and treatment of the person's mental health problem, apart from in exceptional circumstances when an adult or young person with decision-making capacity has said that they do not want them involved.

1.3.5 Give family members, carers and care workers (as appropriate) information about support and interventions in a suitable format and language, including NICE's information for the public.

1.4 Support and interventions for family members

and carers

1.4.1 Advise family members and carers about their right to carer assessment, and assessment for respite care and other support (see the NICE guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers).

1.4.2 When providing support to family members (including siblings) and carers:

- recognise the potential impact of living with or caring for a person with learning disabilities and a mental health problem
- explain how to access:
  - family advocacy
  - family support and information groups
  - disability-specific support groups for family members or carers
- provide skills training and emotional support, or information about how to access these, to help them take part in and support interventions for the person with learning disabilities and a mental health problem.

1.4.3 If a family member or carer also has an identified mental health problem, offer:

- interventions in line with the NICE guidelines on specific mental health problems **or**
- referral to a mental health professional who can provide interventions in line with NICE guidelines.

1.5 Social and physical environment interventions

1.5.1 Health, social care and education services should consider the impact of the social and physical environment on the mental health of children and young people with learning disabilities when developing care plans, and:

- provide positive educational environments that are appropriate to their needs
- when care placements (such as birth family to foster care, foster care to adoptive placement, home to residential school/college) are required, minimise the risk of placement breakdown by taking particular care to fit these to the needs of the person.
- give special consideration and support to looked-after children and young people with learning disabilities and their foster parents or care workers, to reduce the child or young person's very high risk of developing mental health problems, and the risk of changes in their home and carers (see the NICE guideline on looked-after children and young people).

1.5.2 Health, social care and education services should consider the impact of the social and physical environment on the mental health of adults with learning disabilities when developing care plans,and:

- support people to live where and with whom they want
- encourage family involvement in the person's life, if appropriate
- support people to get involved in activities that are interesting and meaningful to them
- plan for and help people with any significant changes to their living arrangements.

1.6 Annual health check

The following recommendations on annual health checks for people with learning disabilities build on recommendation 1.2.1 in the NICE guideline on challenging behaviour and learning disabilities, which relates to the provision of annual physical checks by GPs to all people with learning disabilities.

1.6.1 GPs should offer an annual health check using NHS England's learning disability annual health check electronic clinical template to all adults with learning disabilities, and all children and young people with learning disabilities who are not having annual health checks with a paediatrician.

1.6.2 Involve a family member, carer or care worker (as appropriate), or a

healthcare professional or social care practitioner who knows the person well, in the annual health check. Take into account that more time may be needed to complete health checks with people with learning disabilities.

1.6.3 Include the following in annual health checks:

- a mental health review, including any known or suspected mental health problems and how they may be linked to any physical health problems
- a physical health review, including assessment for the conditions and impairments which are common in people with learning disabilities
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence
- an agreed and shared care plan for managing any physical health problems (including pain).

1.6.4 During annual health checks with adults with Down's syndrome, ask them and their family members, carers or care workers (as appropriate) about any changes that might suggest the need for an assessment of dementia, such as:

- any change in the person's behaviour
- any loss of skills (including self-care)
- a need for more prompting in the past few months.

1.7 Identification and referral

1.7.1 Staff and others caring for people with learning disabilities should consider a mental health problem if a person with learning disabilities shows any changes in behaviour, for example:

- loss of skills or needing more prompting to use skills
- social withdrawal
- irritability

- avoidance
- agitation
- loss of interest in activities they usually enjoy.

1.7.2 Staff should consider using identification questions (adjusted as needed) as recommended in the NICE guidelines on specific mental health problems to identify common mental health problems in people with learning disabilities.

1.7.3 Paediatricians should explain to parents of children identified with learning disabilities that mental health problems are common in people with learning disabilities, and may present in different ways.

1.7.4 If a mental health problem is suspected in a person with learning disabilities, staff should conduct a triage assessment to establish an initial formulation of the problem. This should include:

- a description of the problem, including its nature, severity and duration
- an action plan including possible referral for further assessment and interventions.

1.7.5 Refer people with learning disabilities who have a suspected serious mental illness or suspected dementia to a psychiatrist with expertise in assessing and treating mental health problems in people with learning disabilities.

1.8 Assessment

Conducting a mental health assessment

1.8.1 A professional with expertise in mental health problems in people with learning disabilities should coordinate the mental health assessment, and conduct it with:

- the person with the mental health problem, in a place familiar to them if possible, and help them to prepare for it if needed

- the family members, carers, care workers and others that the person wants involved in their assessment
- other professionals (if needed) who are competent in using a range of assessment tools and methods with people with learning disabilities and mental health problems.

1.8.2 Speak to the person on their own to find out if they have any concerns (including safeguarding concerns) that they don't want to talk about in front of their family members, carers or care workers.

1.8.3 Before mental health assessments:

- agree a clear objective, and explain it to the person, their family members, carers or care workers (as appropriate), and all professionals involved
- explain the nature and duration of the assessment to everyone involved
- explain the need to ask certain sensitive questions
- address any queries or concerns that the person may have about the assessment process.

1.8.4 When conducting mental health assessments, be aware:

- that an underlying physical health condition may be causing the problem
- that a physical health condition, sensory or cognitive impairment may mask an underlying mental health problem
- that mental health problems can present differently in people with more severe learning disabilities.

1.8.5 When conducting mental health assessments, take into account the person's:

- level of distress
- understanding of the problem
- living arrangements and settings where they receive care

- strengths and needs.

1.8.6 During mental health assessments:

- establish specific areas of need to focus on
- assess all potential psychopathology, and not just the symptoms and signs that the person and their family members, carers or care workers first report
- describe the nature, duration and severity of the presenting mental health problem
- take into account the person's cultural, ethnic and religious background
- review psychiatric and medical history, past treatments and response
- review physical health problems and any current medication, and refer to other specialists for review if needed
- review the nature and degree of the learning disabilities, and if relevant the person's developmental history
- assess for problems that may be associated with particular behavioural phenotypes (for example, anxiety in people with autism and psychosis in people with Prader–Willi syndrome), so that they can be treated
- assess the person's family and social circumstances and environment, and recent life events
- assess the level of drug or alcohol use as a potential problem in itself and as a factor contributing to other mental health problems
- establish or review a diagnosis using:
  - a classification system such as DSM-5 or ICD-10, or those adapted for learning disabilities (for example the Diagnostic Manual – Intellectual Disability [DM-ID] or Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation [DC-LD]) **or**
  - problem specification
- assess whether a risk assessment is needed (see recommendation 1.8.18).

1.8.7 Assess recent changes in behaviour using information from family members, carers, staff or others involved in the assessment as well as information from relevant records and previous assessments. Take into account the nature, quality and length of their relationship with the person.

1.8.8 Use the results of the mental health assessment to develop a written statement (formulation) of the mental health problem, which should form the basis of the care plan (see recommendation 1.8.23) and cover:

- an understanding of the nature of the problem and its development
- precipitating and maintaining factors
- any protective factors
- the potential benefits, side effects and harms of any interventions
- the potential difficulties with delivering interventions
- the adjustments needed to deliver interventions
- the impact of the mental health problem and associated risk factors on providing care and treatment.

1.8.9 Provide the person, their family members, carers or care workers (as appropriate), and all relevant professionals with a summary of the assessment:

- in an agreed format and language
- that sets out the implications for care and treatment.

1.8.10 Give the person and their family members, carers or care workers (as appropriate) another chance to discuss the assessment after it has finished, for example at a follow-up appointment.

Further assessment

1.8.11 Consider conducting a further assessment that covers any areas not explored by the initial assessment, if:

- new information emerges about the person's mental health problem **or**
- there are significant differences between the views of the person and the views of their family members, carers, care workers or staff about the problems that the assessment has focused on.

Assessment tools

1.8.12 During any mental health assessment:

- consider using tools that have been developed or adapted for people with learning disabilities **and**
- take cost into account if more than one suitable tool is available.

1.8.13 If using tools that have not been developed or adapted for people with learning disabilities, take this into account when interpreting the results.

1.8.14 When conducting an assessment with a child or young person with learning disabilities, consider using tools such as the Developmental Behavior Checklist – parent version (DBC-P) or the Strengths and Difficulties Questionnaire (SDQ).

1.8.15 When assessing depressive symptoms in an adult with learning disabilities, consider using a formal measure of depression to monitor change over time, such as the Glasgow Depression Scale (the self-report for people with milder learning disabilities or the carer supplement for people with any degree of learning disabilities).

1.8.16 Consider supplementing an assessment of dementia with an adult with learning disabilities with:

- measures of symptoms, such as the Dementia Questionnaire for People with Learning Disabilities (DLD), the Down Syndrome Dementia Scale (DSDS) or the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)
- measures of cognitive function to monitor changes over time, such as the Test for Severe Impairment (TSI)

- measures of adaptive function to monitor changes over time.

1.8.17 Complete a baseline assessment of adaptive behaviour with all adults with Down's syndrome.

Risk assessment

1.8.18 When conducting risk assessments with people with learning disabilities and mental health problems, assess:

- risk to self
- risk to others (including sexual offending)
- risk of self-neglect
- vulnerability to exploitation
- likelihood and severity of any particular risk
- potential triggers, causal or maintaining factors
- whether safeguarding protocols should be implemented.

1.8.19 If indicated by the risk assessment, develop a risk management plan with the person and their family members, carers or care workers (as appropriate).

1.8.20 Risk management plans should:

- set out individual, social or environmental interventions to reduce risk
- be communicated to family members, carers or care workers (as appropriate) and all relevant staff and agencies.

1.8.21 Risk assessments and resulting risk management plans should be reviewed regularly and adjusted if risk levels change.

Mental health assessment during a crisis

1.8.22 Conduct an initial assessment for people who are experiencing a mental

health crisis, which should:

- include an assessment of the person's mental health
- include a risk assessment (see recommendations 1.8.18 to 1.8.21)
- include identification of interventions to:
  - help address the problem that caused the crisis
  - minimise any associated risks
  - bring stability to the individual and their immediate environment
- produce a crisis plan that sets out (using the least restrictive options possible) how to reduce the likelihood of further crises, and what to do if the person has another crisis.

The mental health care plan

1.8.23 Develop a mental health care plan with each person with learning disabilities and a mental health problem and their family members, carers or care workers (as appropriate), and integrate it into their other care plans.

1.8.24 Base mental health care plans on the written statement (formulation) and include in them:

- goals agreed with the person and the steps to achieve them
- treatment decisions
- agreed outcome measures that are realistic and meaningful to the person, to monitor progress
- early warning signs of relapse or exacerbation of symptoms, if known
- risk and crisis plans, if needed (see recommendations 1.8.18 to 1.8.22)
- steps to minimise future problems.

1.8.25 Ensure that the mental health care plan sets out the roles and

responsibilities of everyone involved in delivering it, and that:

- the person can easily access all interventions and services in the plan
- it is communicated to everyone involved, including the person and their family members, carers or care workers (as appropriate)
- there is an agreement on when the plan will be reviewed.

1.9 Psychological interventions

Delivering psychological interventions for mental health problems in people with learning disabilities

1.9.1 For psychological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems and take into account:

- the principles for delivering psychological interventions (see recommendations 1.9.2 to 1.9.4) and
- the specific interventions recommended in this guideline (see recommendations 1.9.5 to 1.9.9).

1.9.2 Use the mental health assessment to inform the psychological intervention and any adaptations to it, and:

- tailor it to their preferences, level of understanding, and strengths and needs
- take into account any physical, neurological, cognitive or sensory impairments and communication needs
- take into account the person's need for privacy (particularly when offering interventions on an outreach basis)
- agree how it will be delivered (for example, face-to-face or remotely by phone or computer), taking into account the person's communication needs and how suitable remote working is for them.

1.9.3 If possible, collaborate with the person and their family members, carers

or care workers (as appropriate) to:

- develop and agree the intervention goals
- develop an understanding of how the person expresses or describes emotions or distressing experiences
- agree the structure, frequency, duration and content of the intervention, including its timing, mode of delivery and pace
- agree the level of flexibility needed to effectively deliver the intervention
- agree how progress will be measured and how data will be collected (for example, visual representations of distress or wellbeing).

1.9.4 Be aware that people with learning disabilities might need more structured support to practise and apply new skills to everyday life between sessions. In discussion with the person, consider:

- providing additional support during meetings and in the planning of activities between meetings
- asking a family member, carer or care worker to provide support and assistance (such as reminders) to practise new skills between meetings.

Specific psychological interventions

1.9.5 Consider cognitive behavioural therapy, adapted for people with learning disabilities (see recommendation 1.9.2 on intervention adaptation methods), to treat depression or subthreshold depressive symptoms in people with milder learning disabilities.

1.9.6 Consider relaxation therapy to treat anxiety symptoms in people with learning disabilities.

1.9.7 Consider using graded exposure techniques to treat anxiety symptoms or phobias in people with learning disabilities.

1.9.8 Consider parent training programmes specifically designed for parents or carers of children with learning disabilities to help prevent or treat mental

health problems in the child, and to support carer wellbeing.

1.9.9 Parent training programmes should:

- be delivered in groups of parents or carers
- be accessible (for example, take place outside normal working hours or in community settings with childcare facilities)
- focus on developing communication and social functioning skills
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow the relevant treatment manual
- use all of the necessary materials to ensure consistent implementation of the programme
- seek parent feedback.

1.10 Pharmacological interventions

1.10.1 For pharmacological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems and take into account the principles for delivering pharmacological interventions (see recommendations 1.10.2 to 1.10.9).

1.10.2 For guidance on adherence and the safe and effective use of medicines, see the NICE guidelines on medicines adherence and medicines optimisation.

1.10.3 Only specialists with expertise in treating mental health problems in people with learning disabilities should start medication to treat a mental health problem in:

- adults with more severe learning disabilities (unless there are locally agreed protocols for shared care)
- children and young people with any learning disabilities.

1.10.4 Before starting medication for a mental health problem in children, young people or adults with learning disabilities:

- take account of:
  - potential medication interactions
  - the potential impact of medication on other health conditions
  - the potential impact of other health conditions on the medication
- when necessary consult with specialists (for example, neurologists providing epilepsy care when prescribing antipsychotic medication that may lower the seizure threshold), to minimise possible interactions
- assess the risk of non-adherence to the medication regimen or any necessary monitoring tests (for example, blood tests), and the implications for treatment
- establish a review schedule to reduce polypharmacy
- provide support to improve adherence (see the NICE guideline on medicines adherence)
- assess whether support from community and learning disabilities nurses is needed for physical investigations (such as blood tests)
- agree monitoring responsibilities, including who will carry out blood tests and other investigations, between primary and secondary care.

1.10.5 Monitor and review the benefits and possible harms or side effects, using agreed outcome measures and taking into account communication needs. If stated in the relevant NICE guideline, use the timescales given for the specific disorder to inform the review, and adjust it to the person's needs.

1.10.6 When deciding the initial dose and subsequent increases, aim for the lowest effective dose. Take account of both potential side effects and difficulties the person may have in reporting them, and the need to avoid sub-therapeutic doses that may not treat the mental health problem effectively.

1.10.7 Prescribers should record:

- a summary of what information was provided about the medication prescribed, including side effects, to the person and their family members, carers or care workers (as appropriate) and any discussions about this
- when the medication will be reviewed
- plans for reducing or discontinuing the medication, if appropriate
- full details of all medication the person is taking, including the doses, frequency and purpose.

1.10.8 For people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms:

- consider reducing or discontinuing long-term prescriptions of antipsychotic drugs,
- review the person's condition after reducing or discontinuing a prescription
- consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems
- annually document the reasons for continuing the prescription if it is not reduced or discontinued.

1.10.9 When switching medication, pay particular attention to discontinuation or interaction effects that may occur during titration. Only change one drug at a time, to make it easier to identify these effects.

1.11 Occupational interventions

1.11.1 In keeping with the preferences of the person with learning disabilities and mental health problems, all staff should support them to:

- engage in community activities, such as going to a library or sports centre
- access local community resources such as libraries, cinemas, cafes and leisure centres

- take part in leisure activities, such as hobbies, which are meaningful to the person.

  Reasonable adjustments may be needed to do this (in line with the Equality Act 2010), such as a buddy system, transport, or advising local facilities on accessibility.

1.11.2 Actively encourage adults with learning disabilities (with or without a mental health problem) to find and participate in paid or voluntary work that is meaningful to them, if they are able.

1.11.3 Consider providing practical support to adults with learning disabilities (with or without a mental health problem) to find paid or voluntary work, including:

- preparing a CV
- identifying personal strengths and interests
- completing application forms
- preparing for interviews
- accompanying the person to interviews
- completing any pre-employment checks.

1.11.4 Health and social care services should take account of an adult or young person's sensory, physical, cognitive and communication needs and the severity of their mental health problem (if any), and consider:

- helping them to identify and overcome any possible challenges during employment
- appointing supported employment workers to provide ongoing support to adults with learning disabilities and their employers
- providing information and guidance to potential employers about the benefits of recruiting people with learning disabilities
- assisting employers in making reasonable adjustments to help them to work (in line with the Equality Act).

Terms used in this guideline

Carer

A person who provides unpaid support to someone who is ill, having trouble coping or has disabilities.

Care pathways

Defined in this guideline as the ways different services interact with each other, and how people access and move between them.

Care worker

A person who provides paid support to someone who is ill, having trouble coping or has disabilities, in a variety of settings (including residential homes, supported living settings and day services).

Children

Aged 0 to12 years.

Key worker

A key worker (also known as a care or case coordinator) is a central point of contact for the person with a mental health problem, family members, carers and the services involved in their care. They are responsible for helping the person and family members or carers to access services and for coordinating the involvement of different services. They ensure clear communication between all people and services and have an overall view of the person's needs and the requirements of their care plan.

Learning disabilities

Learning disabilities are commonly divided into 'mild', 'moderate', 'severe' and 'profound', but these categories are based on IQ and most UK health and social care services do not measure this. Therefore, this guideline uses the terms 'milder learning disabilities' (approximating to mild and moderate learning disabilities that are often defined as an IQ of

35 to 69 and impairment of adaptive functioning with onset in childhood) and 'more severe learning disabilities' (approximating to severe and profound learning disabilities that are often defined as an IQ of 34 or below with impairment of adaptive functioning with onset in childhood).

All people with learning disabilities:

- need additional support at school
- need support in some areas of adult life, such as budgeting, planning, time management, and understanding complex information
- need more time to learn new skills than people who don't have learning disabilities.

Milder learning disabilities

People with milder learning disabilities:

- may be able to live independently and care for themselves, managing everyday tasks and working in paid employment
- can often communicate their needs and wishes
- may have some language skills
- may have needs that are not clear to people who do not know them well.

More severe learning disabilities

People with more severe learning disabilities are more likely to:

- need support with daily activities such as dressing, washing, food preparation, and keeping themselves safe
- have limited or no verbal communication skills or understanding of others
- need support with mobility
- have complex health needs and sensory impairments.

Serious mental illness

Defined in this guideline as: severe and incapacitating depression or anxiety, psychosis, schizophrenia, bipolar disorder or schizoaffective disorder.

Staff

Healthcare professionals and social care practitioners, including those working in community teams for adults, children or young people (such as psychologists, psychiatrists, social workers, speech and language therapists, nurses, behavioural analysts, occupational therapists, physiotherapists and pharmacists); and education staff.

Young people

Aged 13 to 17 years.

Recommendations for research

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the full guideline.

1 Develop case identification tools for common mental health problems

Develop or adapt reliable and valid tools for the case identification of common mental health problems in people with learning disabilities, for routine use in primary care, social care and education settings.

Why this is important

Mental health problems are often overlooked and therefore untreated in people with learning disabilities. This includes common mental health problems such as depression and anxiety disorders, or dementia in Down's syndrome. As a result, the identification of mental health problems in people with learning disabilities was a priority for this guideline.

While case identification tools exist and are recommended for use in the general population, no suitable tools were found that help with initial identification for people with learning disabilities. Research to develop and validate such tools would be valuable when this guideline is updated. More reliable identification should help with early intervention and provide better outcomes, and earlier identification could also reduce costs for the NHS and social care. No relevant ongoing trials were identified.

Existing tools with the best psychometric properties could be adapted and validated for use with people with learning disabilities, or new tools could be developed that are appropriate for use. The tools should be readily available and useable in routine health, social care and education settings (such as by GPs or caregiving staff).

Tools should first be adapted or developed for the most common mental health problems within this population:

- dementia, depression and anxiety in adults

- depression and anxiety in children and young people.

A series of cohort studies are needed to validate the tools (new or existing). The studies could include the following outcomes:

- sensitivity and specificity
- predictive validity.

2 Psychological interventions for children and young people with internalising disorders

For children and young people with learning disabilities, what psychological interventions (such as cognitive behavioural therapy and interpersonal therapy) are clinically and cost effective for treating internalising disorders?

Why this is important

There is some evidence for the use of psychological interventions for internalising disorders in children and young people within the general population, and in adults with learning disabilities. However no evidence was found to indicate which interventions for internalising disorders are effective in children and young people with learning disabilities, or what adaptations are most helpful.

Psychological interventions commonly used within the general population (such as cognitive behavioural therapy and interpersonal therapy) should be adapted and tested in large randomised controlled trials. This research is crucial to improving the mental health outcomes in this population, and would have a significant impact upon updates of this guideline.

Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

3 Psychological interventions for depression and anxiety disorders in adults with mild to moderate learning disabilities

For adults with milder learning disabilities, what is the clinical and cost effectiveness of psychological interventions such as cognitive behavioural therapy (modified for people with learning disabilities) for treating depression and anxiety disorders?

Why this is important

Psychological interventions such as cognitive behavioural therapy (CBT) are clinically and cost-effective treatments for anxiety and depression within the general population. While there is some evidence to suggest that these interventions may be useful in treating depression in people with learning disabilities, this is limited. Further research is also needed for CBT for anxiety disorders such as generalised anxiety disorder, obsessive compulsive disorder and post-traumatic stress disorder. The existing evidence on CBT for learning disabilities is based on small feasibility trials, with various and inconsistent adaptations across the studies. Many therapists are also reluctant to use CBT in this population. As a result, people with learning disabilities may be missing out on effective treatments. Effective treatments would reduce unnecessary suffering and impairment, improve quality of life and ultimately should reduce the demand for mental health and social care services.

Modifications of CBT need to be tested in large randomised controlled trials, and any modifications should be clearly explained and documented. In order to achieve an appropriate sample size, several different services may need to cooperate. Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

4 Pharmacological interventions for anxiety disorders in people with learning disabilities who

have autism

What is the clinical and cost effectiveness and safety of pharmacological interventions for anxiety disorders in people with learning disabilities who have autism?

Why this is important

Anxiety disorders are common in people with learning disabilities who have autism. However, there is no high-quality evidence on pharmacological interventions for anxiety disorders in people with learning disabilities who have autism. They may be more susceptible to adverse events, and have particular difficulty communicating side effects. There may also be differences in effectiveness compared with the general population. These uncertainties about side effects and effectiveness may contribute to the under-treatment of mental health problems in people with learning disabilities who have autism. Research is therefore needed to determine the safety and effectiveness of pharmacological interventions and make it clear what treatments are effective for anxiety in people learning disabilities who have autism. Clarity over this issue could have a substantial impact upon quality of life for people with learning disabilities who have autism and their carers, as well as reducing costs to the NHS.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of pharmacological interventions for anxiety disorders in this population. Several services may need to collaborate in order to ensure sufficient sample size. Researchers would need to take into account factors such as genotype and pharmacological treatment for other conditions when designing these trials. Important outcomes could include:

- effect on the mental health problem
- side effects
- cost effectiveness
- health-related quality of life.

5 Psychosocial interventions for people with more severe learning disabilities

For people with more severe learning disabilities, what is the clinical and cost effectiveness of psychosocial interventions to treat mental health problems?

Why this is important

People with more severe learning disabilities whose communication is non-verbal are likely to need tailored interventions to address mental health problems. Research is particularly limited on mental health problems in people with more severe learning disabilities. Further research is needed into different types of interventions, such as social interactions and building resilience. This research would fill a need within mental health services, which are currently limited in their ability to provide effective interventions to this group.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of psychosocial interventions, which may include multiple components, to prevent and treat mental health problems in people with more severe learning disabilities. Several services may need to collaborate in order to ensure sufficient sample size. Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

When designing these trials, appropriate measures will need to be developed for mental health problems in people with more severe learning disabilities.

6 The experiences of people with learning disabilities and mental health problems in services

What experience do people with learning disabilities have of services designed to prevent and treat mental health problems and how does this relate to clinical outcomes?

Why this is important

Mental health service provision for people with learning disabilities is complex and varies across the UK. There appears to be no high-quality evidence or ongoing research for any particular approach. Evidence on the experiences, aspirations and mental health of young people as they prepare for adulthood would help in the development of preventative strategies. Evidence on what service models are most effective and acceptable to people with learning disabilities would help to improve service design, staffing decisions and patient outcomes. This is also an area of national priority, as explained in the NHS Five Year Forward View.

To understand what experience people with learning disabilities have of services, a series of studies covering the following should be conducted:

- The experiences and life course trajectories of young people (aged 13–17 years) in terms of their aspirations and goals, including whether the support they and their families get affects their mental health and their expected outcomes as they prepare for adulthood.
- The experience people have of mental health inpatient services (specialist learning disability services or non-specialist services), including factors that may have prevented the need for admission and how inpatient admission affects them. Studies should include economic modelling.
- The experience people have of being discharged from mental health inpatient services (specialist learning disability services or non-specialist services), after a stay of one year or more. In particular: the factors that may have helped them to be discharged earlier, what support is effective after discharge, and how to lower the risk of readmission.
- The experiences people have during a crisis, including how effective crisis support is in meeting their needs, minimising risk and helping them recover.
- The experiences of people with milder learning disabilities (including people on the autistic spectrum) and common mental health problems (such as anxiety or depression) in accessing community-based interventions.

Putting this guideline into practice

NICE has produced tools and resources to help you put this guideline into practice.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist

groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Context

People of all ages with all levels of learning disabilities can be affected by mental health problems. When a person is not able to describe or express their distress, and when they have coexisting physical health problems, their mental health problems can be difficult to identify. This leads to mental health problems remaining unrecognised, which prolongs unnecessary distress. Psychosis, bipolar disorder, dementia, behaviour that challenges, and neurodevelopmental conditions such as autism and attention deficit hyperactivity disorder are all more common than in people without learning disabilities, and emotional disorders are at least as common. Some causes of learning disabilities are associated with particularly high levels of specific mental health problems (for example, affective psychosis in Prader–Willi syndrome and dementia in Down's syndrome).

When people with learning disabilities experience mental health problems, the symptoms are sometimes wrongly attributed to the learning disabilities or a physical health problem rather than a change in the person's mental health. Indeed, their physical health state can contribute to mental ill health, as can the degree and cause of their learning disabilities (including behavioural phenotypes), biological factors (such as pain and polypharmacy), psychological factors (such as trauma) and social factors (such as neglect, poverty and lack of social networks).

Population-based estimates suggest in the UK that 40% (28% if problem behaviours are excluded) of adults with learning disabilities experience mental health problems at any point in time. An estimated 36% (24% if problem behaviours are excluded) of children and young people with learning disabilities experience mental health problems at any point in time. These rates are much higher than for people who do not have learning disabilities.

This guideline covers the identification, assessment, treatment and prevention of mental health problems in children, young people and adults with any degree of learning disabilities. In addition, there are recommendations on support for family members, carers and care workers.

The guideline covers all settings (including health, social care, educational, forensic and criminal justice settings).

People with learning disabilities have many needs both as individuals and related to their learning disabilities. This guideline only addresses their needs in relation to mental health

problems.

Finding more information and committee details

You can also see the guideline in the NICE Pathway on mental health problems in people with learning disabilities.

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on mental health and behavioural conditions.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. 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 our guidelines into practice, see resources to help you put NICE guidance into practice.

Update information

Minor changes since publication

December 2020: We linked to our list of other NICE guidelines on mental health services in recommendation 1.1.2 and to the Learning Disability Annual Health Check electronic clinical template (2017) in recommendation 1.6.1.

July 2020: We linked to the NICE guideline on supporting adult carers in recommendation 1.4.1.

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Accreditation



SYSTEMS, NOT STRUCTURES:

CHANGING HEALTH & SOCIAL CARE



Expert Panel Report

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The Panel would also like to record their gratitude to the many organisations and individuals from across the HSC who gave of their time and expertise to informing this work. The report would not have been possible without their involvement.

CONTENTS

SECTION 1
THE PANEL'S REMIT 7

SECTION 2
THE BURNING PLATFORM –
AN UNASSAILABLE CASE FOR CHANGE 9

SECTION 3
THE PANEL'S VISION –
A NEW MODEL FOR HEALTH AND SOCIAL CARE 37

SECTION 4
ROADMAP FOR IMPLEMENTATION 53

SECTION 5
RATIONALISATION 69

SECTION 6
LIST OF RECOMMENDATIONS 79

ANNEX A
THE PANEL'S PRINCIPLES 83

ANNEX B
LIST OF GROUPS & INDIVIDUALS CONSULTED BY THE PANEL 87

SECTION 1

THE PANEL'S REMIT AND THE POLITICAL SUMMIT



In his speech of 4 November 2015, the then Minister for Health, Simon Hamilton MLA, announced that in response to recommendation 1 of **The Right Time, The Right Place** report by Sir Liam Donaldson, he would appoint an expert, clinically led panel to consider and lead an informed debate on the best configuration of Health and Social Care services in Northern Ireland.

Sir Liam's report stated:

"A proportion of poor quality, unsafe care occurs because local hospital facilities in some parts of Northern Ireland cannot provide the level and standards of care required to meet patients' needs 24 hours a day, 7 days a week. Proposals to close local hospitals tend to be met with public outrage, but this would be turned on its head if it were properly explained that people were trading a degree of geographical inconvenience against life and death. Finding a solution should be above political self-interest".

The Panel was appointed in January 2016 and comprises local and international members. The Panel was given the remit to:

- Produce a set of principles to underpin reconfiguration of health and social care services.
- Support and lead debate including at a political summit to be held in early 2016 to agree the principles.
- Use the results of the political summit to develop a clinically informed model for the future configuration of health and social care, which will ensure world class provision for everyone in Northern Ireland.
- Clearly quantify the specific benefits in health outcomes that will be derived from the new model, both for individuals and the Northern Ireland population as a whole.

Political Summit: 17th February 2016

The panel along with MLAs and advisors from the DUP, Sinn Fein, UUP, SDLP and Alliance met for a one day health summit to discuss the need for change and agree a set of principles that would guide the panel in structuring a New Model of Health and Social Care for the people of Northern Ireland. Each party provided both verbal and written comments to a 'draft set of principles'. In turn the panel considered all comments and revised the principles to take as many of these on board as possible.

The final set of principles is attached at Annex A.

Engagement

The Panel has engaged extensively with stakeholders across health and social care, and the following key messages were heard consistently:

- The unsustainable nature of the 'status quo'. Major workforce gaps in all areas of the current model of service requiring significant investment in agency staff to maintain the current distribution of acute care.
- Underinvestment in primary and social care, the very services that can prevent hospital admission, because of over-investment in the current hospital model.
- Even with the funding used to purchase independent sector and 'in-house' waiting list initiatives, there are increasing delays for elective care.
- The contribution of unpaid carers and the voluntary sector, and the desire for the voluntary sector to be a trusted partner in care.
- Independent providers are delivering significant elements of care in domiciliary and residential care home settings and are struggling to cope with current funding levels.
- The need to invest in improving the health of our population and to take a more co-ordinated approach to supporting people with complex needs.

SECTION 2

THE BURNING PLATFORM – AN UNASSAILABLE CASE FOR CHANGE



Context

In the course of its work, the Panel has heard repeated references to 'review fatigue'. In essence, there seems to be a sense that the Health and Social Care (HSC) system has repeatedly spent significant time and resources analysing the challenges it faces, identifying the weaknesses in the current model, making recommendations for change, but subsequently failing to enact the necessary transformation to make these happen. The timeline at fig. 1 gives a sense of the main reforms and reviews that the system has experienced since the 1970s.

Across the system, there has been a broad consensus among those the panel has spoken to that there is a need for transformational change in the way services are delivered and the way our system is organised. It is important to fully understand the nature of the challenges and demands that health and social care services face, and also the reasons why the model that is currently in place is outdated and is not the one that Northern Ireland needs. Many of these issues will not come as a surprise to those working across the system or those who use its services. Indeed, many of these issues were plainly articulated to us from a number of different sources, who made clear their concerns with regard to factors such as rising demand, changing demographics and patterns of illness, financial sustainability, workforce planning and vulnerable services. Although there are committed and talented people at all levels of the system, the system itself is not making the most effective use of the available public funds to meet service users' needs.

Northern Ireland is not alone in facing these challenges. Health and social care systems across the developed world are currently struggling with the question of how to adapt their services to deal with continuously rising and changing patterns of demand. Most countries also recognise that simply adding more money and resources to tackling these issues is not enough to make services higher quality and sustainable, radical transformation is required. This is not an easy thing to do; change and transformation are always difficult, they create uncertainty and they require us to give up what we have in exchange for something new. This is particularly difficult when it involves something that is very important to us, such as the health and social care services that we and our families will all need to call on at some point in our lives.

Fig. 1 – Reviews and Reforms of Health and Social Care in Northern Ireland

1973 The HPSS (NI) Order provided for the establishment of four Health and Social Services Boards, responsible for administering and arranging provision of services.

1989 A Government white paper introduced the concept of an internal market. In Northern Ireland, this led to the establishment of 19 Trusts.

1998 Fit for the Future proposed the abolition of the internal market with commissioning decisions taken as close as possible to patients and clients and centred on primary care.

2001 The Acute Hospitals Review suggests the establishment of a single Strategic Health and Social Services Authority to replace the four HSS Boards. It also recommends moving to a service with 9 acute hospitals

2002 Developing Better Services supports significantly reducing the number of HSC organisations, including the creation of a single regional authority. Also recommends the 15 Local Health and Social Care Groups (LHSCGs) should be brought together.

2002 GP fundholding abolished. Arrangements for LHSCGs, as committees of the four HSS boards are put in place to assess need and design services. 15 were in place by 2005.

2005 The Appleby Review focuses on the need for rigorous performance management and greater incentivisation of strong performance.

2007 The then Minister decides against a regional Health Authority. Instead, he confirms the creation of 5 new integrated Trusts, 5 Local Commissioning Groups, a smaller Health and Social Care Board focused on commissioning, financial and performance management, and a Public Health Agency.

2011 Transforming Your Care sets out a broad new model of care, moving away from hospitals and into primary, community and social care services. Recommends 5-7 hospital networks

2014 Sir Liam Donaldson endorses the policy behind TYC but recommends the appointment of an impartial panel of experts to deliver the right configuration of HSC services.

2015 Following the Donaldson report and an internal review of commissioning, the then Minister launches a consultation on a review of the HSC administrative structures. The review recommends abolition of the HSCB.

2016 The appointment of an international expert panel to develop a clinically informed model for the future configuration of health and social care.

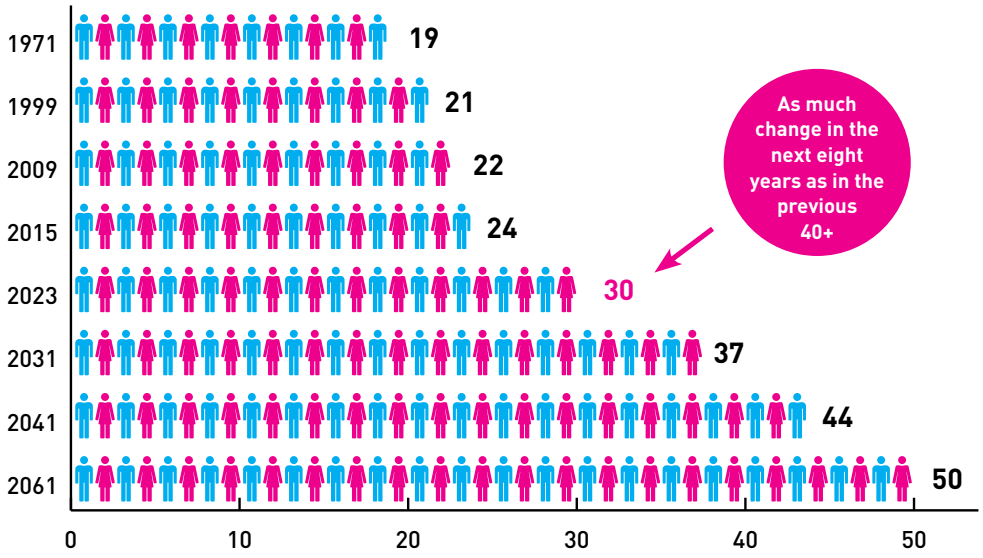
However, it is important that the case for change is clearly understood by those who use and those who deliver these services, and also the risks of not making these changes in a planned and transparent way. In this section of the report, the evidence that the existing system is already struggling to sustain services in the face of these changing circumstances is set out and the case made for new service models. Without systematic and planned change, already stretched services will undoubtedly be forced into unplanned change through fire-fighting and crisis.

The stark options facing the HSC system are either to resist change and see services deteriorate to the point of collapse over time, or to embrace transformation and work to create a modern, sustainable service that is properly equipped to help people stay as healthy as possible and to provide them with the right type of care when they need it. This report presents an opportunity that must be seized and acted upon.

Demographic Change

As a population, we are living longer than ever before and, for most of our lives, are healthier than ever before. When the NHS was created in 1948, life expectancy was 65.8 years for men and 70.1 years for women. It is now 78.1 for men and 82.4 for women. The number of older people in our community is also increasing as a proportion of the overall population. In 2013 there were estimated to be 279,000 people aged 65 and over, with 33,000 of them over 85 years. This is projected to increase considerably in the next 20 years to 456,000 and 79,000 respectively. As the graph below demonstrates, the demographic shift for the period from 2015-2023 will be equal to the demographic shift in the preceding 40 years.

Fig. 2 – Population Projections (2015-2061)



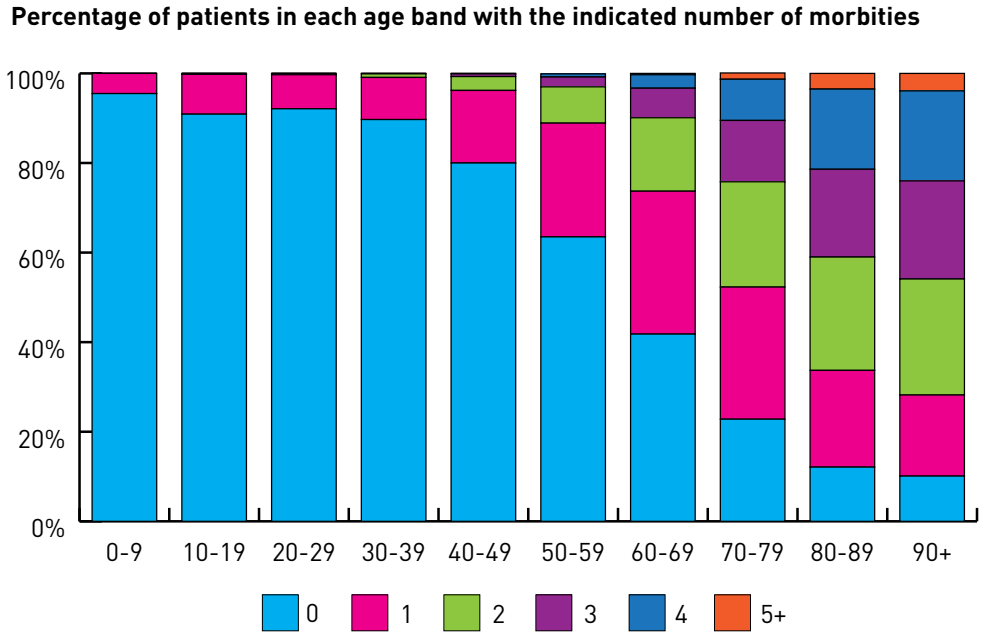
An ageing population: Number of older people (65+) per 100 aged 16-64

It is a similar picture across the UK and Ireland. However, out of all the UK countries, at 43.1% Northern Ireland had the largest percentage growth of people aged 85+ between mid-2004 and mid-2014. This is projected to continue over the 25 year period between mid-2014 and mid-2039.[1]

This increase in life expectancy is a great achievement, but it signals a major shift in demography and in patterns of demand for health and social care services. Ageing brings an increased likelihood of some degree of disability, dependency and illness, and older people are now the main users of Northern Ireland's health and social care services. The rate of disability among those aged over 85 is 67% compared with only 5% among young adults.[2] Dementia is also a growing issue for our older population, with 60,000 people projected to be suffering from the condition by 2051.[3] In addition, the profile of older people requiring care is becoming more complex, with many people now living with multiple chronic illnesses.

As well as living longer, developments in how we are able to treat and manage conditions mean that we are all much more likely to develop and live with one or more long term conditions. The table below[4] clearly demonstrates that as we get older, the likelihood of multiple morbidities increases dramatically, meaning that the care and treatment that we require becomes much more complex.

Fig. 3 – Co-morbidities by Age Band



1. NISRA Statistical Bulletin: 2014-Based Population Projections for Northern Ireland (published 29 Oct 2015)
2. Transforming Your Care, Health and Social Care Board, December 2011
3. Dementia Strategy, DHSSPS, 2010
4. Source – Health and Social Care Board, 2016

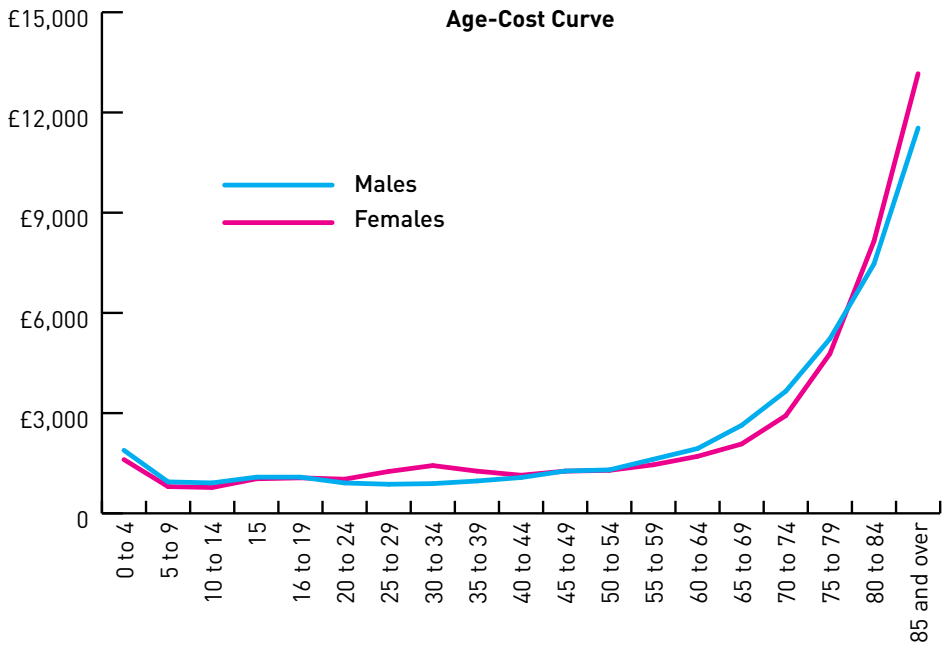
Impact on the HSC system

According to the latest figures, currently in Northern Ireland:

- Two thirds of acute hospital beds are currently occupied by people aged over 65;
- 9,670 people over 65 live in residential care or nursing homes;
- Approximately 23,400 users weekly receive domiciliary care.

In terms of costs, users aged over 65 account for more than two-fifths of HSC spending – 42%, compared to their population share of 14%. Whereas the average cost of treating a 55-59 year old stands at £1,970 per head, this rises to over £6,000 for 75-79 year olds and £14,000 for the over 85s.[5]

Fig. 4 – Age/Cost Curve



Ultimately, all of these figures and statistics illustrate a significant success story for Health and Social Care. As a population, we are seeing a marked reduction in acute life-threatening illnesses, but in their place we are now dealing much more commonly with long term conditions and disability as a result of the population's increased longevity.

The pressure that this is placing on the HSC's finite resources cannot be resolved by continuing to rely on the current acute care model. The change in the nature of the demand facing the system is not reflected in the ways services are designed

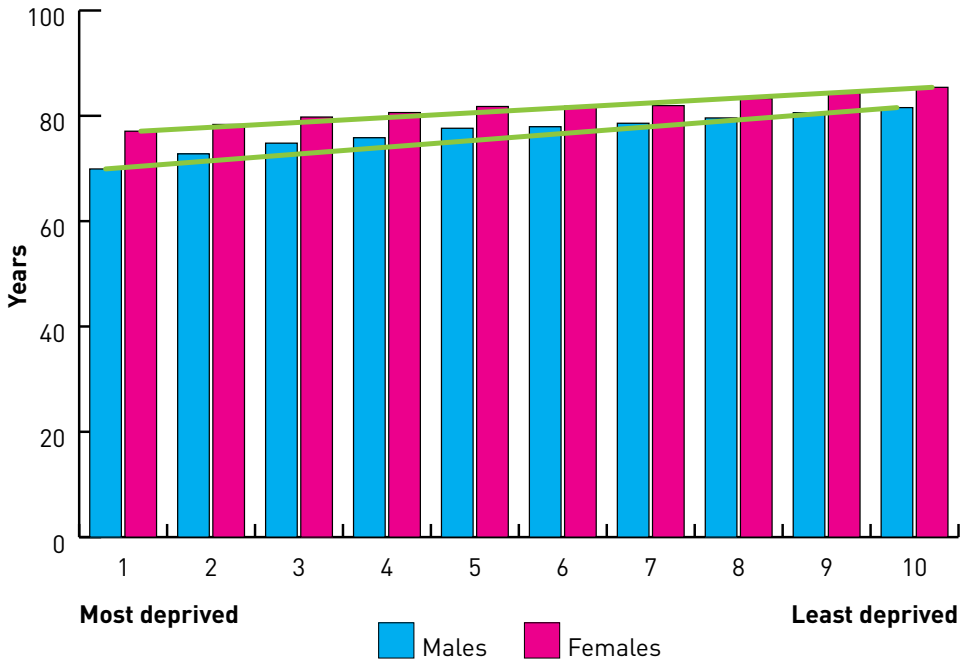
5. Source – Department of Health

and delivered. The vast majority of care is provided in the person's home or in local communities by unpaid carers, primary and community care teams, and the voluntary and independent sector. Acute hospitals are designed to deal with acute illness, not chronic conditions, and yet the beds in acute wards are filled with those whose needs may well be met more effectively and more efficiently elsewhere. The question that needs to be posed is whether the current system, which was set up to meet the needs of the mid to late 20th century, is still the right one to meet the changing patterns of illness and demand that we face in the 21st century.

Health Inequalities

While overall people are living longer and healthier lives, health inequalities continue to be a major issue. Life expectancy for males in the most deprived areas of NI is on average 7.5 years less than their counterparts in the least deprived areas. For females, the differential is 4.3 years.[6]

Fig. 5 – Deprivation & Life Expectancy



6. Source – Department of Health

The healthy life expectancy of people in the most and least disadvantaged areas differs dramatically. On average males live 58. 7 years in good health, females 62.2 years. However, female healthy life expectancy in the most deprived areas is 14.2 years lower than in the least deprived areas; and comparable figure for male healthy life expectancy is 11.8 years.

These inequalities also have a detrimental impact on the HSC system.

- There are 9 admissions to hospital for every 20 people in the most deprived areas compared to 6 admissions for every 20 people in the least deprived areas;
- Emergency admissions to hospital are 74% higher in most deprived communities than in the least deprived;
- Elective admissions to hospital are 25% higher in most deprived communities than least deprived;
- Hospital day cases are 21% higher in most deprived communities than least deprived.

Evidence from Marmot's review of health inequalities in England indicates that addressing health inequalities requires co-ordinated action across the wider determinants of health.[7] Action is required across government, to do more to improve universal public services as well as more targeted services for those with greater need.

In fact, research shows that only about 20% of health outcomes are related to clinical care: 10% is related to physical environment (air and water quality, built environment, etc); 40% is related to socio economic factors (education, employment, social support, community safety); and 30% is related to behaviours.[8] The diagram below shows some of the key indicators highlighting the gaps between most and least deprived.[9]

Fig. 6 – Health Inequality Indicators

Indicator	Baseline Year	Unit of Difference	Simple Gap
Male Life Expectancy	2009-11	Years	7.2
Female Life Expectancy	2009-11	Years	4.4
Infant Mortality[20]	2007-11	Deaths / 1,000 live births	0.8 (16%)
Smoking during Pregnancy	2012	Percentage	22 (280%)
Breastfeeding	2012	Percentage	30 (52%)
Key Stage 2 - Communication	2011/12	Percentage	20 (24%)
Key Stage 2 - Mathematics	2011/12	Percentage	21 (24%)
GCSE	2011/12	Percentage	22 (35%)
Alcohol-related Admissions	2009/10 - 2011/12	Admissions / 100,000 population	1,246 (452%)
Teenage Births	2011	Births / 1,000 Females	3.9 (570%)
Suicide	2009-11	Deaths / 100,000 population	21 (244%)

7. Fair Society, Healthy Lives, Marmot, 2010
8. http://www.countyhealthrankings.org/our-approach, County Health rankings and roadmaps, Robert Wood Johnson Foundation
9. Source – Department of Health

We can see that health and health inequalities are interrelated with the economy, economic inactivity, poverty, social isolation, educational underachievement, criminal justice, regeneration, and many other parts of government.[10]

Access to health and social care services is of course an essential component for the population's health outcomes, but as mentioned above, there is evidence that it is not in itself as important as lifestyle and environment – the circumstances in which people live, work and bring up their children.

While much of this is beyond this panel's terms of reference, it is clear that the Department of Health needs to continue to work in partnership with other departments and sectors to tackle the underlying social, economic and environmental determinants of health across the population. Local health and care partnerships, if properly organised, can also do much through local initiatives and shared budgets to address these fundamental determinants of health and wellbeing. As a major employer, the HSC has much to contribute to 'pathways to employment' through apprenticeships and other schemes to improve employability, and the estate owned by the HSC can provide opportunities for affordable housing. The HSC can also be a leader in the 'green economy' and improve the environment in local areas.

Rising Demand

As mentioned above, the demand for health services is growing and will continue to grow, driven by demography, an increase in chronic conditions, emergence of new technologies and changing practice in health care.

Currently in Northern Ireland:

- 1 in 5 people have a long-standing health condition;
- 60% of people are overweight (37%) or obese (23%);
- Almost one in five adults in Northern Ireland shows signs of a mental illness;
- 10.3% of the population claim Disability Living Allowance;
- The population is getting older;
- People have higher expectations.

These factors are creating pressures across the system and putting increasing demands on an already stretched system.[11]

10. Marmot, 2010

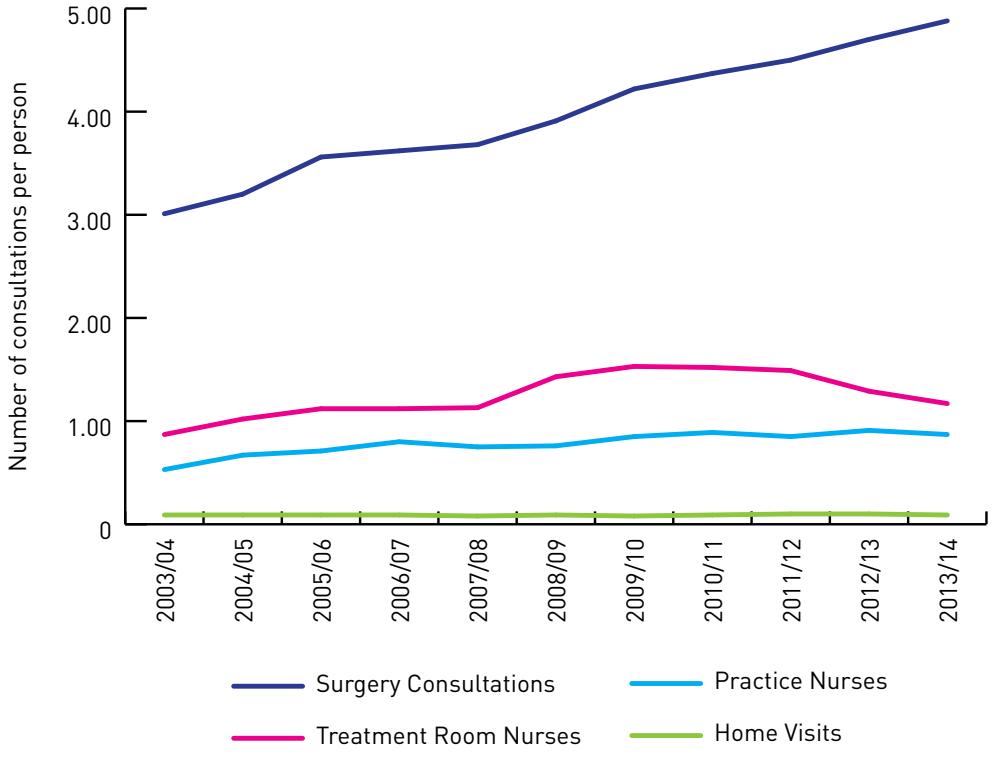
11. Source – Department of Health

Primary Care Service

Primary Care, as provided by General Practitioners (GPs), is the entry point to the Health and Social Care system for the majority of clients. Over the period 2008/9 to 2013/14, the demand for access to GP surgeries has increased on average by 21.5% whilst over the same period demand for GP Out of Hours (OOH) services has increased by 18%.

As the figure below shows[12], since 2003, there has been a steady and persistent rise in consultation rates for GPs. In 2008/9, 10.2 million consultations were undertaken by GP Practices; in 2012/13, 12.4m consultations were undertaken. This equates to an average of 6.9 consultations per patient per year in NI which is at the very high end of the spectrum compared with other OECD countries. In the south of Ireland the figure is 3 consultation per patient per year.

Fig. 7 – Consultation Rates



In conjunction with the rise in the number of consultations, there is also a growing number of complex patients who are more likely to have several co-morbidities.

12. Ibid

This rising demand cannot be resolved by the existing reactive model of care.

Hospital Services

People who require more specialist care are referred by their GP to the acute hospital sector. In addition to this, Emergency Departments provide a 'front door' to people who either self refer or who are assessed by primary care as needing urgent care. In 2011, **Transforming Your Care** forecast that the demand for acute services could grow by around 4% per year by 2015 and suggested that without change this would require:

- 23,000 extra hospital admissions;
- 48,000 extra outpatient appointments;
- 40,000 extra ambulance responses.

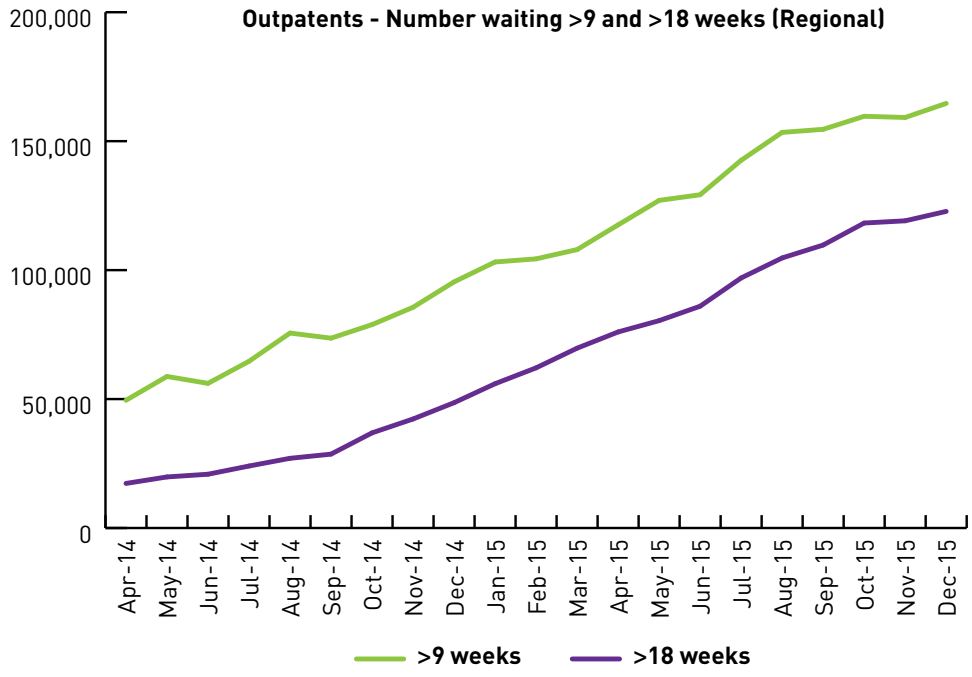
In fact, these estimates have proved to be a significant underestimate. The Department of Health's figures show that:

- The number of outpatient appointments, including appointments in the independent sector, increased by almost 121,000 between 2010/11 and 2013/14.
- The number of inpatient and day case hospital admissions, including those in the independent sector, increased by almost 48,000 by 2013/14.
- The number of Category A, B and C ambulance responses increased by almost 52,000 between 2010/11 and 2014/15.
- There has been a 5.7% increase in the number of inpatient admissions to hospital over the period. However, within the overall figures, there has been a 13.3% increase in non-elective admissions.
- In 2014/15, more than three-quarters (77.9%) of inpatient admissions were non-elective compared to 72.6% in 2010/11. Such an increase in emergency and urgent admissions can impact on hospitals' capacity to meet the demand for elective care, meaning more cancelled operations and appointments, and longer waiting times as priority is given to responding to the increasing demand for urgent care. This has been a major factor in the rise in waiting lists and waiting times for elective care in Northern Ireland.

13. Source - HSCB

In 2014/15 the financial constraints on the public sector led to a reduction in both in-house and independent sector waiting list initiatives. As a result, the number of outpatient appointments and hospital admissions dipped slightly (although still remaining significantly higher than 2010/11) while demand continued to increase. This resulted in sharp increases in waiting times and waiting lists (see table below[13]).

Fig. 8 – Outpatient Waiting Times



These figures more accurately reflect activity rather than demand. The increase in elective care waiting times indicates that there is further, unquantified demand for care.

As the growing waiting lists clearly show, the existing model is not addressing these challenges effectively.

200000

>18 weeks

>9 weeks

150000

Social Care Services

Although health and social care services are integrated in terms of delivery organisations in Northern Ireland there are differences between them. Provision of social care is often determined by different legislation. Unlike healthcare it is not universally free at the point of delivery with adults receiving social care being subject to means testing.

50000

There is a far greater diversity of providers of social care than health care with very significant amounts of social care being delivered by the private and voluntary sectors. How to deliver adult social care on a sustainable basis in ways that reflect people's preferences for how they want to lead their lives is an important challenge but this has not been the focus of this report and it is understood that the Department of Health is undertaking a separate exercise to consider these issues. They are however related. The purpose of social care is to promote social wellbeing including protection from abuse, reducing social isolation and the

Apr-14 Jul-14 Aug-14 Oct-14 Dec-14 Jan-15 Feb-15 Mar-15 Apr-15 May-15 Jun-15 Jul-15 Aug-15 Sep-15 Oct-15 Nov-15 Dec-15

promotion of independence. Poor social wellbeing can have a negative impact on the quality of people's lives, including their health and in turn can have an impact on other public services, including healthcare, criminal justice and the benefits system. Social care can be particularly important in helping prevent people from being admitted to hospital and in facilitating their discharge when medically fit. Pressures on social care will inevitably have an impact on healthcare.

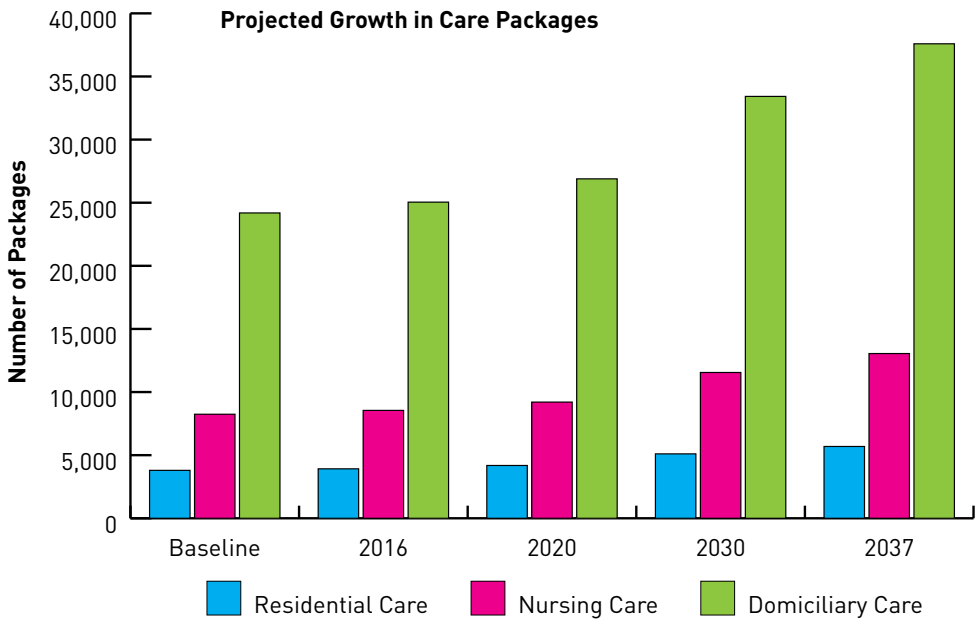
Expenditure on the Elderly Programme of Care amounts to 62% of total expenditure on adult social care services, with £543m of a total £873m being spent in this area.[14] Therefore, it is clear that an increase in the older population will require more support from the adult social care system and will require significant additional resources to adequately provide for people in need of care and support.

Using NISRA 2014 based population projections the Department of Health has carried out a crude projection of future demand for domiciliary care, residential care and nursing home care following the same growth rate as the population (18-64 and 65+).[15] The projections indicate that:

- an additional 4,050 care packages will be required in 2020 compared to current levels, an increase of 15%;
- an additional 20,101 care packages will be required in 2037 compared to 2016, an increase of 68%.

The graph below demonstrates the projected growth in the numbers of packages required:

Fig. 9 – Projected Growth in Care Packages (estimate)



14. Source – Department of Health

15. NISRA 2014-Based Population Projections, Projections by sex and single year of age (published 29 Oct 2015)

Demand and the Patient/User Experience

Of course, none of the preceding three service areas exists in isolation and any increase in demand, or lack of capacity to deal with this demand, in one part of the system has significant implications for the others.

This can be demonstrated most clearly by the impact caused by unmet demand for social care at both the front end (i.e. admission to hospital) and back end (i.e. discharge from hospital) of the system. The level of care people receive in their own community increasingly plays an important role in supporting people to live in their own homes and reducing the need for medical interventions either in a primary or secondary care setting. It also plays a fundamental role in the way the system operates by providing a way out of hospitals and a route back to the community or to an individual's home.

The sum of all this pressure is building to create a perfect storm for the entire Health and Social Care system. Patients are admitted to hospital unnecessarily because they can't access the treatment they need in their community, and, once admitted to hospital, are forced to stay longer than they need to because of the absence of domiciliary care packages to support them at their homes. This immediately causes:

- Pressures on the number of available beds;
- Unnecessarily busy Emergency Departments;
- Reduced capacity for dealing with elective/scheduled care;
- Poorer patient experience;
- Increased pressures on health and social care staff.

Ultimately, if there is insufficient capacity in social care to meet demand, this has a serious impact across the system in terms of increased GP appointments, Emergency Department attendances, higher rates of hospital admission and delayed discharges for patients who are well and ready to leave the hospital setting.

Workforce

The HSC's workforce is its biggest resource, its biggest strength and its biggest cost. Our health and social services cannot function without the commitment and skills of the people who work in them. These are also the people who have to cope at the coalface with the impact of the enormous pressures caused by rising demand.

Health and social care systems in Northern Ireland and in other jurisdictions, are reporting severe difficulties in recruiting and retaining staff. There is a growing doomsday scenario of not having enough GPs, hospital consultants and junior doctors, nurses, Allied Health Professionals, and social care staff that will inevitably lead to people not receiving the care they need.

There is also a recognised frustration among the highly educated and experienced workforce at all levels of the system with the lack of opportunities to work to the full level of competence to which they are trained.

Current health and social care models and the workforce designed to provide and implement those models are not sustainable in the long term and focus too much on a paternalistic approach based on ill health rather than working with patients towards a model of self care that is based on maintaining the health of the population. Breaking down the professional boundaries between staff and creating new generic roles is critical to providing an integrated, sustainable model of care for the population.

The transformation required in workforce will require a significant mind shift from the traditional, hierarchical and often professional silo approach to roles and responsibilities. It will require the relaxing of some of the strong and restrictive professional regulatory barriers that often delineate one professional role from another. For a workforce that maintains patient safety, professional regulation will always remain a prerequisite to protect the public from rogue professional practice.

A key message from the preparatory phase of producing this report was that without a radical review of the workforce in Northern Ireland the ambition to deliver co-ordinated care around patient need at population health level, local community level and individual level, the required transformation will not be possible.

Some of the issues and challenges facing workforce development currently in NI, as in the rest of the UK, have been highlighted in the Nuffield Trust report - Reshaping the Workforce to Deliver the Care Patients Need, 2016. They include:

- Lack of role clarity
- Lack of regulation and competency framework
- Understanding the implications of nurse staffing ratios
- Fragmentation of care
- Professional resistance[16]

16. Imison C, Castle-Clarke S, Watson R, (2016) Reshaping the Workforce to Deliver the Care patients Need, Research Report, Nuffield Trust

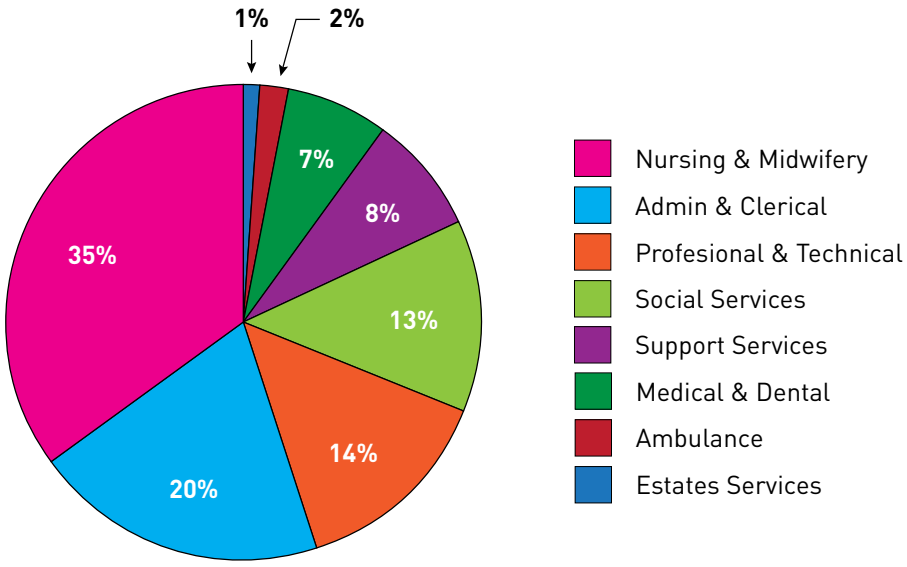
Recent reviews of the service in NI (TYC, the Donaldson Review, Quality 20/20 etc.) have identified that in order to transform services fundamentally, it will require a modern health and social care workforce that can work collaboratively to meet the needs of the population.

An approach to a workforce that responds to a population health model requires one of a blended nature where staff, professional and unregistered/unregulated, are recognised for the combined expertise they bring to a health and social care team that is built around the needs of patients. This will require a real shift from the current, sometimes narrow professional boundaries, to one that recognises that nurses, doctors, allied health professionals, and Health Care Assistants all have a role to play and one that focuses on having the right people in the right place at the right time to provide/contribute to the best care pathway for patients.

The success of any new service model will be absolutely dependent on staff being employed and deployed in such a way that makes the best use of their skills and which allows them to continue to develop as professionals while providing the services that users and patients need. The patient experience, and their perception of the quality of care they receive, depends in a very significant way on having well-trained, experienced and motivated frontline staff.

The HSC currently employs 54,637 whole time equivalent members of staff. The mix of staff is primarily driven by the need to support the existing care model, which is institutionally based. Comparing the most recent data with the mix of staff set out in TYC, it would appear that there has been little progress in attempting to shift resources away from this model. (See chart below)

Fig. 10 – Workforce Mix



The Panel has found that one of the major flaws of the current medical workforce mix is that it is focused on filling rotas and maintaining existing services, even where there are clear signs that these are not sustainable, rather than on detailed forecasting of demography and need. As one professional put it, "we are currently papering over the cracks in the current system, rather than investing in long term strategic change".[17]

As a case in point, it is proving extremely difficult to recruit and retain junior medical staff to deliver services where they would be unlikely to get the experience they need in terms of volumes and case mix in order to maintain their skills and develop new skills. This is reflected in the current, highest ever level of vacancies in training posts.[17]

Locum/Agency Costs

In recent years there have also been stark increases in costs associated with locum and agency staff to provide a safe service where it is not possible to recruit to permanent positions. The Northern Ireland HSC currently spends almost £77 million on locum and agency staff across the HSC workforce and these costs have been steadily rising. This is more than it spends on the entire GP OOH service.

Fig. 11 – Locum/Agency Spend 2010/11-14/15[18]

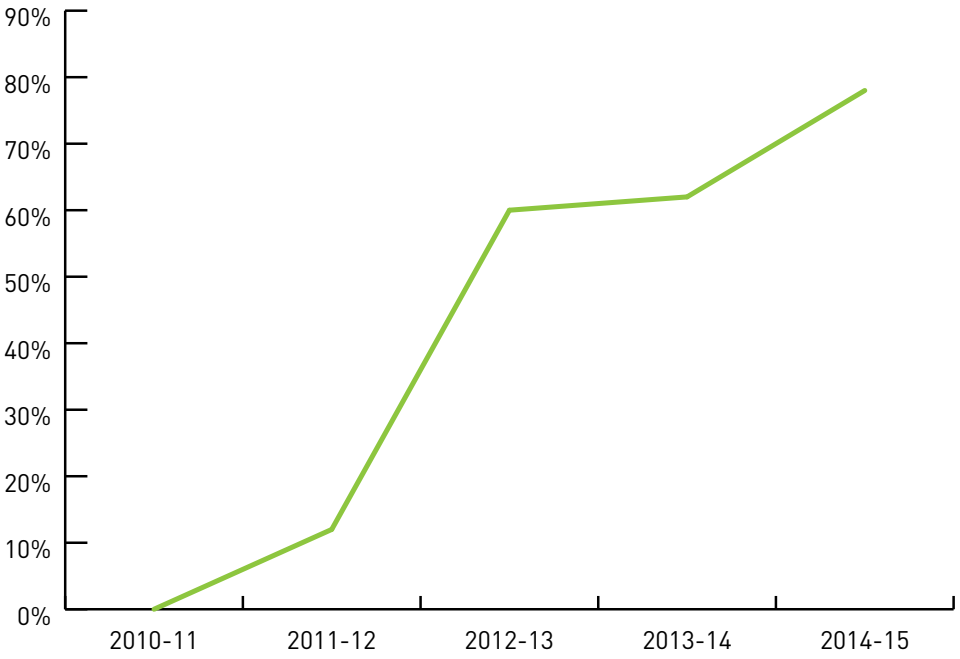
Agency Spend (includes locums)	2010/11	2011/12	2012/13	2013/14	2014/15
Medical & Dental	23,644,956	23,093,817	32,439,996	32,558,600	38,506,733
Nursing & Midwifery	6,916,885	8,641,658	9,852,129	11,116,340	12,094,055
Prof & Tech	1,217,178	2,388,060	4,940,249	3,978,227	3,039,152
Admin & Clerical	5,002,680	6,618,493	10,915,492	10,830,821	10,561,767
Support Services	2,033,150	2,882,374	4,725,091	5,273,308	6,312,881
Estates & Maintenance	0	0	10,084	601	19,945
Social Services	4,082,394	4,620,066	5,529,989	5,819,582	5,811,160
Ambulance	140,208	89,451	140,436	101,210	135,929
Other	0	22,429	124,726	0	26,988
Total	43,037,451	48,356,348	68,678,192	69,678,689	76,508,610

17. Source - NIMDTA

18. Source – Department of Health

In only five years, the amount the HSC spends on agency and locum cover has increased by 78%. The panel has even been presented with anecdotal evidence that for some junior doctors, the benefits of taking on locum work have superseded the benefits of having a permanent position.

Fig. 12 – Total Annual Locum/Agency Spend Increase from 2010 Level



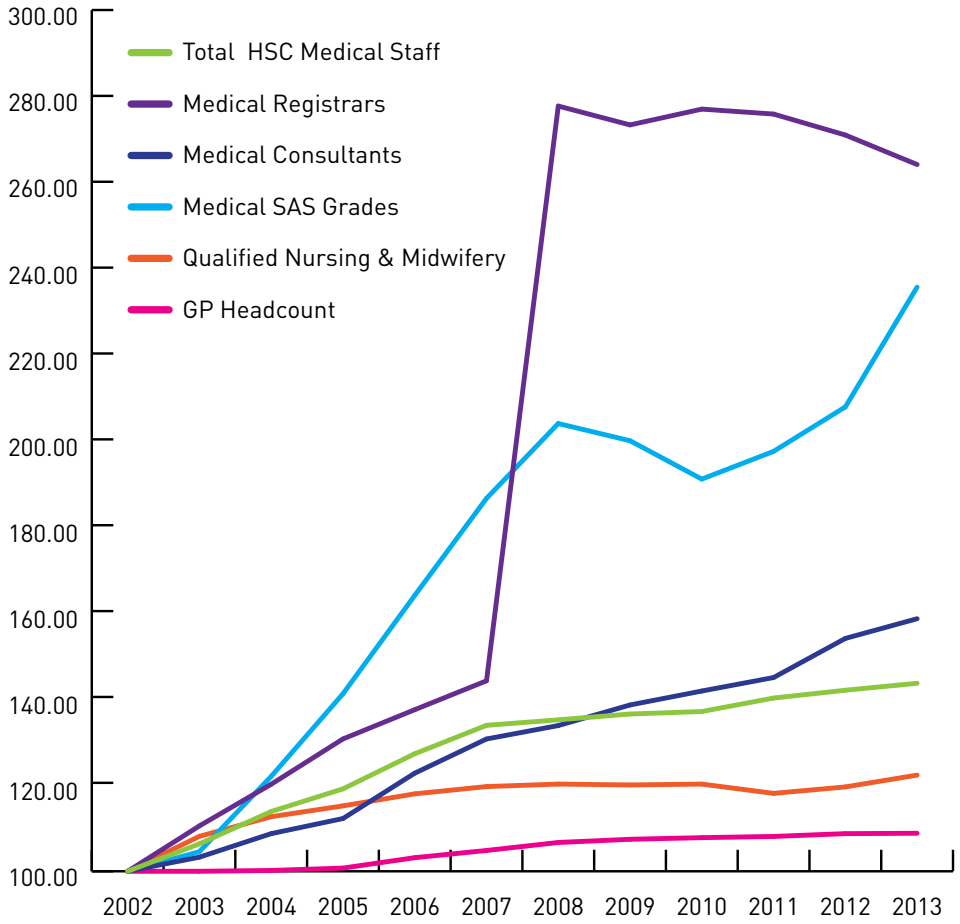
Much of the marked increase shown above is due to the high cost of filling rotas and propping up services where there is little or no chance of recruiting staff into permanent positions. It is also worth highlighting that what the system spends on locums or agency staff is money that is not available for investing in other parts of the HSC. Locums are expensive to employ and this money could be much more effectively invested in developing services that are sustainable in the long term. This would also have real benefits for staff, who would have improved professional development and job satisfaction, and for patients, in terms of the quality of care they receive and the continuity of the people delivering that care.

The locums themselves are of course not the problem, but their presence on this scale is a symptom of the structural problems facing the service. The answer is not providing more funding to try to fill these vacancies. This hasn't worked. The answer is changing the model of care to make sure that we create the right kinds of posts for all health professionals working in the system – posts that give our workforce the opportunity to use and develop their skills as part of wider teams, working together to best meet patients' needs. Many permanent staff have highlighted continuity and consistency issues in a service that relies on transitory locum and agency staff.

Primary Care Workforce

There are 347 General Practices in Northern Ireland, which are staffed by 1279 GPs. Data produced by the Department of Health suggests that the growth in the GP medical workforce has not kept pace with demand, or indeed with the growth in hospital medical staff. Furthermore, the average list size of 1641 patients per GP is the highest in the UK.

Fig. 13 - Index of Northern Ireland Medical and Nursing Workforce 2002 – 2013 (base 100)[19]



19. BMA Northern Ireland, General Practice in Northern Ireland: The case for change, February 2015

20. Ibid

The age profile of the general practice workforce also shows that just under a quarter of GPs here are aged 55 or older, which means that many will be planning to retire in the near future.[20]

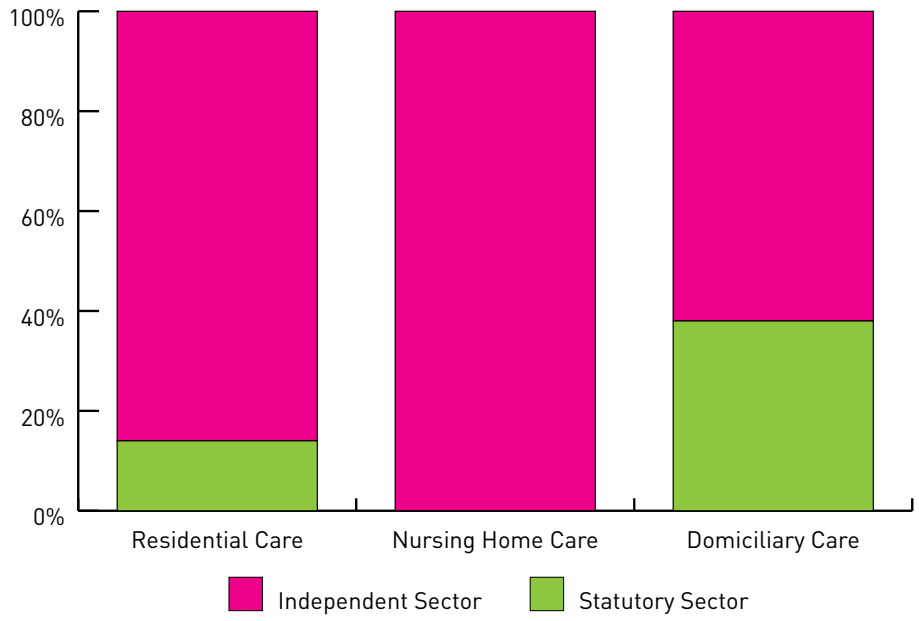
Fig.14 – GP workforce by age band

AGE BAND	% OF GPs
29-34	11
35-39	18
40-44	14
45-49	16
50-54	17
55-59	16
60-64	6
65 and over	2

Social Care Workforce

Social care is different from the other parts of the system insofar that it is largely commissioned by the HSC from for-profit and voluntary sector providers. The independent sector now provides 100% of nursing home care, 83% of residential care and 62% of domiciliary care. There is also still a significant proportion of care that is provided in-house by Health and Social Care Trusts and they and the independent sector are often put in the difficult position of competing for the same pool of staff.

Fig. 15 – Sectoral Distribution of Care Providers



Approximately 12,000 people are employed in the residential, nursing home and domiciliary care sectors.[21]

21. Can we trust the trusts? (ICHP, UKHCA) 2013

There are some significant concerns about the availability of an adequate future workforce to meet growing demographic demand. In England, for example, it is estimated that an additional one million care workers will be required by 2025.[22]

Recruitment and retention difficulties may, in part, be due to terms of employment including the use of zero hours contracts and staff being paid below the minimum wage.[23] The Commissioner for Older People has also identified the need for a well trained and registered social care workforce which is respected, valued and properly remunerated with opportunities for career progression.

In recent years, some providers have argued that the fees paid by the HSC are insufficient to attract and retain staff and that this risks creating instability, threatening the economic viability of their services. Indeed, some domiciliary care providers have already withdrawn from the market, citing affordability as the reason. Similarly, in the residential and nursing home market there have been some high profile closures, with the potential for more in the coming year.

This is a great, and growing, risk to the entire HSC. As we have stated above, if the social care sector fails to meet demand this will place enormous pressure across the rest of the system – particularly in relation to hospital admissions and discharges.

In the context of the demographic challenges outlined above, it must always be remembered that the most important, and the largest group by far, of staff delivering care services in Northern Ireland is unpaid.

Carers NI estimate that carers save the government some £2.4 billion and it is clear that the support of carers is absolutely essential in order to ensure the sustainability and viability of the system. Engaging and supporting carers is a fundamental aspect of maintaining service users within their own home and it is essential that the HSC improves its performance in this area.

22. The Future Care Workforce (ILC) 2014

23. The scale of minimum wage underpayment in social care (Resolution Foundation) 2015

Nursing and Midwifery

There are in excess of 16000 registered nurses and midwives employed by the HSC in Northern Ireland. This constitutes almost one third of the health and social care workforce in a variety of settings.

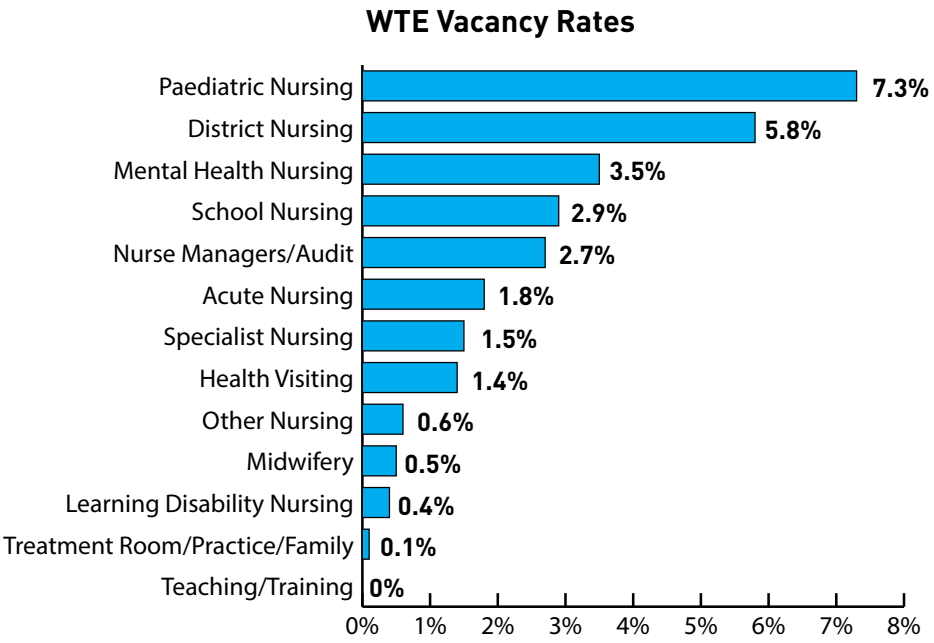
Fig. 16 – HSC Registered Nurses & Midwives as at 31st March 2014[24]

Combined Grades	Staff in Post Headcount (HC)	Whole-time Equivalent (WTE)
Registered Nurses	15,319	13,286.2
Midwives	1,327	1,042.5
Total	16,646	14,328.7

Figures from 1st October 2015 show that there were 531 (480 whole time equivalent) vacancies.

A vacant post is defined as a post '**actively being recruited to**'. The Department of Health collects data on vacancies via a survey twice a year. The figure below presents the available vacancy rates of permanent posts (based on whole-time equivalent) as at 30th September 2013.[24]

Fig. 17 – Available Vacancy Rates of Permanent Posts (based on whole-time equivalent) as at 30th September 2013

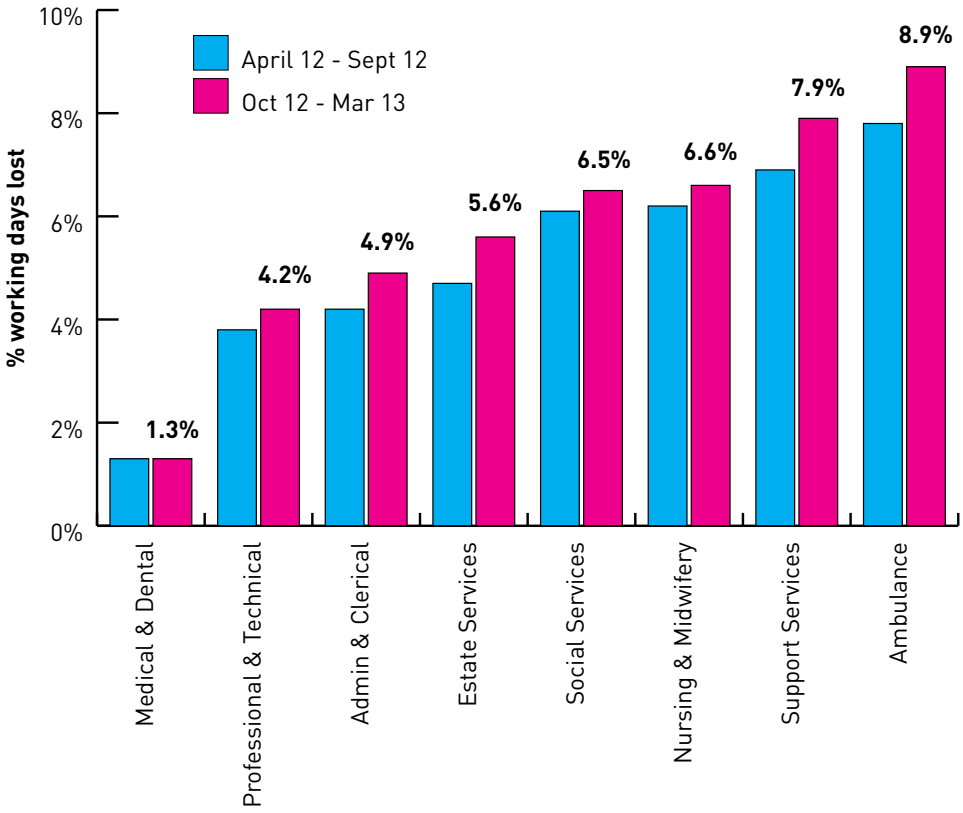


24. Source – Department of Health

Organisations reported that they did not expect to be able fill all these vacancies. In particular, they noted difficulties at a local level in recruiting to a number of specialties, including mental health services, care of older people, non-acute hospital care, theatres, critical care, general medicine, community, learning disability and prison health. However the composition of difficult to recruit specialities varied from Trust to Trust.

In addition, the graph below shows absence rates by occupational family across the HSC. We can see that absence rates are rising across all areas.[25]

Fig. 18 – Absence Rates by Occupational Family

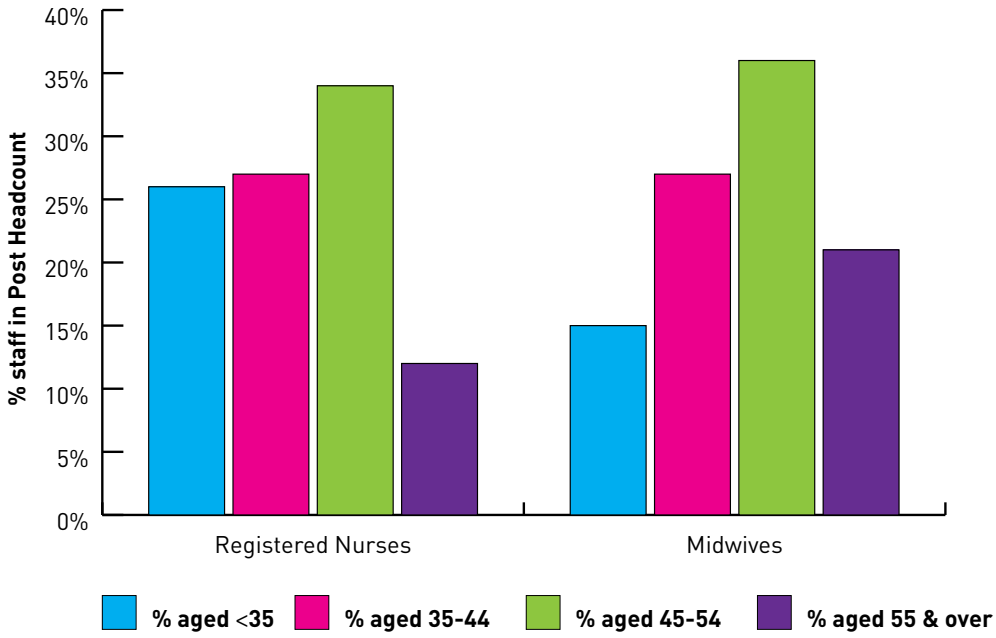


25. Source – Department of Health

26. Source – Department of Health

Furthermore the age profile of the nursing workforce shows the majority of the qualified staff to be above 45 years old, within a 10 -15 year period of average retirement age. The graph opposite shows the nursing and midwifery workforce broken down by age.[26]

Fig. 19 – Nursing and Midwifery Workforce by Age



Working patterns have also changed significantly. Almost half of qualified nurses are now working part time and almost two thirds of midwives.

Earlier this year, the then Minister took action to address these recruitment issues by increasing the number of commissioned student nurse places in Northern Ireland universities by 100 for the 2016/17 intake. This is very positive, but it will not impact on the service until 2019/2020. Steps are currently being taken to support a region wide recruitment process for nurses from EU and Non-EU countries.

Staff Morale

These issues are also reflected in the reported experience of staff in the HSC. In the most recent HSC staff survey, only 35% of staff felt that there were enough staff in their team to carry out the work and a significant proportion (36%) reported having experienced injury or illness as a result of work related stress. HSC Occupational Health Consultants have noted an increase in the number of staff presenting with stress related illness.

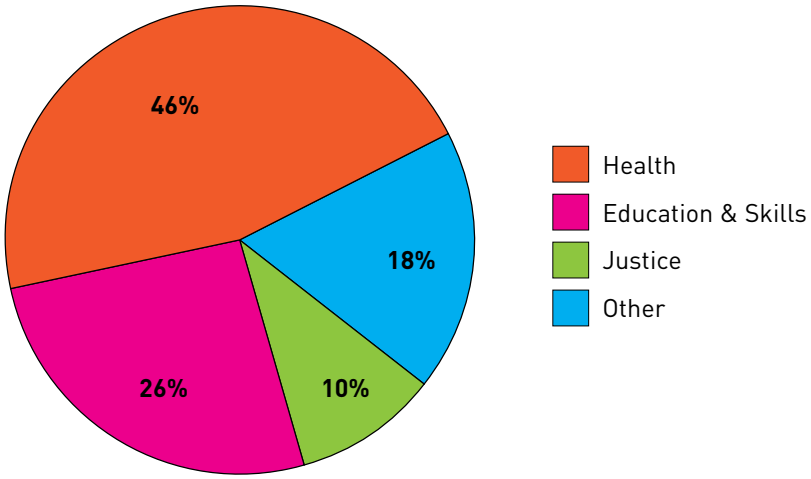
The cumulative effect of staff vacancies is ever-increasing workloads, higher risk of illness and a constant focus on the short term over the strategic. This risks creating a culture that exists by 'fire fighting' only. Innovation, learning from best practice and implementation of new systems are the unfortunate casualties of such a system. In all the encounters with stakeholders, from every part of the health and social care system, the panel have received the same message in terms of the need to invest properly in the staff that provide health and social care in voluntary, community, primary and secondary care settings.

The demands facing the current service model are putting severe pressures on the workforce. This is not fair to them or to the people who rely on them for care. Resolving this is not about money, it is about creating an environment in which staff are enabled and empowered to do the jobs they have been trained to do in a way that meets patients' needs. As the evidence above demonstrates, the current model has the patients in the wrong place and at the wrong time; this brings organisational de-motivation as staff feel unable to provide the highest quality of care to those they serve.

Financial Sustainability

As can be seen in the chart below, the Department of Health's budget is the largest among the Executive departments by some distance, with a budget of almost £4.6 billion, or 46% of the entire NI Executive spend.[27] The next largest sector in terms of budget is Education & Skills, with a little more than half of the health and social care budget.

Fig. 20 – Northern Ireland Budget by Sector



If we accept a conservative estimate of inflation at 1%, new medical developments at 1% and demand rising at 4%, then the Health and Care system as currently configured would require at least a 6% budget increase each year simply to stand still.[28]

Using this rationale, if the system continues in its current form, we can expect costs to double by 2026/27 simply to maintain current levels of performance.

Other

Justice

Education & Skills

27. OECD Reviews of Health Care Quality: United Kingdom 2016, p242

28. http://www.nuffieldtrust.org.uk/node/4190)

Fig. 21 – HSC – Projected Costs 2014/15 – 2020/21

Year	Total (£billion)	Year	Total (£billion)
2014/15	£4.6	2021/22	£6.92
2015/16	£4.87	2022/23	£7.34
2016/17	£5.17	2023/24	£7.78
2017/18	£5.48	2024/25	£8.25
2018/19	£5.81	2025/26	£8.75
2019/20	£6.16	2026/27	£9.23
2020/21	£6.53	2027/28	£9.83

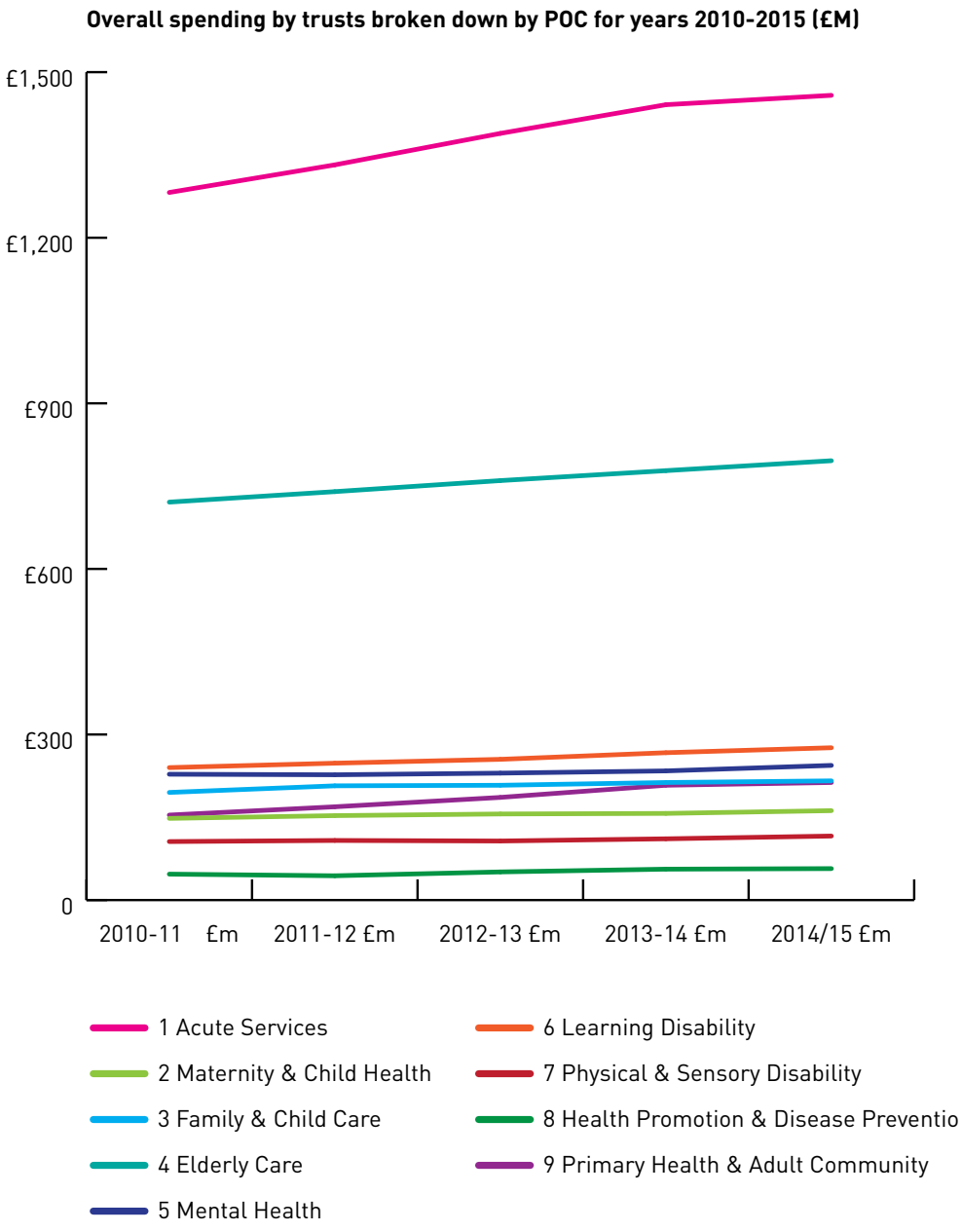
Although it is now more than ten years old, Professor John Appleby's 2005 review was an exhaustive look at how resources were being used across the system, with a particular focus on elective care and waiting times. Appleby updated his own results in 2011 and found that per capita spend in Northern Ireland was roughly 11.5% higher than in England, but that there is an 11.6% higher level of need. We can therefore draw the conclusion that the system is as well funded as other UK jurisdictions, with perhaps a very slightly lower level of funding per head once local levels of need and deprivation are taken into account.

However, Appleby's review also found significant disparities in some programmes of care. For example, according to his figures, mental health needs in Northern Ireland were estimated to be nearly 44% higher than in England, while actual per capita spending on these services was in fact 10-30% lower.[29]

These findings would support the argument that it is not the level of funding that it necessarily the problem, rather than how it is used to deliver services. If we consider the division of funding within the system by programme of care, it can quickly be seen that the majority of resources are invested in the acute hospital sector, which dwarfs all of the other programmes of care in scale.

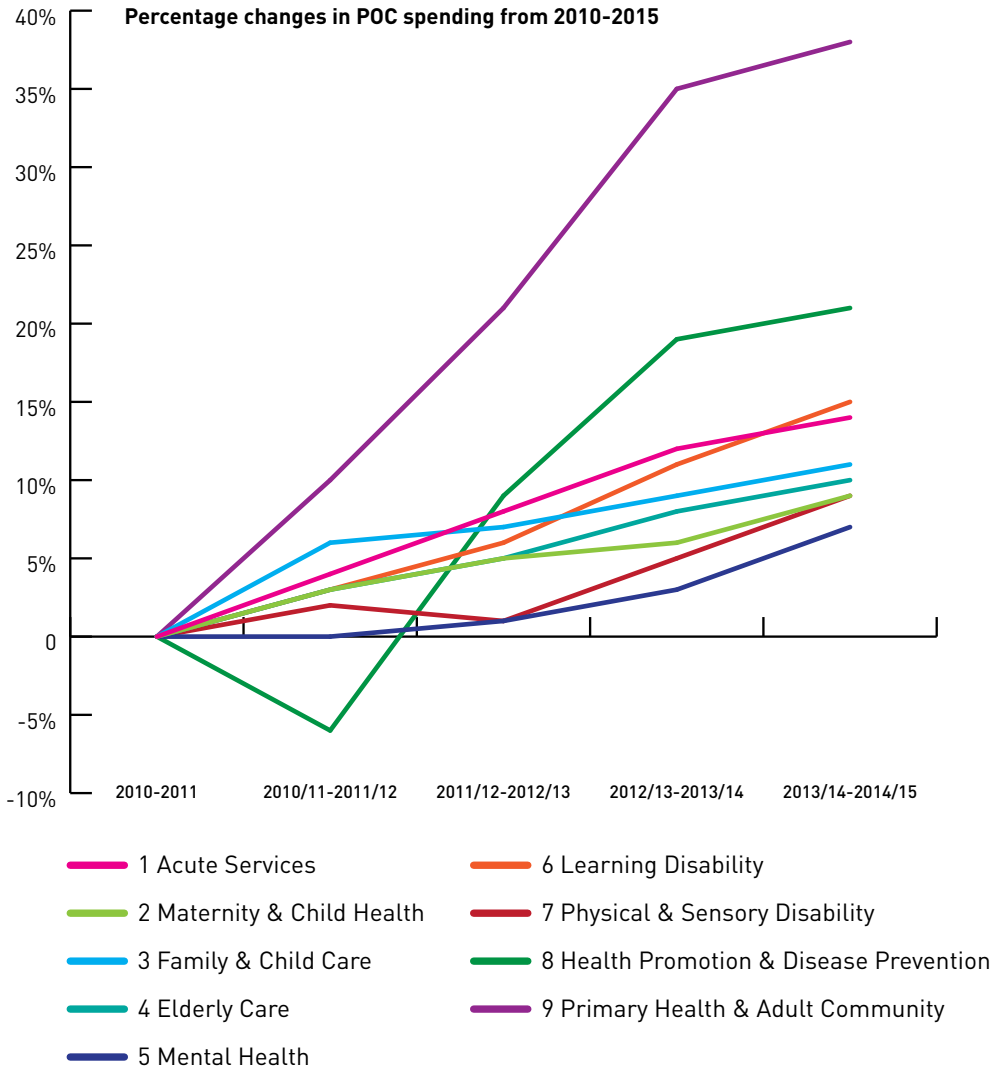
29. Appleby, J (2011) Rapid review of Northern Ireland Health and Social Care funding needs and the productivity challenge: 2011/12-2014/15, Department of Health

Fig. 22 – Funding by Programme of Care 2010/11-2014/15



As we can see from the graph above, spending on the acute sector continues to grow, although it is reassuring to note that the rate of increase has slowed down when compared to other programmes of care. While this may be indicative of a push by the system towards community based services, it also illustrates clearly that there is still a long way to go in making the shift from acute to community real and meaningful.

Fig 23 – Rate of Increase of Spending by Programme of Care 2010/11 – 2014/15



The OECD's report on Healthcare Quality across the United Kingdom, published in 2016, concluded that while there were examples of good practice in shifting resources from the acute sector to the community sector, there was no evidence that this was being managed systemically or strategically. Their report also concluded that funding was largely managed in silos and was often based on historical funding arrangements rather than an assessment of population need.

For a budget this size, the current one year commissioning cycle is also far too inflexible and short term to allow for any sustained investment or innovation. The Panel has heard from many sources that this prevents long term strategic planning and encourages a short term 'sticking plaster' approach to services, perpetuating the status quo rather than enabling transformation.

A real strategic approach to this will require a greater level of inter-sectoral funding, longer term commissioning cycles, and increased work across government to address the wider health determinants.

SECTION 3

VISION FOR A NEW MODEL FOR HEALTH AND SOCIAL CARE – ORGANISING FOR SUCCESS



There is an unassailable case for change. If we do not change the way we provide health and social care, the situation will only continue to get worse – the demand will continue to increase, activity will remain static and waiting times will continue to lengthen.

Following on from the evidence above, it is clear that:

- Given the challenges of today, business as usual, even if optimally managed, will not be enough to meet future demand.
- Transformation will require key cultural and operational changes in health care systems and in the way these systems are accessed by the public.
- Something very different has to happen at the delivery of care level.
- The funding mechanisms are not currently sufficiently aligned with the need to integrate care at the provider level.
- Health and social care are not working together as effectively as they might. If they were, there would be better outcomes and reduced waste.
- Front line improvements and innovation at the provider level need to be encouraged, sustained and scaled up where they can demonstrate three outcomes of the Triple Aim.
- The workforce needs to be empowered and engaged in designing the new models of care.
- The public should be honestly informed about why change is needed. Service users should be supported and encouraged to become 'informed and expert patients' who take individual action to manage their own health and well-being.

Given the challenges of today, business as usual, even if optimally managed, will not be enough to meet future demand.

The Panel has heard a strong sense of frustration among those working in the system, particularly from those on the front line, that the current pattern of investment which is prioritised to maintaining the current configuration of hospital

care would be better utilised in a new model of care outside hospital which better supports improved population health and well-being. The Donaldson report also identified the need to rationalise hospital infrastructure as a key part of reform.

Put simply, this work is not about closing hospitals. It is about fundamentally changing the way the HSC provides services.

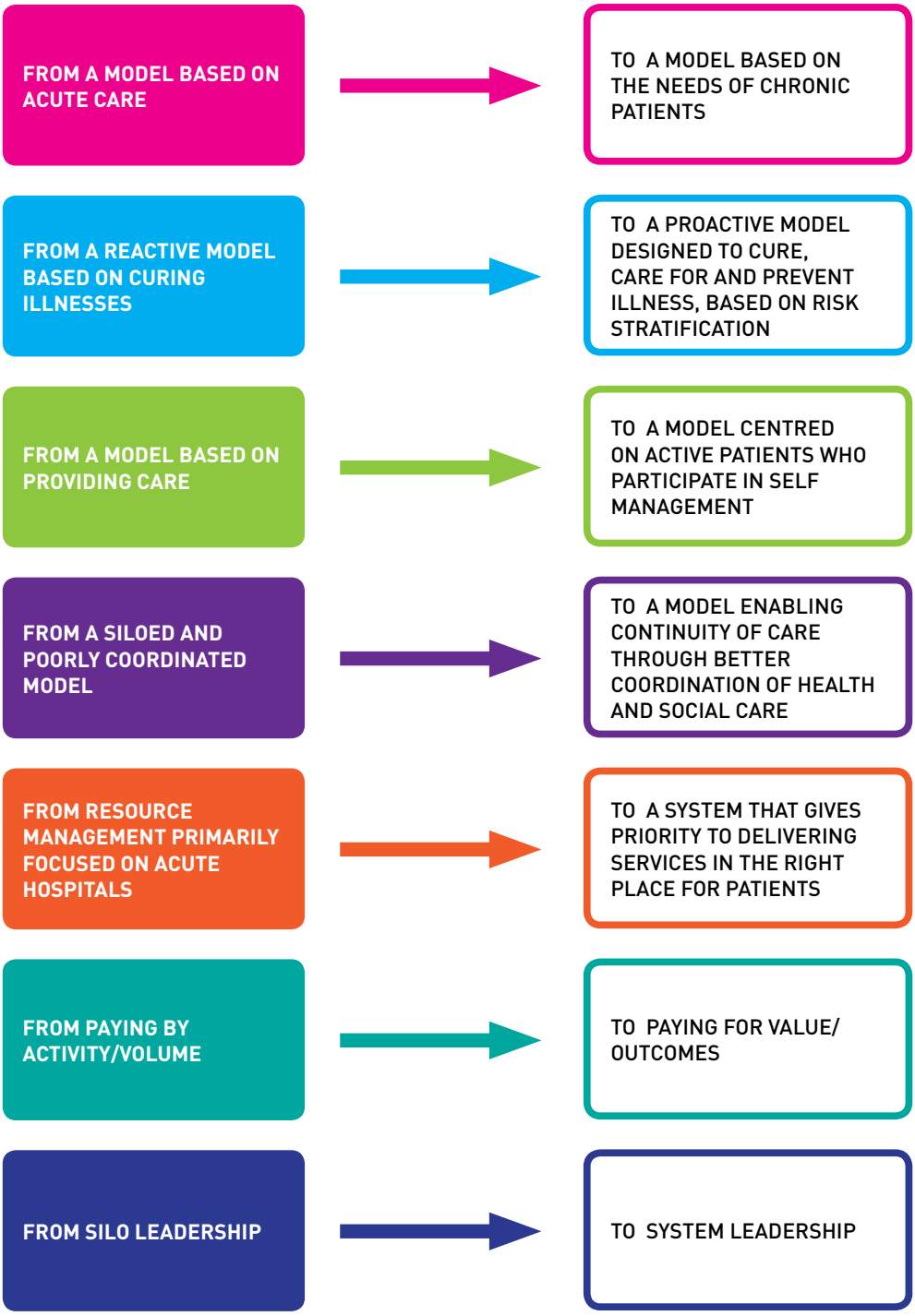
As a panel, we agree that it will absolutely be necessary to rationalise the provision of some specialist acute services as part of changing the service delivery model. As identified by Hayes, Compton and Donaldson, the current configuration of acute services is simply not sustainable in the short to medium term. As part of the transformation process, it will be necessary to reorganise services in such a way that resources are freed up from some parts of the existing model in order to allow them to be used for implementing new models that will offer higher value care. With respect to how this rationalisation is achieved, we will come back to this later in the report.

However, rationalising services is not the same as transforming the health and care system and the two should not be confused. The current overreliance on acute infrastructure is a contributory factor to the challenges facing the sector rather than their sole cause. While some rationalisation and concentration of specialist resources will be necessary to allow new delivery models to take effect, they are not ends in themselves. The meaningful transformation is in moving to a more patient centred, population health model, delivered at a sustainable cost.

Put simply, this work is not about closing hospitals. It is about fundamentally changing the way the HSC provides services. In some cases this may mean that some buildings/hospitals will close; in others it may mean that these buildings are used in different ways to provide a more effective and responsive service to meet the local population's needs.

The table opposite shows the main ways in which the system needs to change.

Fig 24 – Transformation



The Triple Aim

There are numerous health care systems in the world facing similar pressures and undertaking similar reforms in health and social care. These are the most important reforms in decades and an increasing number of them build around the Triple aim as a framework.

Although health care systems internationally are different from each other in many ways, they all have the same fundamental challenges:

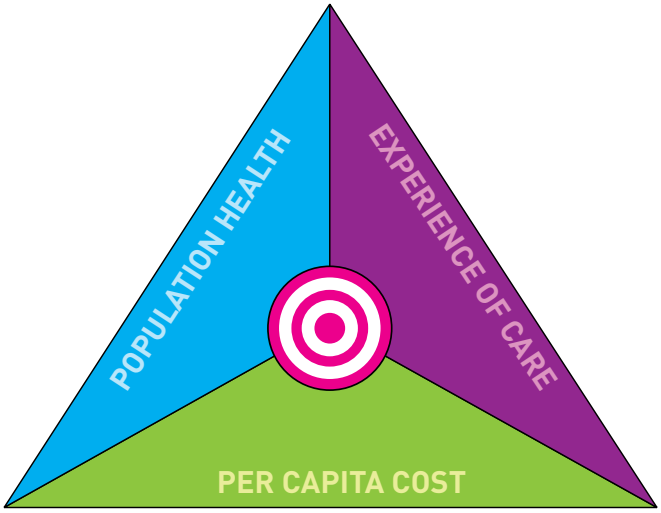
- All have sub-optimal organisation of care;
- Most are paying for volume and not for value;
- All use about 50% of expenditure on only 5% of the population;
- All have key challenges in prevention, quality and patient safety;
- Chronic patients receive fragmented and non continuous care; and,
- All could do more to reduce costly hospital admissions and readmissions.

There are numerous health care systems in the world facing similar pressures and undertaking similar reforms in health and social care. These are the most important reforms in decades and an increasing number of them build around the Triple aim as a framework.

The Triple Aim is a framework developed by the Institute for Healthcare Improvement (IHI). It is characterized by a simultaneous focus on three objectives:

1. Improving the patient experience of care (including quality and satisfaction);
2. Improving the health of populations; and,
3. Achieving better value by reducing the per capita cost of health care.

Fig. 25 – The Triple Aim



The Triple Aim is perceived by many as a key framework to improve services, but it will not happen at scale unless there is a powerful policy intervention regionally as well as empowered innovation at a local level. The Panel proposes to use this framework to move forward on the broader health and social care transformation.

Of course, all of the policies and strategies in the world will not succeed if they do not pay attention to the people who deliver services on the front line. On this basis, the panel recommends including a fourth dimension (sometimes called the quadruple aim) based on improving the work life of those who deliver care.

RECOMMENDATION 1

The Panel recommends using the dimensions of the Triple Aim as a framework for reform, including an increased emphasis on the experience of those who deliver care.

The ongoing economic crisis in Europe has made the numerous vulnerabilities of all health care systems more visible. The immediate reaction in many countries has been cost containment. Senior leaders have reacted to this difficult immediate context by seeking efficiencies and, as a result, day to day crisis management has been centred on taking some major cost containment decisions, especially regarding human resource salaries, the pharmaceutical budget and co-payments.

However, there is a growing acknowledgement that these interventions do not correct the main problem of health care – its basic design around reactive episodic care and a weak focus on population health.

In other words, even if these crisis decisions are handled in an effective way, they do not create in themselves the capacity for health systems to cope with the future challenges of demography, chronicity, prevention, fragmentation, sustainability and patient centeredness.

Today in Europe, as well as elsewhere, most of the policy decisions in health care are not about having to decide whether to ration or to transform. Rather it is about finding the right balance of both and not letting rationalisation dominate the broader transformation. This document considers both agendas, and the Panel would recommend progressing and managing them both simultaneously.

The Triple Aim provides a new framework for a strategic response. While it may sound theoretical, it is practical in its application and has already been used to guide a number of prototypes in Northern Ireland which are already showing powerful results. We will cover some of these projects later in the document.

Advancing towards a Local Accountable Care System

The present model of care is not delivered on a population agenda. It is not providing continuity of care in an organised way and the organisations delivering care are still operating as silos.

The Panel has heard consistently and agrees that care should be personalised, preventative, participative and predictive. However none of those objectives can be achieved in the present reactive and fragmented system. The HSC therefore requires a new organisational form at the local delivery level, an organisational arrangement which will allow those approaches to be embedded in the culture of everyday health care.

The present model of care is not delivered on a population agenda. It is not providing continuity of care in an organised way and the organisations delivering care are still operating as silos. We need to move away from this hospital centred model of care to a more integrated model.

The Panel has heard of changes to the provider sector that are already being carried out to achieve the size and scale required to better manage, and indeed change, the current demand for services. General Practice is moving from the 'small business' approach to bring together Practices within larger geographies as 'Federations'. By working more collectively, it is hoped these Practices can share skills and services, manage workforce pressures, operate more efficiently and more effectively meet the rapidly increasing demand for primary care services. Services within Trusts are increasingly networking on a cross-Trust, cross-profession and indeed NI-wide basis where these services are specialised and there is a need to collaborate to meet demand. Trusts sub-contract with the community, voluntary and independent sectors for health and social care provision. There is a mix of provider models for GP OOH services.

So the provider sector – Primary Care, Trusts, 3rd sector and independent sector – is already becoming increasingly integrated and inter-dependent without structural reform. However, this is happening in the absence of strategic intent, and is operating under traditional contract models and output targets that do not support the system transformation which is required to address the challenges set out in section 2. This report proposes the development of Accountable Care Systems to integrate – by agreement, and without the need for structural reform – the provider sector to take collective responsibility for all health and social care for a given population and with a joint capitated budget linked to population based outcomes under agreement with the commissioning system to be decided by the Minister.

There are models where this collective provider model is starting to emerge. For example, the Sustainability & Transformation Plans (STPs) in England, where 44 planning and delivery systems have been set up based on geographical footprints, and charged with planning and delivering system-wide change. This will include a more integrated approach to health and well-being, self care, more proactive care for those with the most complex needs, and a smaller, more efficient hospital sector. This is all intended to both improve care outcomes and drive out collective financial deficits in their areas. Accountable Care Systems will also provide a structure for better patient engagement, empowering people to become active participants in their own care.

There are lessons learned from Accountable Care Systems elsewhere that provide evidence of the key components that can be put in place to drive more integrated working without structural reform. These are:

- Size and scale – the population footprints must be of sufficient size to manage the majority of population's care needs, to take accountability for managing variations in demand and expenditure, and to take 'internal decisions' to change the delivery of care, but also importantly to support local partnership working and risk sharing;
- A defined population where the new model of care can be delivered at pace, focusing on the stratified risk of that population – already available in General Practice if this information is collated and shared;
- New working arrangements, including shared leadership, shared accountability and devolved budgets, development of new roles to push the boundaries of the skilled but not qualified workforce and the 'generic professional case manager', and a partnership approach with the 3rd sector to deliver a more standardised service offering within local communities to reduce loneliness and isolation, improve well-being and to provide high quality care;
- New support tools, including shared information, accessible patient and client records, and a capitated funding system that incentivises an integrated provider response;
- Service user engagement, at population, service and individual level;
- Cost and quality measures which are measurable, comparable and outcome based.

Under an ACS, providers would collectively be held accountable – under a shared leadership model – for achieving a set of pre-agreed quality outcomes within a given budget or expenditure target, with agreed risk share arrangements and incentives. They would also need to have maximum autonomy to make rapid and sustained changes to improve care and outcomes for the population they serve.

Of course, not all services will be amenable to this model. Some services are so specialist that they must be delivered at a Northern Ireland level. These will require a different commissioning or provider model – set at a regional level – to ensure specialised resources are concentrated on a small number of high volume sites, that they are sustainable in the long term, that inefficient duplication is avoided, and that they can be supported and incentivised to innovate and to develop world-class treatment.

Some services are so specialist that they must be delivered at a Northern Ireland level. These will require a different commissioning or provider model — set at a regional level

Transformation to deliver the Triple Aim will also require a new approach to the commissioning and delivery of care. The Department of Health carried out a review of commissioning in 2015 and found that the current system was complex, slow to take strategic decisions, unresponsive and with too much emphasis placed on

activity/volume over value/quality. The current commissioning model has also failed to effectively shift accountability to the provider level and this has led to an overly transactional approach. It is worth highlighting that the lack of a devolved budget and insufficient autonomy have been identified in other jurisdictions as key reasons why some population based models have not achieved their potential.

RECOMMENDATION 2

The Panel recommends that the HSC should move to:

- Formally invest, empower and build capacity in networks of existing health and social care providers (such as Integrated Care Partnerships and the developing GP Federations) to move towards a model based on Accountable Care Systems for defined population based planning and service delivery; and,

- Regionalised planning for specialist services.

Northern Ireland already has many of the building blocks to move towards Accountable Care Systems — perhaps even more so than many other nations.

Building on Existing Foundations

Northern Ireland already has many of the building blocks to move towards Accountable Care Systems – perhaps even more so than many other nations. The Panel believes that many of the key elements of a more integrated organisation, such as Integrated Care Partnerships as 'learning labs' for what will make integrated delivery systems work best and the emerging GP Federations, are already in place, but these building blocks need to be taken to the next level and be fully enabled with devolved autonomy and incentivising funding mechanisms linked to measurable population outcomes in order to truly become local Accountable Care Systems.

Furthermore, Northern Ireland has already made real progress in establishing an array of management and organisational processes, all of which help to provide the tools needed to move forward quickly. However these need to be further developed and strengthened in the following ways:

Adding Depth to Structural Integration of Health and Social Care

The formal integration of health and social care should be a key strength of the existing system and will provide a strong foundation to pursue reform. However,

in practice, the benefits of integration have not been fully exploited and it would seem that there are still significant administrative silos that prevent this happening. Integration in name only is not enough and if the Panel's proposed model is to be successful there has to be better integration between all parts of the health and social care system. This level of integration will require a great deal more work on how the system plans, funds and purchases care across acute care, general practice and community health, and social care provided by statutory, independent and community , voluntary and charitable providers.

The development of the Accountable Care Systems suggested in this report will greatly reinforce the necessary health and social integration on the ground.

The primary function of social services is to improve and protect people's social wellbeing when it is vulnerable. Social wellbeing refers to the extent that people are socially connected, engaged in purposeful activity, in control of their own lives and are protected from abuse and exploitation. The primary reasons to promote and protect people's social wellbeing are because it is essential to people's quality of life and it safeguards people's human rights. However not surprisingly there is also a strong relationship between people's social wellbeing and their health. This is one of the main reasons integration between health and social care services is seen as a desirable feature of healthcare systems.

The health impact of better integration between health and social care services is reinforced by more and more studies. The impact of social factors such as income, educational attainment, access to nutritional food, good quality housing and employment status is well documented. There is a growing evidence base and literature about the importance of social determinants of health in improving the health of populations. The relative contributions of genetics (20%), health care (20%), and social, environmental and behavioral factors (60%) are well documented.[30]

Northern Ireland is better placed than others to continue reinforcing the combined action of health and social services. The move to local integrated systems of care will provide an even better platform for this happen. However it can also present challenges.

When difficult funding decisions need to be made it can be difficult to secure investment in social services when faced with competing demands for healthcare investment. However there is a strong economic rationale for investing in social interventions.

The increasing use of new commissioning models (payment models) will be a key lever towards improved health and social integration. New payment models that hold these local integrated care organisations accountable for people's health and the cost of treatment can be used to maximise the benefits of integration. A focus on holistic outcomes that includes the promotion of social wellbeing and penalises outcomes that undermine it, such as unnecessary hospital readmissions, will make the health and social care system more sustainable and more importantly improve people's quality of life.

30. Chiu, G. et al. (2009) Relative contributions of multiple determinants to bone mineral density in men. Osteoporos Int, 20(12), 2035-2047

Payment schemes such as these would give these local organisations an economic logic to incorporate social interventions into their approach to care.

Targeted programmes can link individuals with chronic conditions to social support schemes. For example, community health workers can conduct home visits to low--income families with children with uncontrolled asthma. There are examples in which this type of intervention has reduced the use of emergency care by two thirds.[31] Managerially the children in such a scheme would be identified by a risk stratification approach in a community. This type of intervention is a practical example of targeting inequalities in a community as the targeted group are children of low income families.

Furthermore it makes economic sense as unmet social needs are associated with higher rates of emergency care, hospital admissions and readmissions. A recent study found that the 10 health conditions that accounted for the highest health care expenditure are linked to unmet social needs. These include heart disease, mental disorders, asthma, diabetes and hypertension.[32]

There are therefore numerous reasons for this integrated approach to become progressively the standard of care in Northern Ireland.

Expanding and investing in eHealth infrastructure

eHealth is a broad concept, defined as the use of electronic means to deliver information, resources and services related to health.

Data and enabling technologies are vital components of a modern healthcare system. We hold large amounts of information on behalf of our patients and we need to look after this, but we also need to use it as effectively as possible to deliver improved outcomes for individual patients, for the wider population, and for society as a whole.

31. Greineder, DK, Loane KC, Parks P (1999) A randomized controlled pediatric asthma outreach program. J Allergy Clin Immunol March 1999;103(pt 1):436-440

32. Agency for Health Care Research and Quality. DHHS . USA . 2011 - Medicla expenditure panel survey

The introduction of the Electronic Care Record (NIECR) has revolutionised the way health and care can be delivered by providing care staff with an up-to-date record that avoids duplication of tests and information gathering, and allows information to be used in ways that can lead to better decisions on prevention, treatment and care.

However, while a great deal of good work has already been carried out, much of the data that is held on patients is inaccessible to other systems within the HSC; it exists in data silos that do not communicate with other core datasets. More work needs to be done in terms of linking these systems and increasing interoperability. The Department of Health and the network of Chief Clinical Information Officers are in an ideal position to lead in setting the direction for eHealth, and in ensuring engagement from the wider clinical community.

Northern Ireland should continue to invest in this area, with the ultimate aim of providing patients with ready access to their own records. A conversation with patients and their representatives may also need to occur to discuss how the system uses HSC data and linked public sector datasets in medical research, population health planning and infrastructure development.

Patients should also have the right to see their own data and the system should move towards greater openness and access. This would allow patients to see this information and use it in managing their own health needs.

Advances in telecare, telemonitoring and electronic assistive technologies are also making a significant difference to the way services are delivered. Used effectively, they can make a valuable contribution to the quality of services by improving coordination of services, overcome geographical distances between patients and providers, enabling patients to live independent lives for longer, and engaging patients in their own health and well-being.

In a population health model such as that proposed by the panel, data, analytics and new technologies are key enablers in driving clinical innovation, and also in supporting patient self management and health ownership.

Northern Ireland is in an ideal position to take advantage of opportunities in eHealth, and position itself as a global leader in this field. There is a single HSC system, a collaborative network of organisations, engaged patients, two high quality universities and a thriving commercial IT sector. The Health and Social Care Board's eHealth strategy, which was published earlier this year, sets out how the HSC will work with industry, academia, the community and voluntary sector, other public sector bodies and government departments, and international partners to further develop uses of e-Health as a driver to improve health, well-being, prosperity and job creation.

Developing the Workforce

In addition, the health and social care system here has a powerful and expert workforce.

Despite the challenges, Northern Ireland already performs strongly in many aspects of health and social care delivery and, building on the strong foundation of its integrated workforce, has the existing capacity and capability to continue to lead the way in developing and implementing new and modern care pathways.

However, reconfiguring health and social care services will depend on the ability to reshape the workforce to support the new models of care.

An effective workforce where skills and competence are aligned and support new service models needs to have as its key aims:

- The improvement of quality;
- Financial efficiency;
- The long term health and wellbeing of communities.

Having the right number of appropriately skilled staff is a critical determinant of the quality and efficiency of the health and social care system, yet there is a growing and recognised gap between patient needs and the skills and knowledge of the workforce that cares for them.

While across health and social care systems here, as in other countries, organisations are reporting severe difficulties in recruiting and retaining staff, it is also recognised that there is a frustration among the highly educated and experienced workforce, of the inability to progress to the level of competence to which they are educated.

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There is also a clear need to invest not only in the immediate and short term future workforce but also on the pipeline for the longer term.

In Northern Ireland there is a real opportunity to adapt the current nonclinical workforce to meet the growing needs for patients to remain at home in local communities. There is an emerging body of evidence that shows that integrated workforce models configured around defined populations support improved population health outcomes, a better care experience, and also a reduction in the per capita cost of health care.

Immediate actions need to be taken to support the workforce to continue to deliver high-quality care to patients, clients and carers through this period of transformation. The Panel suggests that work is commenced to remove the artificial governance barriers that make role developments difficult to achieve and therefore the transferability referred to above difficult to attain.

For this to be successful, the HSC will need to:

- Put in place strong supporting systems and governance structures, including supervision of new and extended roles;
- Create a culture that supports experimentation and change; and
- Cultivate good relationships with local workforce and training bodies.[33]

33. Imison C, Castle-Clarke S, Watson R, (2016) Reshaping the Workforce to Deliver the Care patients Need, Research Report, Nuffield Trust

Within primary care in Northern Ireland there is a need to move from the predominantly GP led model of care to a more blended approach that accommodates the rich range of professionals working in partnership to meet the needs of the practice population. This can create a robust, extended primary care team serving a local population level, including Nurses, Doctors, Allied Health Professionals, Health Care Assistants, Pharmacists, Mental Health Professionals and Social Care workers all have a role to play in improving the service offering delivered by primary care, with an increased focus on prevention and early intervention and the active management of complex patients to support them to better manage their conditions.

In order to achieve this, it will be necessary for those at the head of the HSC to create a safe environment for local innovation. This means the workforce is not only engaged for clinical purposes, but also organisational and managerial innovation.

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A recent Vanguard document **"New Care Models and Staff Engagement: All Aboard"** draws out an approach to ensure staff are at the heart of decisions about new models of care.

This approach includes:

- Enabling different groups of staff across organisations to "break down the barriers" – to allow them to break out of old working patterns and think differently.
- Recognising that those on the front line of care have the best ideas about how to improve it – but also that they need to feel empowered to do so.
- Recognising that if staff feel that their contribution is valued, they will want to do all they can to make new care models a success.

The panel strongly believes it will be essential to reinforce this work and to invest heavily in staff engagement.

Improving Quality – Frontline Innovation

Quality improvement has taken on increased importance internationally in recent years. Drawing on the successful practice of 'improvement science' which was first applied in manufacturing and industry, a number of countries have sought to adapt this and apply the principles to health and social care services. To date, there have been some impressive results with this approach in areas such as Qulturum, in Sweden, Ko Awatea, in New Zealand, and Healthcare Improvement Scotland.

In Northern Ireland, the Panel has seen impressive examples of innovation and improvement going on across the HSC. However, it is also clear is that there is a lack of capacity and capability to scale these projects up and to sustain them across the system. While the Quality 2020 strategy shows that there is a clear

While the Quality 2020 strategy shows that there is a clear commitment to quality improvement at the top of the organisation, it is not clear that this has pervaded the HSC to the extent that it can be considered to be part of everyday business.

commitment to quality improvement at the top of the organisation, it is not clear that this has pervaded the HSC to the extent that it can be considered to be part of everyday business. The Panel was told that "quality improvement is still viewed as peripheral, an activity for a small number of HSC staff". This may be a reflection of the operational pressures in the current system, which restrict opportunities for staff to become informed and experienced in improvement methodology.

A new approach may be required to support staff across the system to adopt a 'right fit' methodology dependent on their need for improvement, whether this is to:

- Do it right – standardising/removing variation to improve efficiency;
- Do it better – improving existing systems to achieve better performance;
- Do it differently – innovate and change existing systems to improve outcomes.

The previous Minister announced that the Department of Health would develop plans for an Improvement Institute to drive forward innovative improvements in how health and social care services are delivered. The intention is that this would be able both to build on the emerging improvement and innovation hubs in each Trust and to bring them together regionally, but also to support individual professional and managerial staff to develop their skills and expertise in leading and delivering innovation and quality improvements and to share these skills and expertise with others.

The Panel would endorse this approach – any system that aspires to be world class must take a strong position on quality improvement, with the patient and service user voice represented as part of this. The purpose of the Institute should be to create the conditions in which this improvement becomes the norm, from the bottom of the organisation up and the top of the organisation down.

Health and the Wider Economy

Health and social care is a significant part of Northern Ireland's Gross Domestic Product and it accounts for a sizeable proportion of jobs and public spending. A report by the Economy and jobs initiative task and finish group found that:

- Annual spend in the sector is £4.5 billion, with capital expenditure of £200 million.
- Staff employed within the Health and Social Care sector account for 9% of all employee jobs in Northern Ireland.
- The Health and Social Care sector creates approximately 10% of the total economic output of Northern Ireland.

Economic discussions about the HSC most commonly focus on the cost of running it. However, we should also recognise the enormous contribution it makes to the Northern Ireland economy.

Northern Ireland has previously been described as "small enough to be agile but big enough to matter." If the health and social care sector here can lead the way in transforming how services are delivered, then it has the potential to be a world leader in developing innovative services and products. The proposed new model, based around Triple Aim, would help to support healthcare market opportunities for Northern Ireland going forward, particularly in terms of the range of enabling technologies and processes that need to be developed to meet modern patterns of demand.

Any system that aspires to be world class must take a strong position on quality improvement, with the patient and service user voice represented as part of this.

RECOMMENDATION 3

The Panel recommends that the HSC should continue its positive work to invest in and develop the areas listed above.

There should be particular focus on the three key areas of workforce, eHealth and integration:

- As a key enabler of Accountable Care Systems, the HSC should continue to invest in eHealth to support improved self management, care at home and use of information to drive better population health outcomes.
- The HSC should immediately develop innovative primary care based models that will allow non-medical staff to work in a way that makes the most of their skills. (For example, these could be based on the community nurse-led care models being implemented in the Netherlands, or the use of pharmacists in community development here in Northern Ireland).
- Work should be carried out to identify which social interventions are most cost effective in addressing the social needs and improving health for Northern Ireland.
- Any new approach to commissioning should be aligned with the need to build integrated health and social organisations on the ground which target specific inequalities and social groups.

Emerging Practices

In addition to these areas where work is already ongoing, there are some emerging processes which the HSC may wish to explore and adopt.

Value Based Care

This Panel considers the present resources would be better used in a value based care model. This report strongly recommends Northern Ireland should start taking this route as the short term changes will in themselves be insufficient to provide a high quality and sustainable health and social care system.

A value based model in Northern Ireland would need to reinforce an integrated primary and community health and social care delivery model so that more can be done out of hospitals, encouraging work across organisational boundaries, as well as strengthened primary care sector in order to effect a shift in the balance of care. This will involve paying for value instead of simply paying for activity, accelerating home care technological support schemes, and improving coordination with the voluntary, community and independent sector as true partners in care.

This process has the potential to harness the strengths of different parts of the system, across organisational silos, across sectors and beyond what is traditionally considered to be the health and social care sector.

Co-Production

The relationship between health and social care professionals has changed significantly in recent years. There has been an increasing acceptance that people who use services and have healthcare needs will have views on how they should be treated as individuals and as groups who have interests in services. It is now recognised that people should be treated with respect and listened to and that major changes to services should be consulted upon.

Co-production describes an approach that takes this changed relationship to a new level. Co-production involves breaking down barriers between professionals and the people they serve, recognising people who use services as assets with unique skills. It involves a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities.

There is a difference between co-production and participation: participation means being consulted while co-production means being equal partners and co-creators. The benefits of adopting co-production include delivering change that is owned by service users rather than being resisted by them and designing services that reflect the knowledge and expertise that comes from using services.

SECTION 4

ROADMAP FOR IMPLEMENTATION



Creating a Compelling Vision

Together, all of actions set out above will strengthen services in the community so that more can be done out of hospitals, encouraging work across organisational boundaries, as well as with strengthened primary care in order to effect a shift in the balance of care.

This is of course the strategic direction of travel that was outlined in Transforming Your Care – and it is still the direction that the system needs to move in. However, as the previous pages indicate, the Panel feels that we need to go much further. There is now a significant body of evidence internationally to show the elements that are necessary to achieve this kind of transformation, and also to demonstrate that this kind of strategic shift can produce better outcomes for local populations.

However, in order for this to happen, all these approaches need to be aligned around a common vision of transformation and not be a series of isolated initiatives. The Panel has concluded that at least part of the reason that TYC has not been the success many hoped, is that it became just one initiative among many and not the overriding strategy guiding the entire organisation's decision making.

However, in order for this to happen, all these approaches need to be aligned around a common vision of transformation and not be a series of isolated initiatives.

For these reforms to be successful, they have to become the strategy for health and social care. It will not be enough for senior managerial and clinical leaders to pay lip service to the concepts outlined here, they must underpin every decision that is made and every new policy that is developed. The Minister will need to take some time to consider what this vision will be and how it will be communicated to staff and to the public. The Panel hopes that this report will help to provide the foundations for this vision.

RECOMMENDATION 4

The Minister should create, communicate and lead a clear, powerful, long term vision for the Health and Social Care system as a first step in the implementation process.

Components of Transformation

Transforming the HSC is an enormous and complex task that will need to be progressed steadily over at least the next ten years and which will require a combination of change strategies. The Panel has identified three separate components for practical implementation:

1. **Driving the system towards Accountable Care Systems**
2. **Aggressively scaling up good practice**
3. **Rationalisation and stabilisation**

The HSC operates within a parliamentary democracy and as the political context cannot be avoided, it must therefore be managed.

While each of these stages has a different lifespan, they are all urgent, they are all connected, and they should all be launched simultaneously.

The mid-term goal is to establish new accountable care systems. The second component helps to create the conditions for the new delivery model by scaling up good practice where it is consistent with the overall vision. The third component does not change the model of care, but it is necessary to free up resources to allow the system to transform.

1. Driving the system towards Accountable Care Systems

This is a mid-term agenda, but it must start now.

The political context is of critical importance in any transformation process, as is the impact of politics on shaping the environment governing large-scale change. The Panel has frequently heard that there is a need to remove health from politics but in reality the importance of politics is a feature of all health systems and can ultimately determine whether and how far large-scale change succeeds or not. To paraphrase Tip O'Neill, the former House Speaker in the USA, all politics is local and this is nowhere more apparent than in decisions about local health services. The HSC operates within a parliamentary democracy and as the political context cannot be avoided, it must therefore be managed. Those seeking to introduce change, need to provide compelling evidence for why the change is necessary and a clear sense of the benefits the new model will offer.

The longer term demands of transformation are especially acute since electoral cycles often militate against long-term change. Results are looked for in the short term and this is especially evident in the type of change favoured which tends towards short term impact rather than long term reform.

If a health system transformation is going to thrive, it will require supportive policies that incorporate longer time horizons[34] with regular milestones to build confidence in the direction of travel. The work on the Principles carried out with the local political parties in a political summit earlier in the year was intended precisely to help future implementation and help to get beyond those short timeframes that drive output targets (principles at annex 1) by demonstrating the need for long term and sustained reform that will deliver improvements in population outcomes.

The Principles helped to create the right environment but much more needs to be done to reinforce and strengthen that environment.

As stated above, one absolutely fundamental component in creating this environment is the development and communication of a clear vision for health and social care and a robust implementation plan to deliver it.

The task in the mid-term is to transform the model of care in Northern Ireland. This has been indicated in previous reviews. All stakeholders interviewed by the Panel agreed with the need to drive towards new models of care but they called for a stronger implementation agenda.

To this end this Panel offers an approach to implementation for these mid-term changes. These actions should start now. Northern Ireland is investing a considerable amount of resources into health care but the present payment and delivery system will not create the organisation of the future.

Northern Ireland has the scale and capacity to do this. However this transformation will not happen at scale unless there is a powerful policy intervention. It needs to be conceived and implemented as an integrated package.

We therefore propose a series of time bound actions linked to the three dimensions of the Triple Aim framework which will take the health and care system in Northern Ireland to a population based model of care. Following on from the work of Sikka, Morath and Leape, we also suggest adding a fourth component – that of the health and care professional's experience.[35]

Northern Ireland is investing a considerable amount of resources into health care but the present payment and delivery system will not create the organisation of the future.

RECOMMENDATION 5

Alongside the Minister's vision for health and social care, the Panel recommends that plans, costs and timescales for introducing each of the following actions should be prepared within the next 12 months. It is vital that the implementation of these actions is led by health and care professionals and managers.

34. Halfon N & Conway P (2013) The Opportunities and Challenges of a Lifelong Health System N Engl J Med 2013; 368:1569-1571

35. Sikka, R, Morath, J, & Leape, L (2015) The Quadruple Aim: care, health, cost and meaning in work

Population Health

- Some work on risk stratification has already been carried out at General Practice level. This should be built on to introduce a comprehensive, system wide approach to risk stratification in of the entire NI population.

- Governance arrangements to be developed for new Accountable Care Systems (ACS), including integrated capitation budgets based on the services (excluding the most specialised services) required by the population served by the ACS to be devolved to these new autonomous and accountable provider partnerships.

- Starting immediately, progressively phase in early adopter accountable care systems, bringing together the provider sectors for a defined population into a single accountable leadership. The ACS would be responsible for utilising a capitation based budget across organisational and professional boundaries including local infrastructure to achieve agreed improvements in population outcomes.

- The Programme for Government is moving towards outcome based measures to judge the impact of political decisions and the use of public funding on the population, and the success measures for the new ACS should also be outcome focused, and should be measures of population health with priorities for improvement. The Panel recommends the development of a relatively small set of outcome based metrics which set the challenge for the new Accountable Care Systems.

Patient Experience of Care

- The use of co-production as an approach should be mandated in accountable care systems and service redesign.

- Provide the population with individual access to their health and care information.

Per Capita Cost

- Introduce new cost and quality measures which are measurable, comparable and outcome based.

- Start the process of paying for value and not only paying for activity. By the year 2020, 50% of the budget should be commissioning value.

- As new value based commissioning approaches are implemented and local integrated organisations take form, ensure that the metrics being used include combined social and health indicators.

- Move to a rolling three year budget cycle to allow for more strategic commissioning/planning of services.

Staff Experience

- The Department to lead on the development of an 8-10 year workforce strategic framework, aimed at identifying immediate workforce challenges and planning the workforce to meet the demands of the new delivery model.

- New workforce models to be designed around defined populations and associated care functions. This should include enhanced roles for the skilled but not qualified workforce.

RECOMMENDATION 6

Many of these recommendations will require additional, transitional funding. The Panel recommends that the Minister should establish a ring fenced transformation fund to ensure this process is appropriately resourced.

The transformation process will take years, and must be sustained over the longer term. The political administration can expect some short term results from the process but must create a mid-term strategy which is sustainable over time.

RECOMMENDATION 7

For this purpose, the panel recommends the creation of a transformation board, supported by the Department, linked to the Executive's health and well-being strategy.

- This board would set the mid-term strategy, oversee the transformation process and would be tasked with creating the right conditions for the local system of care to develop successfully.

- It should help to transform organisational structures and management processes by promoting local decision making, local innovation and scaling up of best practices among the local systems of care.

2. Aggressively Scaling up Good Practice

Not only does Northern Ireland have many of the elements that are necessary to allow it to move forward, it has numerous examples of good practice that are consistent with the overall vision described above. Many of these could simply be scaled up and implemented on a regional basis where they will drive the system change and improved population outcomes set out in this report.

Targeting Mental Health

Implementation of the Rapid Assessment Interface and Discharge Project

This project was developed in recognition of the fundamental role that mental health plays in promoting and sustaining positive physical health. There are strong relationships between presenting physical ill-health and underlying mental health problems and by addressing these needs we can support better health outcomes and recovery rates.

The Rapid Assessment, Interface and Discharge Team (based on the Birmingham RAID model) is a multidisciplinary mental health team based in an acute hospital setting. It brings together diagnosis, treatment, psychosocial and psychological based approaches to ensure the best outcomes for patients. The service is a specialised multidisciplinary liaison psychiatry and psychological medicine team that provides rapid, timely and high quality interventions to promote the recovery and well-being of patients who present at Emergency Departments and/or are admitted to general hospitals.

The service replaces the multifaceted approach to mental health referrals with a single point of contact for all mental health referrals. The team operates 7 days per week and over 24 hours, responding within 2 hours to all Emergency Department referrals and within 24 hours to routine ward based referrals or quicker if deemed necessary.

Whilst the Northern Trust RAID is a hospital based service, one of the key benefits of the service is its ability to outreach into the community and to act as a conduit to mental health services. Improved communication with community teams such as community mental health teams and Older Persons Teams have supported discharge planning within wards and support earlier discharge from Hospital. There is enhanced communication with Primary Care and GP's are provided with a report, in respect to RAID involvement.

This innovative model has required a new way of thinking and approach to service delivery. It has required staff who previously worked on their own to adopt a different way of working which included; working as part of a strong cohesive team, working across organisational boundaries, and working shifts for previous 9am-5pm workers.

The RAID concept has been evaluated by the London School of Economics in Birmingham. This has shown reduced length of stay and enhanced discharge processes. Early indications show similar emerging patterns in Antrim Area Hospital. RAID input has also contributed to the reduction of emergency hospital readmissions within 30 days, thus reducing the overall cost of care.

Dealing with Chronic Conditions

An Integrated Respiratory Service

Within the Western Health and Social Care Trust in 2013, deaths due to respiratory diseases accounted for 16.2% of the total number i.e. 2% higher than the NI average. In addition, the majority of deaths occur in the elderly population and this is therefore expected to rise. This has implications for service provision, including an increased need for social and emotional support, especially for those patients with chronic respiratory diseases and their families and carers.

Having mapped existing services and reviewed good practice elsewhere, it was decided to create a WHSCT Integrated Respiratory Service that would enable patients with a chronic respiratory condition to be cared for in the most appropriate setting, by the most appropriate person, with access to specialist respiratory advice to enable the patients to achieve maximum health and improved health outcomes.

Previously patients with a chronic respiratory disease may have received care from a diversity of core services and this contributed to confusion for patients, duplication of services, inconsistency of approach, and inequity of access.

A new Community Respiratory Team (CRT) ensured that the patient population and their carers would receive a high standard of co-ordinated care, be better informed and educated about self-management, have improved functional ability, and have enhanced access to other services e.g. palliative care, pulmonary rehabilitation, oxygen services, support networks and voluntary agencies.

A single point of contact was put in place at each of the three sites. Referral processes were streamlined to an electronic referral system. A new operational framework was developed and communicated to all services that refer and work with the CRT. To support the CRT, a respiratory consultant rota was established as well as a monthly multi-disciplinary team meeting for complex patients managed by the CRT in the home setting. Direct referrals from GPs to the team were introduced as well as from the Northern Ireland Ambulance Service. Databases to record data were developed for all sites.

This team provides a streamlined service for GPs, hospital staff and patients. This model ensures a more coordinated and responsive service and acts as the interface between the acute hospitals, the community service, primary care and the

community and voluntary sector. Referrals are accepted from Hospital Discharge Service, GPs, NIAS, self-referral (patients previously with the service), Out of Hours and Respiratory Outpatients Service.

The programme has delivered great benefits in terms of patient experience, reduced waiting times, improved self management, reduced admissions to hospital, and, above all, better outcomes for patients.

Providing Alternatives to Hospitalisation

Acute Care at Home

The Southern Health and Social Care Trust (SHSCT) has the fastest growing over 65 years population in Northern Ireland and is set to grow by 35% from 2012 to 2023, with the over 85 year old population set to grow by 73% in the same period.

Emerging evidence from models in Torafen and Lanarkshire indicated that a consultant led community Acute Care at Home (AC@H) service was proving to be an effective way of caring for acutely ill older patients in their home as an alternative to an admission to an Acute hospital.

Following 18 months of planning, Phase 1 of the consultant led AC@H service commenced in September 2014 aiming to assess patients within 2 hours of referral. The primary focus of the service is to maintain older people at home in the event of an acute illness or unexpected deterioration in health through the prevention of inappropriate admission or facilitation of early discharge. The service provides medical triage, assessment, diagnosis and treatment as an alternative to in-patient care specifically to those at risk of or potentially requiring admission to hospital, i.e. in the absence of such care, they would otherwise require inpatient treatment.

The patients have the same access as patients in an acute hospital ward to laboratory results and to diagnostic appointments (for CT scans, Ultrasound scans, X-ray, MRI scan).

The Team consists of Consultant Geriatricians, Speciality Doctor, Specialist Occupational Therapist, Specialist Physiotherapist, Specialist Nurses, General Nurses, Pharmacist, as well as Healthcare Rehabilitation Assistants and Clerical support. Clinical and managerial leadership provided strategic direction and inspired confidence in other stakeholders.

In the 19 months from 22/9/2014 to 30/4/2016 the service has safely cared for over 830 acutely unwell patients in the community who otherwise would have been admitted to an acute hospital. Consultants and other professionals report that older people are recovering much quicker, the risk of acquiring a hospital acquired infection is eliminated and risk of falls is greatly reduced, with little or no incidence of delirium, than if they had been in an inpatient setting.

The Trust worked in partnership from the outset with the Local Commissioning Group and the Integrated Care Partnerships throughout the development and implementation of the service. Working with the LCG enabled agreement on a service model with key performance indicators. The ICP were key to developing strong interfaces with primary care and community pharmacy.

The service could be replicated across the regions however it will be slow to develop fully at scale due to workforce issues.

Better Aftercare for Patients

Transforming Cancer Follow Up (TCFU)

TCFU is a strategic partnership between Macmillan, DoH, HSCB, PHA and NICaN which commenced in 2011. The TCFU project team and wider multidisciplinary cancer teams across all five Trusts have striven for transformational change to the follow-up and survivorship needs of patients on completion of cancer treatment. TCFU is a large scale, complex, service improvement programme testing new models of cancer follow up that has begun to transform how after care services are delivered. It was initiated through a patient workshop in 2009 where key messages were heard from people affected by cancer.

More people are now living with a cancer diagnosis which is an indication that things are improving and that the cancer landscape is changing for the better. Services need to adapt to those changes.

It's widely acknowledged that the current system of review and follow-up is not sustainable – it is not efficient and it does not fully meet the supportive care needs of patients.

TCFU allows patients to be provided with information tailored to their specific needs, provided in a format that signposts them to self-management support services and provides guidance on life style changes to maximise health and well-being and get their lives back on track; while at the same giving reassurance and a clear point of access back into the system if required.

The TCFU project team and wider multidisciplinary cancer teams across all 5 Trusts in NI have delivered transformational change to the follow-up and survivorship needs of patients on completion of cancer treatment.

TCFU has shown that by taking full account of the views of patients and by carefully adapting the services we provide it is possible to develop better more patient centred services whilst at the same time working more efficiently to meet increasing demand for scarce resources.

In the interests of space, each of these projects is only briefly summarised here, a full case study of each project is included at the end of this report.

International Good Practice

Other countries and regions are heading in the same direction using best practice examples as an approach to change the model of care. They indicate both better health outcomes and higher efficiency in the use of resources.

These are a few examples.

- Pharmacist Consultations for High-Risk Patients. Pharmacists meet with high-risk patients and their caregivers at primary care clinics or in their homes to provide medication management and education. Pharmacist consultation programmes have demonstrated a 30% reduction in 30-day readmissions.

- Nurse led models of care. In the Netherlands, ongoing financial pressures within the health sector led to home care providers cutting costs by employing a low-paid and poorly skilled workforce who were unable to properly care for patients with co-morbidities, leading to a decline in patient health. Giving district nurses far greater control over patient care broke this lose-lose approach and is demonstrating significant care improvement as well as an overall reduction in cost.

- This community nurse-led care model sees management functions shared between staff and ensures at least 60% of time spent is with patients. The Buurtzorg – or "neighbourhood care" – model uses teams of district nurses to deliver care in people's homes. These teams are self-managed and co-ordinate care with other healthcare professionals, such as GPs and Allied Health Professionals. They work within guidelines including the requirement to use 3% of their turnover for training, have a diversity of nurse specialisms, and to share eight defined management and administrative responsibilities between them. The nurses have access to coaches for wider support and a central back office that processes their billing, but are responsible for their team's own finances and use of time.

- Reinforce Tele-Primary Care Visits consultations with primary care physicians (also known as Virtual Primary Care or Tele-Outpatient Visits) decrease total cost of care and help patients avoid more complex interventions. Studies comparing e-visits with face-to-face care demonstrated net savings.

RECOMMENDATION 8

The system should identify and scale up at least two innovative projects per year where there is clear evidence of improved outcomes for patients or service users.

RECOMMENDATION 9

The Panel recommends that the Minister should adopt a continuous improvement methodology to support the reform of health care towards local systems of care.

To make this actionable, it is necessary to continue with plans to create stronger quality improvement systems. While the exact remit for this will need to be decided by the Minister, the Panel feels that it should be locally owned and tasked with providing support and intelligence to enable new projects at the provider level.

There is clear and unambiguous evidence to show that specialised procedures concentrated on a smaller number of sites and dealing with a higher volume of patients, will improve outcomes.

3. Rationalisation and Stabilisation

Rationalisation

One key aspect of this is the need to rationalise services to liberate resources that can be invested in transformation. The majority of resources in the HSC are still invested in delivering acute care, and within this some services are being delivered sub-optimally in terms of both quality and value. There is clear and unambiguous evidence to show that specialised procedures concentrated on a smaller number of sites and dealing with a higher volume of patients, will improve outcomes.[36 37 38 39]

Continuing to invest large sums of money in trying to keep unsustainable services in place will only serve to delay their collapse and represents a significant opportunity cost to reforms elsewhere in the system. More importantly, it is also contributing to variation in terms of the quality of care received by those using services in different Trust areas. In a population the size of Northern Ireland, this is unacceptable. In changing the way services are provided, it will be important that decision makers clearly demonstrate the evidence for, and benefits of, change.

Given the importance of this process as an enabler for wider reform, it is dealt with separately in the following section.

Stabilisation

The significant rises in waiting lists and waiting times in the past year have received significant media coverage. While clinicians and managers have made every effort to ensure that the clinical impact on patients has been kept to a minimum, it is clear that this mismatch between demand and capacity has had a negative impact on the public's confidence in the HSC. While the longer term transformation must

36. Bilimoria, K et al (2008) Directing surgical quality improvement initiatives: comparison of perioperative mortality and long-term survival for cancer surgery, J Clin Oncol
37. Morris, S, (2014) Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis, BMJ
38. Crawford, R & Greenberg, D (2012) Improvements in survival of gynaecological cancer in the Anglia region of England: are these an effect of centralisation of care and use of multidisciplinary management? BJOG: An international Journal of Obstetrics and Gynaecology
39. Meyer, J et al (2014) Assessment of Cardiology and Cardiac Surgery for Congenital Heart Disease in Northern Ireland and the Republic of Ireland

be progressed, it will also be important to increase public trust in the system by reducing waiting times to an acceptable level.

The Department of Health and the Health and Social Care Board are currently developing an elective care plan which will set out proposals for dealing with this issue in the short and longer term. Although the plan is still being developed, the Panel has been briefed on the direction of travel. In the Panel's view, this is consistent with the vision articulated in this document and should be implemented as a matter of urgency. It is expected that the elective care plan will be ready by the time that this report is published.

RECOMMENDATION 10

The Panel recommends that the Minister takes steps to address elective care performance. However, while this is important, it should not be allowed to overshadow the need for long term transformation.

Leadership for Implementation/Organisational Culture

This report signals the need to rationalise services as well as to implement transformational change. Both of these are extraordinarily difficult and will require a planned approach to change. Furthermore, the requirement to accelerate the development of local integrated care organisations implies a new profile of leadership both locally and centrally.

It has been estimated that the success of any transformational change initiative is likely to result largely from a mix of politics and context.[40] The Panel has tried to create a positive and constructive political context for these changes by holding a political summit at the beginning of the process, providing a safe space for discussion and debate on these important and contentious issues. We have also been engaging with the political parties both before and after the elections in NI. The continued involvement of the political representatives will be an important factor in the process from now on.

Based on previous analysis (Ovreveit 2012) the Panel believes that transformational change can be successfully implemented if senior management leans on:

- the growing evidence on community based integrated networks;
- the development of the right implementation competence;
- a favorable financial and regulatory context.[41]

40. Hunter D et al (2015) Doing transformational change in the English NHS in the context of "big bang" redisorganisation : Findings from the North East transformation system, Journal of Health Organization and Management 2015 29:1 , 10-24

41. Ovretveit J &Klazinga N (2012) Learning from large-scale quality improvement through comparisons Int J Qual Health Care, 24(5):463-9

The Panel sees no reason why these conditions cannot be created in Northern Ireland. One can see from the existing building blocks explained above that Northern Ireland has an at least as good, and probably better, chance than others to move forward successfully.

The Panel believes that one key element of that implementation competence is to develop a balanced top down/bottom up approach to leadership.

That balanced approach of top down and bottom up leadership will be key to implementation. It is people, not strategies, that bring about change and it is relationships, not systems, which make it work. The model of care proposed for the future in this report will require a new form of system leadership in order to achieve integration of care and true networking among delivery organisations.

This requires an environment where staff can innovate on organisational issues that improve delivery of care

A planned approach to a transformative process needs some form of 'system leadership' at a senior level and most likely a combination of approaches such as 'push' which could imply top down policies, targets and timescales, and 'pull' which is more focused on shared values, empowerment and vision. At this level, health care transformation seems to be best achieved by a 'channeling' leadership, i.e. people who facilitate and direct the organisation's energy in a way that gets the most out of people.

This implies avoiding pushing policies onto the system. Rather, it implies developing a vision and creating the conditions for local improvement as a key mechanism to facilitate implementation.

A key component of this channeling leadership will be to develop a "high involvement culture" with health care professionals. They are the key agent of change.

That is to say that the one key predictor of positive patient outcomes and satisfaction is the level of employee engagement. Evidence indicates that staff engagement is also linked to improved financial performance in an organisation.[42]

This approach to "high involvement cultures" requires an environment where staff can innovate on organisational issues that improve delivery of care (and not only on clinical issues).

Command and control from above will not accomplish this and it will fail to exploit the energy in the organisation. The changes required by the Triple Aim approach will be more successful if they are implemented in a setting which encourages clinician and health professional engagement.

In this sense change is everybody's business.

Finally, if these difficult decisions are going to be made, they must be taken and supported by leaders at all levels of the HSC. Changes such as these are not easy to pull off. They will require political, managerial and clinical leadership to

42. West M & Dawson J (2012) Employee engagement and NHS performance, Kings Fund

Changes such as these are not easy to pull off. They will require political, managerial and clinical leadership to come together to ensure that the case for change is fully evidenced, efficiently implemented and effectively communicated.

come together to ensure that the case for change is fully evidenced, efficiently implemented and effectively communicated.

This can only work if every part of the system is moving in the same direction and working towards a common goal. Clinicians must identify the evidence for change, managers must ensure that the correct processes are followed, and the Minister, supported by the Executive, must act quickly to take the final decision. **All three groups will need to be prepared to defend the decision publicly.**

This approach will not happen spontaneously. It has to be made **actionable**.

One key approach for this will be to continue eliminating regulatory obstacles and simplifying the structures which block local innovation. The focus on health and social integration implies local networking and local leaders building partnerships. Local innovation is key to achieve integration of delivery organizations.

RECOMMENDATION 11

The Panel recommends that at the strategic leadership level, the HSC should:

- Foster new system leaders by protecting and empowering clinical leaders who take on leadership roles.
- Analyse and eliminate regulatory obstacles which may get in the way of implementing the new networked local health and social care organisations.
- Take the formal decision to empower leadership close to the front line.

Starting the Conversation

If we are to fully support transformation, as well as reconfiguration of services, there is a potential to more fully engage the power of our staff, partners and the public. The new "social movement" approach, currently being adopted in the NHS, provides helpful context.

These new approaches, often underpinned by social media, can act as catalysts for discussion and a way of mobilising communities and individuals to become more involved in the way health and social care is delivered. They offer greater connectivity with voices that might otherwise be hard to reach, opportunities for collaboration, thought diversity, and a culture of openness.

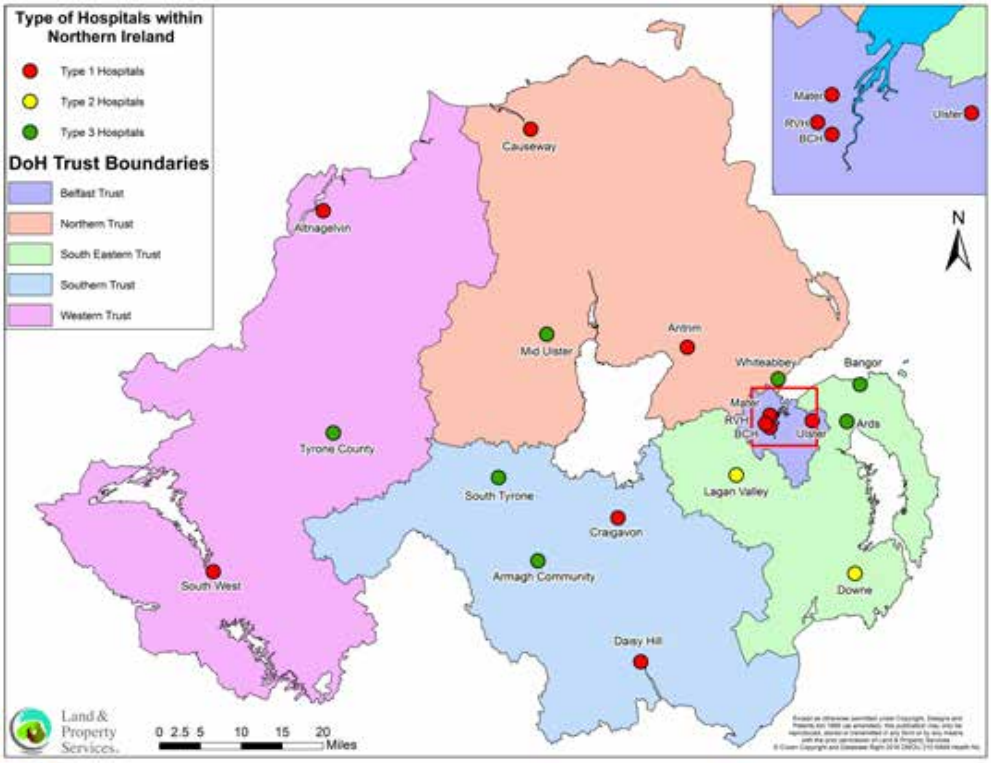
Some existing projects in the HSC are leading the way on this type of work. The Safety, Quality and Experience programme (SQE) in the South Eastern Trust, the HSC Knowledge Exchange, NICON and HSC Change Day are all good examples of initiatives that try to engage with staff or service users beyond the traditional, more formal processes.

At the 2016 NICON conference, more than 450 delegates expressed their support for the panel's final principle – that Northern Ireland could be a world leader in health care transformation – and these people were joined by over 2 Million people on social media, who were in some way able to be part of the conversation. There is significant opportunity to build on this approach and use new forms of media to communicate far more widely than has been possible in the past.

RECOMMENDATION 12

The Panel recommends that the HSC should consider whether there needs to be a platform for a more open and immediate conversation with staff and service users.

Fig. 26 – HSC Hospitals by type and HSC Trust



SECTION 5

RATIONALISATION



Through the extensive engagement held by the Expert Panel, we heard many common messages. These included:

- That previous reports over many years had signalled the need to rationalise acute services in Northern Ireland, but that implementation was slow due to resistance to change and the absence of a strong strategic approach to transformation.
- That some hospital services were increasingly vulnerable because of workforce shortages and junior doctor training requirements.
- That much needed investment in community services development was hindered because of the high costs of maintaining the current configuration of hospitals, particularly for these vulnerable specialties where often expensive locum and agency staffing was the only option for safe staffing, thus preventing development of those services that would provide an effective alternative to hospital-based care – a vicious circle resulting in ever increasing pressure on all parts of our health and social care system and increasing concerns about the quality and safety of some services.
- That the system is inconsistent from site to site.

Put bluntly, there is no meaningful choice to make. The alternatives are either planned change or change prompted by crisis.

Earlier in this report we referred to the sense of frustration among clinicians and senior leaders at the slow pace of change up to this point. Indeed, we have heard the view expressed that unless this report contains a detailed list of hospitals and services that should close, then it will be judged to have failed.

If the model proposed in this report is to be successfully implemented, then it is inevitable that the way services are currently provided will need to change. The evidence contained in the burning platform shows the clear impact of inaction. Furthermore, changing these services is not optional; it is inevitable. The choice is not whether to keep services as they are or change to a new model. Put bluntly, there is no meaningful choice to make. The alternatives are either planned change or change prompted by crisis.

Implementing these changes is not about making savings, it is about how we use the money we have to deliver the highest possible quality and value of care to patients and service users. The money that is currently being used to prop up

The difficulty does not lie in deciding what needs to be done. The difficulty lies in doing it.

unsustainable services does not deliver good value or the best quality of care for patients and could be reinvested in other parts of the system, particularly in areas such as general practice and primary care, mental health, learning disability and community care.

Focusing resources on specialist sites means that:

- Patients are seen in the right place and by the right person as soon as possible. Evidence shows that having all the services available on the same site improves the care delivered to the patient and the clinical outcomes;
- Staff have the necessary support and equipment to allow them to deliver the highest quality care to patients;
- It is possible to attract and recruit sufficient staff to deliver a safe, high quality, 24/7 service;
- The services are more stable and there is a better environment for patients and staff;
- There are the right conditions for professional development, quality improvement, leadership, teaching and other activities that are essential to a vibrant workforce expert in delivering care to acutely unwell patients;
- There is capacity for research and a greater ability to engage with academia and industry in generating new solutions and accelerating testing, adoption and introduction of existing solutions; and,
- This achieves the Triple Aim of better population health, better quality care and better use of resources.

However, as a panel we do not agree either that a prescriptive list should form part of this report. Changing the delivery of services is not like flicking a switch; they cannot simply be turned on and off at will. Hospital and community based services do not exist in isolation from each other and decisions in one area will inevitably have implications for the others. Decisions such as this must be taken carefully; they must be evolutionary; and, they must be carried out service by service, understanding the connectivity between clinical services that form the infrastructure of a hospital.

Furthermore, in the course of the many meetings, seminars, events and visits that the Panel has held and attended, it has become clear that clinicians and managers here already have a strong vision of what needs to be done to make services sustainable. The difficulty does not lie in deciding what needs to be done. The difficulty lies in doing it.

Process

While it is not appropriate for this report to dictate to people in different parts of Northern Ireland what services they should and should not expect to be located in their area or local hospital, it can provide a basis for a process within which these difficult but necessary decisions can be made.

1. Rationale for Reviewing Services

If we are serious about improving services and instituting large scale transformation, then these kinds of decisions:

- Must only be made in order to improve services – to create a more stable, sustainable service, to reduce waste and increase value;
- Must contribute to the overall vision – they should help to achieve the Triple Aim of better population health, better quality care, and better use of resources;
- Must be evidence based and clinically led – to ensure that the service meets patient and user needs more effectively, and that it can attract and retain high quality staff;
- Must be transparent – to include open communication and discussion with affected communities; and,
- Must contribute to the overall vision – they should help to achieve the broader model of integrated, community based care networks.

2. Criteria for Assessing Sustainability

This panel has developed a set of criteria for assessing the sustainability of services. We believe that those taking the decisions on the sustainability of a service should apply the following criteria:

- There is clear evidence that the outcomes for patients using these services are below acceptable levels either in the services as a whole or in particular hospitals, or where there are safety concerns.
- There is a clear clinical pathway for the patient population. Co-produced with patient groups.
- The service cannot meet professional standards or minimum volumes of activity needed to maintain expertise.

- The permanent workforce required to safely and sustainably deliver the service is not available/cannot be recruited or retained, or can only be secured with high levels of expensive agency/locum staff.
- The training of Junior Doctors cannot be provided to acceptable levels.
- There is an effective alternative 'out of hospital' care model or an alternative 'shared care' delivery model.
- The delivery of the service is costing significantly more than that of peers or of alternative 'out of hospital' alternatives due to a combination of the above factors.

3. Centralising Services – Case Studies

The use of the above criteria implies the centralisation of certain services. This section provides some examples of its benefits when carried out by clinicians and managers working in partnership. The examples show how services can be changed in ways that benefit patients, improve quality and make more efficient use of resources whether they are at local, regional or international level.

A. London Stroke Services

The English Department of Health's National Stroke Strategy identified that care in a stroke unit was the single most important factor in improving patients' outcomes after stroke. Based on these findings, in 2010 acute stroke services were centralised across in London. Prior to this, acute stroke services were provided in 30 hospitals. After reconfiguration, specialist care was provided in eight designated hyperacute stroke units 24/7.

Following the reforms, there was a significant reduction in mortality at 3, 30 and 90 days after admission. There was also a significant reduction in length of hospital stay.[43]

43. Morris, S, (2014), Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis, BMJ

B. Trust Level – Stroke Services in the Southern Trust

In 2012, the RQIA carried out a review of stroke services. Overall the key findings were that stroke services in NI were too fragmented between hospital sites, many patients were not being cared for in optimal environments, community services were underdeveloped and new time-critical interventions, such as thrombectomy, were not always available on a 24/7 basis. The review also highlighted the need for progression of clinical competencies and training relating to stroke and the establishment of clearly defined stroke units and dedicated stroke wards. This has proved difficult to achieve and sustain in smaller hospitals where recruitment and retention of specialist staff is a recognised problem.

In 2014, following public consultation, a decision was taken to create a single specialist stroke inpatient unit within the Southern Health and Social Care Trust, at Craigavon Area Hospital. The Trust is proposing to provide a consistent and specialist service 24/7 in one centre rather than spreading the specialist team of staff across four sites. Daisy Hill Hospital will continue to provide ongoing rehabilitation and support through community stroke teams working to a regionally agreed care model.

The proposals are consistent with clinical evidence which shows that patients are 25% more likely to survive or recover from stroke if treated in a specialised centre. Other benefits will include:

- High quality medical care
- Improved levels of Stroke Care in line with National Audit (SSNAP) recommendations – appropriate staffing levels to allow early assessment, observation and early rehabilitation input.
- The highest quality medical care in hospital (more concentrated levels of specialist medical, nursing and AHP care).
- Patients being admitted to a Stroke Unit as a ward of first admission. Latest medical evidence demonstrates that where patients are treated in specialist stroke units they achieve best outcomes.
- Better rehabilitation outcomes - a specialised service which will bring community and hospital based staff together as an integrated team providing care to Stroke patients. This will provide more focused care and continuity of service provision throughout the patient's pathway.

Reduced length of stay in hospital - more focused community based rehabilitation to allow Stroke patients to be discharged from hospital earlier and recover at home.

C. Regional level – Primary Percutaneous Coronary Intervention

Heart attack is a leading cause of mortality and morbidity in Northern Ireland. Approximately 40% of hospitalised heart attack patients have the more serious ST Elevation Myocardial Infarction (STEMI) heart attack. Traditionally a STEMI heart attack was treated by giving patients a clot-busting drug (thrombolysis). Patients then went a few days later to a catheterisation laboratory (cath lab), while still in hospital to have a metal stent inserted.

Primary Percutaneous Coronary Intervention (pPCI) involves the patient being taken immediately to a cath lab to widen the artery, clear the blockage and have a stent inserted, instead of using clot-busting drugs. Primary PCI reduces the mortality, complication rates and length of stay in hospital. A pPCI service needs direct admission to a designated centre with dedicated cath lab facilities capable

of undertaking the procedure 24/7. Running this requires many highly skilled staff, including interventional cardiologists, clinical physiologists, nurses and radiographers. Each centre needs to do a minimum number of cases each year to maintain standards.

The best fit which gave maximum geographical coverage for the NI population within an agreed travel time, while having enough caseload to maintain team skills, was to have 2 pPCI centres, one in Belfast (RVH) and one at Altnagelvin.

Making this work required commitment, coordination and agreement from senior clinical staff and managers in all six Trusts. A regional group was set up, chaired by a Consultant in public health from PHA, supported by the regional cardiac network coordinator, senior commissioner and finance officers from HSCB.

Obtaining agreement on clinical pathways and protocols was relatively straightforward. What was more difficult was trying to recruit the right number of trained interventional cardiologists to provide a sustainable out of hours rota for the Altnagelvin service, while ensuring sufficient workload to maintain their skills.

The group explored options to provide the night-time rota cover by consultants who would have daytime commitments in other hospitals, crossing Trust boundaries. The same approach was used for the Belfast pPCI service, seeking to offer opportunities to interventionalists working in other hospitals who wished to join the pPCI rota. In tandem, where there were other known gaps in cardiology services, such as in outpatient clinics, or cardiac MRI, if options were available to sort those within the overall configuration of new consultant posts then that was considered.

New IT systems were also agreed to share important patient information, both for patients waiting a daytime cath lab procedure and those waiting for cardiac surgery.

This regionally coordinated process ignored organisational boundaries when seeking the best solution for the population. Rather than focussing solely on pPCI, it used the opportunity to improve other aspects of cardiology services, with the end result that local services were strengthened as well as providing a new regional service. Primary PCI was centralised into 2 locations, because that was the best way to achieve a sustainable high quality service for patients, but others such as cardiac MRI and non-complex pacemaker implantation were able to be decentralised. This required close cooperation between clinical and management teams in all six Trusts. All had to make compromises to deliver a better, stronger cardiology service for the people of Northern Ireland.

D. Cross-Jurisdictional Level – Children's Congenital Heart Surgery

In recent years the regional Paediatric Congenital Cardiac Surgical (PCCS) Service, provided by the Belfast Trust, developed vulnerability in its surgical service due to new international safety and quality standards which could not be met because

of our relatively small population size. As evidenced by clinical reviews neither surgical centre (Belfast or Dublin) had been delivering a service which meets current international standards of both institutional case volume and consultant staffing: the service in Belfast did not meet the surgical case volume threshold, and the Dublin service has a medical staffing level in both intensive care and cardiology that is significantly lower than in comparably sized UK and European centres.

By December 2014 Belfast could not continue to provide an emergency and elective surgical service, and by April all interventional cardiology procedures ceased in Belfast (as these require the presence of a surgeon).

An International Working Group (IWG), led by Dr John Mayer from Boston Children's Hospital recommended the establishment of an all-island congenital heart disease (CHD) service, with a single surgical centre in Dublin capable of meeting international standards for surgical practice volumes, supported by specialist cardiology hubs in Belfast and other locations. The 'hub and spoke' network would involve all stakeholder groups including patient representative organisations in its governance structure, and be supported by enhanced telemedicine links, improved transportation, and a clinical research programme.

The all-island CHD Network was established in April 2015, following a public consultation on the recommendations of the expert group. In endorsing the IWG's recommendations, commitment was also given to the development of a specialist Children's Heart Centre in Belfast, enhancing existing facilities at the Clark Clinic within the current footprint of the Royal Belfast Hospital for Sick Children and making it fit for purpose until the new Children's hospital opens in 2021/22. This will secure the role of RBHSC as an integral part of the in the all-island 'hub and spoke' network, functioning as a 'Level 2' cardiology centre, i.e. providing the full range of non-surgical care required by CHD patients until they are ready to transition into the adult service.

The all-island CHD Network involves the two Health Departments, commissioners, service providers (management and clinicians) and patient representatives in a collaborative non-statutory structure to deliver an all-island CHD Service in line with the relevant legal and accountability arrangements that apply in each jurisdiction.

4. Maintaining Momentum

While criteria were previously developed as part of TYC, there is little evidence of these being applied in a systematic way to services or conditions. The panel believes that the Department should consider formal endorsement of these criteria and that a timetable for applying these should be developed, prioritised by specialty.

Based on the evidence the panel has received, the specialties that are currently in most need of reform would seem to be:

Priority 1

- EMERGENCY & URGENT CARE
- STROKE SERVICES
- PRIMARY CARE INCLUDING GP OUT OF HOURS
- GENERAL SURGERY
- PATHOLOGY
- VASCULAR

Priority 2

- PAEDIATRICS
- PALLIATIVE CARE
- OBSTETRICS
- RADIOLOGY
- NEONATAL SERVICES[44]
- TRAUMA
- UROLOGY
- REHABILITATION
- COMMUNITY BASED ELDERLY CARE
- BREAST SERVICES

RECOMMENDATION 13

The Panel recommends that the Department should formally endorse the criteria and apply them to five services each year to set out the future configuration of services to be commissioned (or not) from the Accountable Care Systems.

If applying the criteria leads to the conclusion that the service is vulnerable, plans for reconfiguration should be developed and actioned within this twelve month period.

44. Paediatrics, obstetrics and neonatal services are clinically linked and should be considered together.

5. Seeing the Big Picture

Having heard from many different leaders in different parts of the system, the Panel is in no doubt that local clinical leaders know exactly what they would like to do to optimise delivery of services for their patients and service users. However, it is also clear that in the interests of patients across the whole of Northern Ireland, decisions that will have a significant impact regionally or across Trust boundaries, must be taken in a regional context and must be consistent with the long term vision.

We therefore recommend the establishment of an appropriately resourced transformation business unit, based in the centre of the system. This unit should be tasked with providing a strategic view on projects with a regional impact – joining local and regional considerations while firmly focused on delivering better outcomes for patients. We are not advocating an expansion of bureaucracy and the past tendency to create unwieldy process management in taking forward change must be avoided.

The projects themselves would still be clinically/locally led and the role of the unit would be to bring a regional perspective to such decisions ensuring that patients' requirements are fully met. Given the inter-connections between medical conditions, this would also ensure that all the related regional impacts arising from proposed change are not being taken in isolation of the wider vision.

RECOMMENDATION 14

The Panel recommends the identification of a senior leader to lead this process at a regional level.

This process should be collaborative and inclusive and based on the criteria above.

6. Change is Everybody's Business

In taking these decisions, it is of course vitally important that there is clear engagement with communities both at a local level and regionally. People will need to be able to understand why a service is changing and what will take its place. The Panel considers this to be a fundamental component of any changes. Health professionals must support local representatives in explaining the rationale for change and the alternatives which will provide better care. Where the centre is leading and co-ordinating changes to hospital services, this should be led by professional leaders with support from clinical leaders in those services.

Finally, if these difficult decisions are going to be made, they must be taken and supported by leaders at all levels of the HSC. Changes such as these are not easy to pull off. They will require political, managerial and clinical leadership to come together to ensure that the case for change is fully evidenced, efficiently implemented and effectively communicated.

When developing the criteria above, the Panel met with clinical leaders from across the Health and Social Care system and was struck by the support for and commitment to driving these difficult changes and wider transformation forward.

This can only work if every part of the system is moving in the same direction and working towards a common goal. Clinicians must identify the evidence for change, managers must ensure that the correct processes are followed, and the Minister, supported by the Executive, must act quickly to take the final decision. All three groups will need to be prepared to defend the decision publicly and openly, and to honestly communicate the need for change with local politicians, the public and individual service users.

SECTION 6

LIST OF RECOMMENDATIONS



Recommendation 1

The Panel recommends using the dimensions of the Triple Aim as a framework for reform, including an increased emphasis on the experience of those who deliver care.

Recommendation 2

The Panel recommends that the HSC should move to:

- Formally invest, empower and build capacity in networks of existing health and social care providers (such as Integrated Care Partnerships and the developing GP Federations) to move towards a model based on Accountable Care Systems for defined population based planning and service delivery; and,

- Regionalised planning for specialist services.

Recommendation 3

The Panel recommends that the HSC should continue its positive work to invest in and develop the areas listed above.

There should be particular focus on the three key areas of workforce, eHealth and integration:

- As a key enabler of Accountable Care Systems, the HSC should continue to invest in e-health to support improved self management, care at home and use of information to drive better population health outcomes.

- The HSC should immediately develop innovative primary care based models that will allow non-medical staff to work in a way that makes the most of their skills. (For example, these could be based on the community nurse-led care models being implemented in the Netherlands, or the use of pharmacists in community development here in Northern Ireland).

- Work should be carried out to identify which social interventions are most cost effective in addressing the social needs and improving health for Northern Ireland.

- Any new approach to commissioning should be aligned with the need to build integrated health and social organisations on the ground which target specific inequalities and social groups.

Recommendation 4

The Minister should create, communicate and lead a clear, powerful, long term vision for the Health and Social Care system as a first step in the implementation process.

Recommendation 5

Alongside the Minister's vision for health and social care, the Panel recommends that plans, costs and timescales for introducing the actions detailed in the main body of the report should be prepared within the next 12 months. It is vital that the implementation of these actions is led by health and care professionals and managers.

Recommendation 6

Many of these recommendations will require additional, transitional funding. The Panel recommends that the Minister should establish a ring fenced transformation fund to ensure this process is appropriately resourced.

Recommendation 7

For this purpose, the panel recommends the creation of a transformation board supported by the Department, linked to the Executive's health and well-being strategy.

- This board would set the mid-term strategy, oversee the transformation process and would be tasked with creating the right conditions for the local system of care to develop successfully.

- It should help to transform organisational structures and management processes by promoting local decision making, local innovation and scaling up of best practices among the local systems of care.

Recommendation 8

The system should identify and scale up at least two innovative projects per year where there is clear evidence of improved outcomes for patients or service users.

Recommendation 9

The Panel recommends that the Minister should adopt a continuous improvement methodology to support the reform of health care towards local systems of care.

To make this actionable, it is necessary to continue with plans to create stronger quality improvement systems. While the exact remit for this will need to be decided by the Minister, the Panel feels that it should be locally owned and tasked with providing support and intelligence to enable new projects at the provider level.

Recommendation 10

The Panel recommends that the Minister takes steps to address elective care performance. However, while this is important, it should not be allowed to overshadow the need for long term transformation.

Recommendation 11

The Panel recommends that at the strategic leadership level, the HSC should

- Foster new system leaders by protecting and empowering clinical leaders who take on leadership roles.
- Analyse and eliminate regulatory obstacles which may get in the way of implementing the new networked local health and social care organisations.
- Take the formal decision to empower leadership close to the front line.

Recommendation 12

The Panel recommends that the HSC should consider whether there needs to be a platform for a more open and immediate conversation with staff and service users.

Recommendation 13

The Panel recommends that the Department should formally endorse the criteria and apply them to five services each year to set out the future configuration of services to be commissioned (or not) from the Accountable Care Systems.

If applying the criteria leads to the conclusion that the service is vulnerable, plans for reconfiguration should be developed and actioned within this twelve month period.

Recommendation 14

The Panel recommends the identification of a senior leader to lead this process at a regional level.

This process should be collaborative and inclusive and based on the criteria above.

APPENDIX A

THE EXPERT PANEL'S PRINCIPLES FOR HSC REMODELLING



Vision Statement

"To create a fair and sustainable, including financially sustainable, Health and Social Care system that delivers universal, high quality, safe services that meet the Northern Ireland population's needs and which deliver world class outcomes for patients and service users."

Ethos

1. **The system should be collaborative, not competitive.**
   There are several components to this principle. Firstly, even in the short term it will not be safe or effective to deliver all services locally. Organisations must work together to provide high quality care to patients. Secondly, unwarranted variance across the system should be minimised. Patients should be able to receive the same standard of care anywhere in the region. Thirdly, the HSC should continue to work in partnership across government, with industry, academia, the community and voluntary sector, staff and patients to deliver new models of care. Finally, remodelling of the system should be a transparent and collaborative process.

2. **The system should adopt a population health and well-being model with a focus on prediction and prevention rather than reaction.**
   Like many health services worldwide, HSC resources and service developments are often locked into reactive 'disease care', which focuses on increasingly expensive diagnostics and treatment. It must be acknowledged that there should be an increased emphasis on investment in prevention and health promotion, particularly for vulnerable communities who are at highest risk of experiencing inequalities. It must also be acknowledged that addressing wider health determinants requires a cross-sectoral approach, although there is much that the HSC can do in terms of designing new models of care.

3. **Patients should be active participants in their own care, not passive recipients.**
Patients should be treated with respect and empowered to stay healthy and care for themselves where possible. Patients should also be supported and encouraged to take greater ownership of their own health outcomes. The public rightly expects access to safe, sustainable and high quality health and social care services; however, as part of the relationship between the HSC and citizens, the public should also be enabled to take greater responsibility for their own health and well-being, and to use services appropriately.

Delivery Model

4. **Health and Social Care is already integrated in Northern Ireland. Remodelling must build on this strength and take a whole system perspective.**
The HSC in Northern Ireland is an integrated system, to the envy of many countries. Remodelling must ensure that different parts of the system are connected, interdependent, that they talk to each other and that they form an integrated whole. Patients should be able to transition smoothly between social care, community care and hospital care.

5. **Only people who are acutely unwell need to be in a hospital.**
Hospital is often not the right answer. There is evidence that for patients who do not need acute care, being in an acute hospital can be harmful. Research also indicates that hospital use is affected by deprivation, with people in poorer areas more reliant on emergency services, and making insufficient use of planned elective services. Studies have shown extremely positive feedback and satisfaction levels from patients who were treated in community settings and the HSC must continue to develop strong community care models.

6. **Very specialist services can be based anywhere in Northern Ireland.**
In the face of increased specialisation and ever rising demand, it is not practical or desirable to try to deliver specialist services everywhere. However, it is true that specialist services could be delivered anywhere. Any acute hospital in Northern Ireland has the potential to become a regional centre. Furthermore, the HSC should continue to explore and realise the mutual benefits of collaboration with other jurisdictions in ensuring patients have access to high quality, sustainable services.

7. **The location and composition of resources should be based on meeting patients' needs and achieving the best outcomes.**
Co-ordinated workforce and service planning should be carried out on the basis of the population's need rather than with the aim of maintaining services which are not sustainable in the long term.

8. **The real value of Health and Social Care is in its people, not its buildings.** HSC staff should be given the freedom to innovate and deliver services in a way that best meets people's needs, safely, quickly, and with respect and compassion. This implies more local autonomy and innovation within a defined policy framework. Northern Ireland has a wealth of knowledge and expertise that should be harnessed and developed to allow us to provide the highest quality services to patients. Local initiatives should be encouraged and best practice should be shared across the region.

Implementation

9. **Whole system remodelling is a medium to long term process.** Funds will continue to flow into the health and social sector but simultaneously there must be significant gains in productivity. New care models allow for increased productivity. Reform and remodelling on this scale will take time and must be supported by an evidenced, costed and resourced implementation plan. This will need policy and political commitment in the long term.

10. **The system must be supported to implement change with pace and scale.** Change is inevitable and must be embraced. There is an appetite and a will to implement planned change among staff. Service developments and investment from this point should be geared towards supporting and complementing a long term strategy for sustainable and quality care.

11. **Technology should be developed and adopted where it can support and enable transformation.** Northern Ireland has one of the most advanced electronic care record systems in Europe. New technologies offer enormous potential for improved self-management, telemedicine, information sharing and communication across sub-systems. Innovation and new technologies should be embraced in collaboration with industry where they offer the potential to deliver better or more efficient services. This will bring benefits to patients, the HSC and the economy.

Leadership and Culture

12. **The panel will engage constructively with elected representatives when designing and communicating a remodelled HSC. The Panel will also engage openly with HSC staff and the public.**
Implementation will require strong political and technical leadership. Without change, the Northern Ireland Health and Social Care system is not sustainable in the medium to long term. Elected officials will play a key role in analysing proposals and enabling the public to understand the need for change.

13. **Northern Ireland can be a world leader in transforming health and social care**
Many countries are facing the same challenges and difficult choices as Northern Ireland. This process is an opportunity for Northern Ireland to be a pioneer in designing and delivering health and social care services fit for the 21st Century.

APPENDIX B

LIST OF ENGAGEMENT MEETINGS



CO3

DOH

NIASW

RCN

BMA

Patient & Client Council

PPI Seminar event

Sinn Fein

DUP

UUP

SDLP

Alliance

BHSCT

NHSCT

Meeting with representatives from all HSC Trusts

HSCB

PHA

Dr George O'Neill, GP

QUB

Clinical leaders seminar event

NIPSA

RQIA

Pathology Network NI

NICON

Royal College of Surgeons

Royal College of Paediatricians

Age NI

NHS England

Greater Manchester Health & Devolution

ICP & LCG Delegation

AHP Delegation

Senior Nurse Delegation

ABPI

Contact NI

Commissioner for Older People for NI

Chief Clinical Information Officers

Unison

BMA – NI GPC

Safety Forum

Institute for Healthcare Improvement

Community Pharmacy NI



HEALTH AND WELLBEING 2026

DELIVERING TOGETHER



Department of Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

CONTENTS

	FOREWORD BY MICHELLE O'NEILL, MLA	**3**
1	**THE CHALLENGE**	**4**
	Organisational	6
	Workforce	6
	The Needs of a Rapidly Changing and Ageing Population	7
	Health Inequalities	8
	Our Opportunity	9
2	**THE AMBITION**	**10**
3	**THE CHANGE NEEDED**	**12**
	Build capacity in communities and in prevention	12
	Enhancing support in primary care	14
	Reforming our community and hospital services	15
	Organising ourselves to deliver	18
4	**THE APPROACH**	**19**
	Partnership Working	19
	Improving Quality and Safety	21
	Investing in our Workforce	22
	Leadership and Culture	22
	Ehealth and Care	23
5	**THE ACTIONS**	**24**

FOREWORD



The World Health Organisation defines health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity". That is the health outcome I want to deliver for all our people.

But without new approaches and in the face of ever growing demand - often driven by successful interventions and improving life expectancy - we will increasingly struggle.

Change is quite simply essential to deliver the world class service - free at the point of delivery and based on need - that is our collective commitment.

We must move beyond simply managing illness and instead ensure that our health service supports people to stay well; physically, mentally and emotionally.

In other words, we need to rethink how we deliver our health and social care service.

My predecessor, Simon Hamilton, asked a panel led by the internationally recognised expert, Professor Rafael Bengoa, to help us identify how to tackle the challenges in our Health and Social Care system.

Their report tells us clearly that we need to re-organise how we do things - and that we need to do this in partnership with the people who use the service and those who work in it. Critically, we must prioritise prevention and early intervention to ensure that people stay well. This approach will produce better health and wellbeing outcomes and it will reduce demand on our over stretched acute services. It will also help us tackle what the Expert Panel Report calls "striking health inequalities" in our society.

This document, Health and Wellbeing 2026: Delivering Together, is the outworking of the Expert Panel's recommendations. It sets out a commitment to tackle the issues we face in our Health and Social Care system through decisive political leadership. We are determined to move beyond short-term approaches and crisis management.

This Executive is united as never before in its commitment to take the right, perhaps difficult, decisions. But we know this is the only way to deliver better outcomes for our people.

We are facing into a time of change for our health system but it is change that must happen. This document sets out a direction of travel that I hope all of our society can embrace and support in the challenging but exciting time ahead.

Michelle O'Neill, MLA
Minister of Health

1 THE CHALLENGE

My desire for world class health and social care is based on firm foundations - we have a health and social care system staffed with many talented and dedicated people working extremely hard to deliver high quality services to those in need. But increasingly those efforts are frustrated by a system which is clearly under mounting pressure. This is impacting on both those within the system and those it serves. Without radical change there is no doubt the situation will further deteriorate. That is why I am convinced that change is needed now.

Before I set out the case for change, it is important to acknowledge and celebrate where Health and Social Care, in collaboration with wider government, is making a real difference to our health and wellbeing.

Standardised
CIRCULATORY DEATH RATE
in under 75s
decreased by a fifth over the last 5 years

ENGAGEMENT WITH EDUCATION TRAINING OR EMPLOYMENT FOR THOSE AGED 16-21 WHO ARE IN CARE OR HAVE LEFT CARE HAS RISEN 5.7% IN THE PAST YEAR

SMOKING PREVALANCE FELL
from 26% in 2004/05
to 22% in 2014/15

7677
CARERS RECEIVED SUPPORT FROM TRUSTS IN 2015 COMPARED TO 1414 IN 2011

Over **1 in 3** adults (36%) reported that they ate the recommended **5 PORTIONS** of fruit & veg a day (2014/15)
increased by a third over the last 10 years

FAMILY SUPPORT HUBS
In 2015/16, **4522 families with children** were referred to Family Support Hubs, a **72% increase** on the previous year. Of the 5346 children referred to Hubs in 2015/16, **around 18% were children with a disability**

BOWEL CANCER DECREASE
Since **bowel cancer screening** was introduced, the percentage of people diagnosed with early stage disease has increased from **14% to 22%** thereby **improving their life chances**

LOOKED AFTER CHILDREN
achieving Key Stage 1: Level 2 or above

in English
7.5% INCREASE

in Maths
7% INCREASE

INCREASE IN ADOPTIONS
Between 2014/15 and 2015/16, there has been a **24% INCREASE** in the adoptions of Looked After Children

LIFE EXPECTANCY
over the last 5 years life expectancy has increased

1.3 YEARS
for males
(78 years)

1 YEAR
for females
(82.3 years)

Standardised
RESPIRATORY DISEASE DEATH RATE
in under 75s
decreased by a fifth
over the last 5 years

MMR VACCINE
over 95% of children received the MMR Vaccine which means we have not seen the outbreaks of measles that have occurred elsewhere

At the heart of the many successes of the Health and Social Care (HSC) system is the hard work and dedication of all staff, in every grade and role, who are delivering care at higher levels than ever before.

However, while there is much to celebrate, we must recognise the challenges in the current system. The reality is that we increasingly cannot properly meet people's needs with our current structures. In the past, and for a range of reasons, it has not been possible to achieve the whole system transformation at the scale and with the pace we need to meet the evolving health needs of our people. More and more the impact of this is felt on a daily basis and takes its toll on both those who use services and those working in the sector.

Our Health and Social Care System faces a number of significant challenges:

Organisational

In many past reviews, professionals and staff have expressed their frustration at the limitations of our current arrangements and their desire for change, most recently in the Expert Panel report. The 20th century configuration of our services is simply not optimised to meet the needs of 21st century care.

The point has now been reached where maintaining the current delivery models is having increasingly negative impacts on the quality and experience of care for many service users, while constraining the ability of the system itself to transform to meet today's health needs.

While staff work increasingly hard to mitigate these structural issues, the overall impact is experienced by service users and their families every day in every part of the system. Regrettably, delays in accessing services and unacceptable waiting times for treatment are commonplace. The quality of our service, and the experience of those providing and receiving it, is not as good as it should be.

Modern research shows that outcomes for patients requiring complex or specialist treatment improves where high levels of specialist expertise is available and these teams are able to keep pace with innovation. The current spread of such HSC resources, too often committed to buildings rather than outcomes for patients, is a central challenge we must address.

If we persist with our current models of care, even with the best efforts of all staff and more investment year on year, waiting lists will continue to grow, our expertise will continue to be diluted, and the best possible outcomes for patients will not be realised. This is both unsustainable and unacceptable.

In addition, the way we are organised means that opportunities are being missed to create sustainable employment, drive economic investment, and maximise the contribution of the HSC to the economic goals of the Executive. For example, the life and health sciences sector provides 10% of all of the North's exports. Closer working between the HSC, our world class universities and life and health science organisations and maximising the potential for growth in this high value sector, is fundamentally dependent on centres of clinical excellence with the right level of expertise and the necessary capacity.

Workforce

A further challenge relates to the workforce itself. People who work in health and social care are its greatest strength, working ever harder to provide the care needed by patients and service users. Year on year, investment has been directed to front line services in an effort to meet the ever growing need for treatment and care.

However, if we accept, as a whole range of reviews have, that our services are not best configured for our needs, then it follows that recruiting additional staff alone to prop up outdated service models, is not the answer. We must be able to provide safe and high quality care which keeps up with the fast pace of innovation and health and social care developments. I recognise that staff need the opportunity to develop their skills and expertise in an environment which allows for a greater degree of specialisation, whilst maintaining personalised compassionate care.

It has also become clear that even when resources are made available to recruit additional staff, it has simply not been possible to fill all vacant posts. This in turn puts additional pressure on already hardworking staff and has seen our service become increasingly reliant on short term solutions such as locums and agency staff. This creates additional expense with negative implications for the quality of care. It has become a vicious circle which we must stop.

We must invest in our staff and provide the environment to allow them to do what they do best - provide excellent high quality care. This means providing opportunities to develop their skills and find suitable career paths at all levels. Where necessary, we will increase the numbers we train and consider ways of delivering care more effectively through the development of new roles and skills.

I am determined that we will make the health and social care system an employer of choice in the north of Ireland.

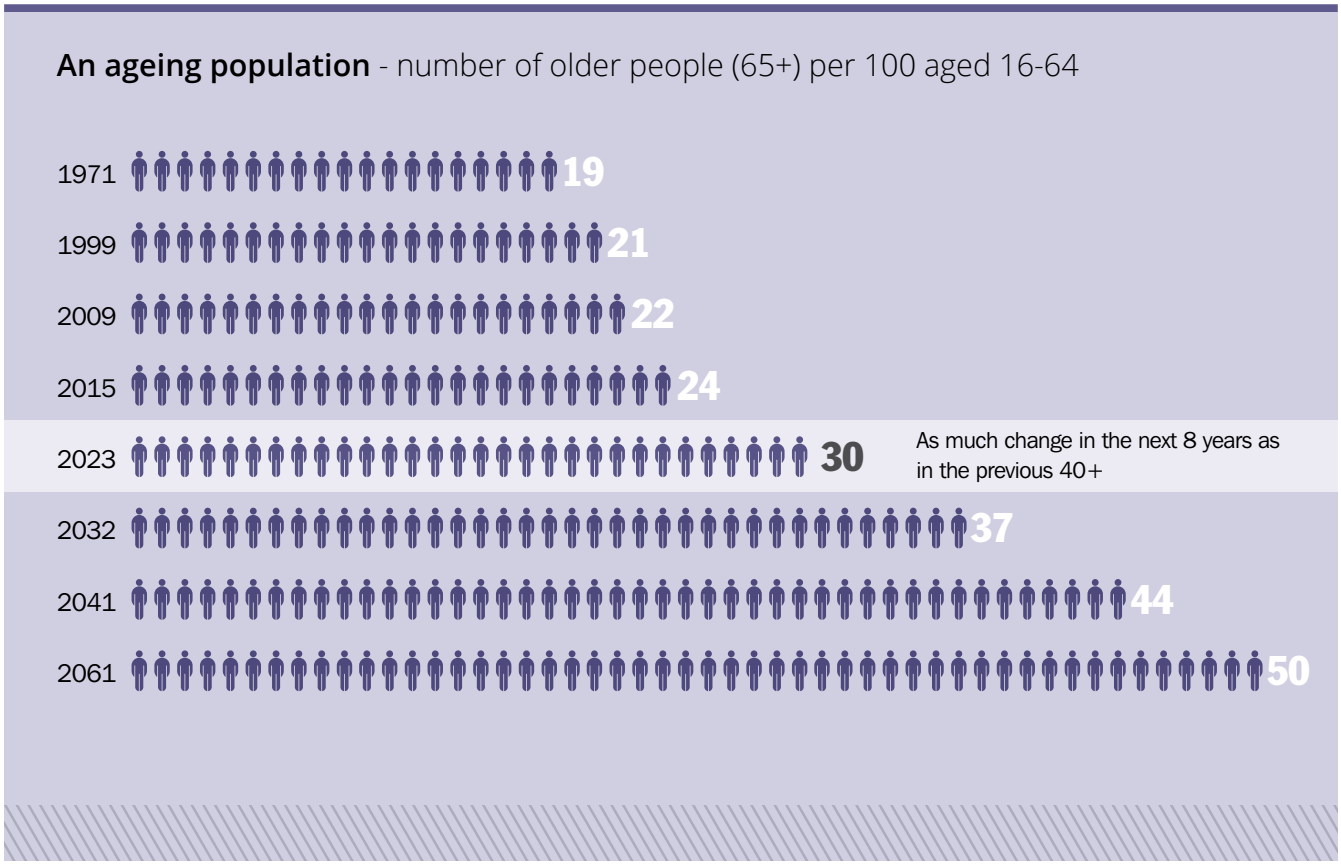
The Needs of a Rapidly Changing and Ageing Population

Our society is getting older: people are living longer, often with long-term health conditions, and we are having fewer children. Estimates indicate that by 2026, for the first time, there will be more over 65s than under 16s.

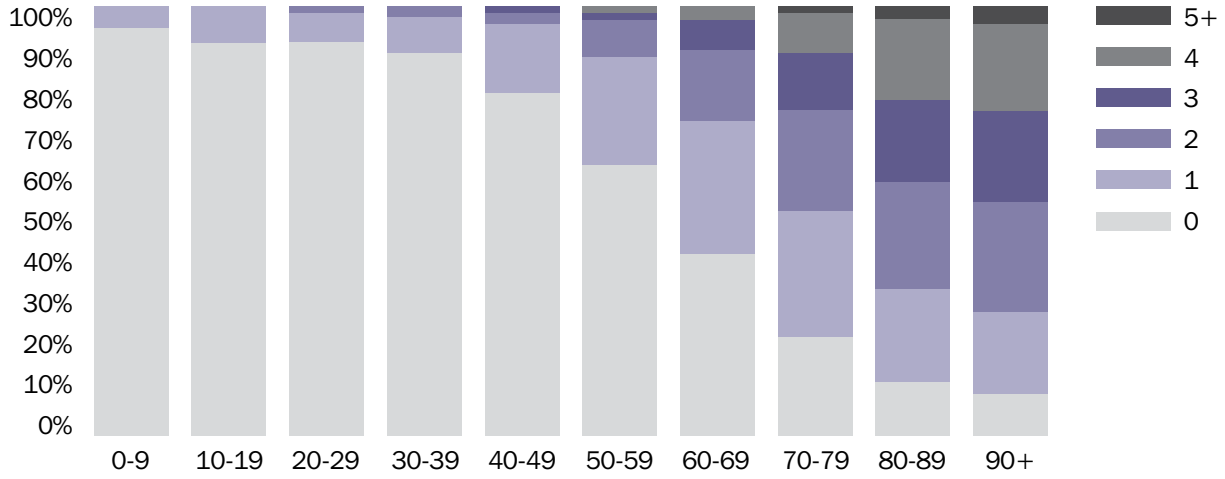
By 2039, the population aged 65 and over will have increased by 74% compared to the position in 2014. This will mean that one in four people will be aged 65 and over.

Similarly, the population aged 85 and over will increase by 157% over the same period, which will see their share of the population increase from 1.9 % to 4.4%.

By any analysis, this is a massive success to which our health and social care service has made a significant contribution. That said, it does present a huge and growing challenge in terms of the demands and pressures on health and social care services.



Percentage of patients in each age band with the indicated number of morbidities



Developments in how conditions can be treated and managed mean that as we get older we are much more likely to develop and live with one or more long term conditions. The table above demonstrates that as we get older, the likelihood of having more than one condition at the same time increases dramatically, and with that the care and treatment that we require becomes much more complex.

Furthermore, people's health and social care needs have changed, and their expectations are rightly higher than at any other time before. In the past, for many conditions, where there was an effective treatment available, it often required hospital attendance or an in-patient stay. Increasingly, such treatments are available in the community, or can be provided on a day care basis; which in many instances is more appropriate to the needs of people with longer-term chronic conditions.

People today want to lead full and productive lives, staying independent for longer. In line with wider societal changes, we all expect improved access, choices and control when it comes to public services.

Health Inequalities

Despite people living longer, health inequalities continue to divide our society. The differences in health and wellbeing outcomes between the most and least deprived areas are still very stark, and completely unacceptable.

For example, men in the least deprived areas live 7.5 years longer than men in the most deprived areas. For women, the difference is over four years. In the most deprived areas, 30% of people report a mental health problem - double the rate in least deprived areas. Rates of suicide are also higher, and leave a devastating impact on people, families and those communities.

Birth weight is an important indicator of foetal and neonatal health, and a low birth weight has a strong association with poor health outcomes in infancy, childhood and throughout someone's life. Between 2010 and 2014, the proportion of babies born at a low birth weight was 44% higher in the most deprived areas than in the least deprived areas.

In 2013/14, the rate of obesity among children in Primary 1 was 71% higher in the most deprived areas than those in the least deprived areas. 42% of Looked After Children (LAC) come from the most deprived areas in the North. Being looked after is associated with poorer socio-economic outcomes in adulthood.

It is clear that economic, social and environmental factors, and experiences early in life, play a major role in determining not just the health outcomes at an individual and community level, but also their social, educational, economic and other outcomes. There is also growing evidence that children who experience adversity in childhood are far more likely to experience health issues in adult life. Specifically, these children are more likely

to adopt health harming behaviours during adolescence which can lead to mental health illness and diseases such as cancer, heart disease and diabetes later in life. Adversity in childhood also means that children are more likely to perform poorly in school, more likely to be involved in crime and more likely to experience poverty and disadvantage in adult life.

Our future health and social care system needs to not only treat people who become sick or need support now, but also needs to do much more to ensure that the next generation is more healthy with more equitable life opportunities for all.

Our Opportunity

The problem and the compelling case for change is not in itself new, and has been made repeatedly by experts, staff and patients over many years. The Expert Panel's Report "Systems, not Structures: Changing Health and Social Care" once again reaffirms this. But despite the overwhelming evidence, the opportunity has thus far not been grasped. However, both as Minister and as an Executive we believe there is now no alternative but to transform how we design and deliver health and social care services.

The political summit hosted by the Expert Panel in February 2016 secured a political mandate for the need for change and the principles to underpin it, and I look forward to all parties engaging with and supporting the HSC to make the difficult decisions required to improve our population's health, and build a sustainable health and social care system. This is the time for political leadership.

The advent of a new outcomes based approach in the draft Programme for Government puts an onus on us all to work together, across traditional silos and boundaries to deliver the best outcomes for the people of the North. Now is the time for us to work collectively to deliver a world class health service.

Across this island, the health and social care fabric of both jurisdictions face the same challenges. We have the opportunity to work more collaboratively with colleagues to address those challenges, and deliver services in a way that improves care for our population as a whole. There are many good examples of where this is already working well, such as cancer and cardiac services in the north west or the partnership with Dublin for children's heart surgery. There are many more such opportunities, including the transplantation of organs and rare diseases, and we have developed a programme of work with the Department of Health in the South to identify areas of mutual benefit.

Staff, clinicians and professionals from right across our health and social care system are telling us loud and clear that change is now necessary. If we do not grasp this opportunity change will happen anyway but in a reactive and unplanned way, with more potential for detrimental impacts on those who use and deliver our services.

In addition, the HSC itself is a huge contributor to the economy in many ways, through skills development, spending power and employment practices.

As the single biggest employer in the North, we have a real opportunity and responsibility to make a tangible and positive contribution to the health and wellbeing of our staff, and society as a whole. We will be an employer of choice, leading by example and investing in the wellbeing of our staff. Despite the demand, resource and service pressures being experienced, I am committed to ensuring the wellness dimensions of being an employer of this scale will be better achieved across the HSC.

In the way we operate, we have the opportunity to promote a new way of working with the community and voluntary sectors through the innovative use of social procurement clauses, and commissioning services based on social value rather than simply on the basis of lowest cost.

Working with our world class universities, skilled graduates and world leading companies, we can grow our life and health sciences sector, creating new jobs. This will mean access to cutting edge technology and therapies, and the dual benefit of improving care and economic growth. To do so requires further collaboration between HSC, academia and industry. The HSC can only play its part if it can provide the centres of expertise and excellence that will continue to attract partners, and support the recruitment and retention of experts in their fields.

2 THE AMBITION

Health is a human right. I am deeply committed to the principle of universal health care, free at the point of delivery to those in need.

Aligned with the aspirations the Executive set out in the draft Programme for Government, my overarching ambition is for every one of us to **lead long, healthy and active lives**.



Therefore, we want to see a future in which:

- people are supported to keep well in the first place with the information, education and support to make informed choices and take control of their own health and wellbeing;
- when they need care, people have access to safe, high quality care and are treated with dignity, respect and compassion;
- staff are empowered and supported to do what they do best; and
- our services are efficient and sustainable for the future.

All of these aims are of great importance and must be addressed if we are to meet the future needs for our population.

They will underpin a new model of **person-centred care** focussed on prevention, early intervention, supporting independence and wellbeing. This will enable the focus to move from the treatment of periods of acute illness and reactive crisis approaches, towards a model underpinned by a more holistic approach to health and social care.

We will create the circumstances for people to stay healthy, well, safe and independent in the first place. We will anticipate the needs of individuals for support and care and this new model of person-centre care will intervene early to avoid deterioration.

This model will be designed for and with people and communities rather than by organisations and services. Instead of thinking about buildings and hospitals as the only place to deliver services, we will deliver care and support in the most appropriate setting, ideally in people's homes and communities. In most instances people should only have to go to hospital when they need treatment that can't be provided in their community.

The way we design and deliver services will be focussed on providing continuity of care in an organised way. To do so we will increasingly work across traditional organisational boundaries, to develop an environment characterised by trust, partnership and collaboration.



3 THE CHANGE NEEDED

If we are to support everyone to lead long, healthy, and active lives, we need to change the focus of our services, and how and where those services are delivered. The Expert Panel has clearly said that 'something very different has to happen at the delivery of care level'.

We must:

- **Build capacity in communities and in prevention** to reduce inequalities and ensure the next generation is healthy and well;
- **Provide more support in primary care** to enable more preventive and proactive care, and earlier detection and treatment of physical and mental health problems;
- **Reform our community and hospital services** so that they are organised to provide care when and where it is needed;
- **Organise ourselves to deliver** by ensuring that the administrative and management structures make it easier for staff to look after the public, patients and clients.

Build capacity in communities and in prevention

We will work with communities to support them to develop their strengths and use their assets to tackle the determinants of health and social wellbeing.

We will support the development of thriving and inclusive communities, through the work of the HSC working closely with Executive colleagues and other providers such as councils, schools, police, housing and transport.

In particular, the HSC will become better at tapping into the innovative ideas and energies in communities themselves, and in the community and voluntary sectors. In all communities, every child and young person should have the best start in life, people should have a decent standard of living, and all citizens should be supported to make healthier and better informed life choices.

We will invest in HSC community development resources to work alongside all communities to enable social inclusion and tackle health inequalities and the underlying contributory factors including poverty, housing, education and crime.

It will take time to realign and grow the community development resource, and as a first step we will review existing capacity and then invest to meet any gaps, including a programme of training.

Alongside this, we will link social care more strongly with improving and safeguarding the wellbeing of individuals, families and communities. We will strengthen the social work profession by fully implementing my Department's Improving and Safeguarding Social Wellbeing Strategy.

To give every child and young person the best start in life, we will further increase the support we provide to children, young people and families from before birth to adulthood. The universal Health Visiting and School Nursing service will enable and support children and young adults to be successful healthy adults through the promotion of health and wellbeing; this will include the full delivery of the Healthy Child, Healthy Future programme. This will support the implementation of the Executive's Public Health Framework "Making Life Better" and its ambition to give every child the best start.

I will work with other Ministers to build on the success of the Early Intervention Transformation Programme and enhance early intervention services and the Family Support Hub network by exploring ways to build on the capacity of the hub model. This would include both better coordination of existing early intervention services and increasing the assessment capacity of the Hubs. This will enable us to respond quickly and flexibly to meet the needs of families early on before the problems they face become more intractable and severe. By increasing our early support to families we will reduce the need for later intervention, such as the need for children to come into care.

For children who are in the care system we will work to improve their life chances. Looked After Children experience much worse health, social, educational, and employment outcomes than other children. We will honour our corporate parenting responsibilities to the fullest extent and will be as ambitious for children in care as we are for our own children.

The range of placement options available to Looked After Children will be expanded. Through service redesign and, if necessary, new legislation we will better meet the individual needs of each child and put in place more effective supports for their caregivers, including kinship carers and families who adopt children from care. By working with the courts we will secure permanence for them more quickly helping their mental and emotional wellbeing, educational attainment and health in particular. Support will also be extended so that they are better prepared for independent living in adult life.

FAMILY SUPPORT HUBS

Family Support Hubs provide an accessible, flexible and responsive point of contact for families in need of support.

As of June 2016, 29 family support hubs were operational, providing full regional coverage across the North.

The engagement of local communities in the planning and commissioning of local services has been a key component to the successful delivery of Family Support Hubs.

In 2015/16 there were 4522 families referred through family support hubs, an increase of 1887 compared with 2014/15.

In 2015/16 a total of 5346 children were referred, 953 of which were children with a disability.



PRACTICE BASED PHARMACISTS

This initiative will see pharmacists working as an integral part of the GP surgery practice team. This means we can use their skills and experience to improve patient outcomes through reviewing their medication and reducing errors.

Practice Based Pharmacists (PBP) can help to alleviate some of the pressures faced by general practice through triaging patients to appropriate services and in some instances undertaking the diagnosis and initiation of treatment and follow-up appointments in patients with long term conditions.This will enable GPs to spend more time with patients with complex needs.

By December 2016, it is anticipated that 54 PBPs will have been placed in GP practices across the North with further PBPs appointed and in place over the period January-May 2017.



Enhancing support in primary care

Primary care is the bedrock of our health and social care system and provides around 95% of the care people need throughout their life. General Practitioners (GPs) and multidisciplinary primary care teams have a key role to play in improving population health and wellbeing, as well as developing care pathways and services to meet the population needs.

Our primary care service is still largely based on GPs working independently with some input from other disciplines. In future, the focus of our system will be increasingly on keeping people healthy and well in the first place. The World Health Organisation defines good health as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity. In the future we need a model that provides fully integrated multidisciplinary care, not just medical or nursing care.

Our future model of primary care is to be based on multidisciplinary teams embedded around general practice. The teams will work together to keep people well by supporting self management and independence, providing proactive management of high risk patients. They will identify and respond earlier to problems that emerge whether related to health or social circumstances or the conditions in which people live, providing high quality support treatment and care throughout life.

These teams will include GPs, Pharmacists, District Nurses, Health Visitors, Allied Health Professionals and Social Workers, and new roles as they develop, such as Advanced Nurse Practitioners and Physician Associates. There will be capacity and skills to proactively support individuals to address the lifestyle choices that impact upon their health and wellbeing. They will have the right tools and skills to diagnose, treat and coordinate the majority of care for their practice. They know the people they serve, and understand their needs better than anyone.

These teams will work in a more integrated way with all other community services and development work in their area, including Community Pharmacy. Community Pharmacy is an important part of primary care and can help to reduce pressure on other parts of the HSC. We must use them better, especially to support improved public health and engaging in with the public to ensure medicines are being used appropriately.

This model is radically different from what we have at present. It will require significant change in the way staff across the HSC are organised and deployed, and in the way GPs and other members of the new teams work together. This new model will therefore be rolled out incrementally over the next 5 years, learning and addressing gaps in staffing as we proceed. The roll-out of Practice Based Pharmacists will be completed by March 2021. GP surgeries will have named health visitors and named district nurses to work with by the end of March 2017. In addition, the way that core district nursing is delivered will be transformed, and a District Nursing Framework will be published by the end of this year.

We will maximise the potential for developing social prescribing models in the multidisciplinary primary care teams, through the embedding of social workers and building linkages to the range of early support services available to service users, such as Mental Health Hubs and other early help initiatives.

Additional funding for primary care will be focussed on developing these teams, with more funding for mental health interventions in primary care and funding to test the impact that specialist allied health professionals, such as physiotherapists, can have when working alongside the primary care team. Training for the first Advanced Nurse Practitioners for primary care and a new Physician Associate post-graduate degree programme have been developed and will start in early 2017. We will work closely with GPs and other professionals on the roll-out and evaluation of this model.

Together, the enhanced community capacity, the focus on prevention based approaches and the multidisciplinary teams in primary care will provide much greater capability to keep individuals and communities well.

Reforming our community and hospital services

Sometimes, the primary care or community care teams cannot fully meet a patient's needs but it isn't appropriate for them to be admitted to a hospital.

With developments in treatments and technology, we are able to do so much more without the need to admit people to hospital. Therefore in future we want to build on new services and models which are already emerging, and ensure that these are implemented across our health and social care system, working in partnership with those who deliver and use these services.

Acute Care at Home is an example of this type of service. Patients, often frail and elderly, are treated in their own homes by doctors, nurses and other staff. Conditions such as chest infections, urinary tract infections and dehydration can all be safely treated without the need to go to hospital, which can be a worrying and anxious experience for many. Patients have, within their own home environment, the same access to specialist tests as hospital inpatients and receive consultant led assessment and treatment.

We will make Acute Care at Home available to the whole population. We will better integrate it with social care and ensure it is supported by other services, including short stay hospital services, GPs and palliative care. This new model of care will be rolled out to all areas within the next three years.

We are committed to the further development of **Ambulatory Assessment and Treatment Centres**, to provide a more joined up, 1-stop service. Evidence from here and elsewhere shows there are significant benefits to be gained from this approach. Our current model is based on the traditional outpatient model of care where a GP refers a patient to the specialty the GP believes most closely relates to the possible cause of the person's symptoms. But as people live longer and develop more problems, diagnosis and treatment becomes more complex. So the traditional model is no longer fit for purpose.

Over the next 12 months, we will start to design these centres in partnership with clinicians and patients. They will provide simpler and easier access to the healthcare professionals and diagnostic equipment (such as X-Rays, CT scanners) needed to assess and diagnose conditions. Importantly, if a treatment or procedure is needed this will be possible on site with the aim of getting patients safely home the same day.

This avoids multiple outpatient visits and enables earlier diagnosis and appropriate treatment, and is therefore much better for those who use our services, and makes better use of our resources. Staff will have all the facilities they need to make the right diagnosis there and then, and to provide high quality care.

Elective Care Centres will be established to provide a dedicated resource for less complex planned surgery and other procedures. Evidence from elsewhere shows that such centres can reduce waiting times for planned care, and provide a better experience for both patients and staff. The current approach of delivering both planned and unplanned care using the same facilities and the same resources, means that waiting times can be adversely affected when the demand for urgent and emergency care is very high.

By making better use of our existing resources, and organising these in a different way, we will be able to provide larger volumes of activity, to a higher quality and in a more timely manner. The centres will be a resource for the region and the way they operate will be designed around the needs of patients. The number and location of these centres will be developed in partnership with clinicians and patients, and I expect proposals to be brought forward in the next 12 months.

Acute inpatient care will change. By changing the way preventive care, primary, community and less complex elective care is provided, and by looking after people in settings that are more appropriate to their needs, the nature of acute inpatient care will change.

Acute inpatient care will therefore focus on complex planned surgery and emergency care of patients who need an acute inpatient setting, for example, patients who have had a stroke, heart attack, or trauma, and those needing obstetric, neonatal or paediatric services or those with a significant worsening of a long term health condition. Multidisciplinary working will be a key feature of good quality inpatient care.

Across many different services there is very strong evidence that concentrating specialist procedures and services in a smaller number of sites produces significantly better outcomes for patients, as well as a much better and more supportive environment for staff

The role of our hospitals will therefore fundamentally change as they will focus on delivering the highest quality of specialist and acute care. However, not every service will be available in every hospital.

In the past few years we have seen the successful development of region-wide and cross-border **networks for highly specialist services** such as cancer, neonatology or cardiology as well as the development of the first truly all-island service in children's congenital cardiology. These are delivering innovative, world class services and we will seek to maximise opportunities to expand this approach and deliver more services on an all-island basis, where clinically appropriate to do so.

This is about changing the way that services are delivered, improving safety and quality, and making the best use of the resources we have. The Expert Panel, working with clinicians, has developed criteria which will help us to assess the sustainability and future of how services are provided, and this provides us with a route-map to work in partnership with those who use and deliver our services.

Mental Health

The North has a particular challenge with mental health, having the highest rates of mental illness in these islands. There are many talented and hardworking professionals in the system and the voluntary and community sector, who do excellent work in the services they provide. It is clear that our services need to continue to evolve and improve, building on the Bamford reforms from the last decade.

Mental health is one of my priorities as Minister of Health, and it is an issue that I will champion at every opportunity. I want better specialist mental health services. This would include further support for perinatal mental health and inpatient services for mothers, with potential to address the need that exists across the island. We will expand services in the community and services to deal with the trauma of the past. Underpinning all of this, I am committed to achieving a parity of esteem between mental and physical health to ensure that we are tackling the true impact of mental health on our communities.

Carers

Families and friends take on most of the caring responsibilities for their loved ones and this makes an enormous contribution both to the HSC and to society as a whole. I fully recognise that carers are an equal partner in providing care, and they need our support to be carers. They also need support to enable them to do the things that those without caring responsibilities take for granted such as working, going out socially, having a break or going on holidays. In the case of young carers, they need help and support just to do the things that young people do. I am committed, along with other government departments and their agencies, to providing that support.

We know that the needs of carers are changing, this means the type of support we need to give them is also changing. We need to encourage greater take up of carer's assessments and expand the options for short breaks, as well as enabling the greater use of personalisation and personal budgets where appropriate. We need to ensure carers can access up to date information and crucially consider how we can support carers to live their own lives. The role of carers and how we can better support them will be central to the Review of Adult Care and Support and I encourage everyone to make their views known when we bring proposals forward for consultation in spring 2017.

DELIVERING ACUTE CARE AT HOME

This service enables this vulnerable patient group to retain their independence and dignity and prevents unnecessary and stressful hospital admissions.

It was designed and implemented by East Belfast Integrated Care Partnership (ICP) and subsequently rolled out across Belfast. Similar services are available in some other Trust areas.

In the Belfast area, the average length of stay for Acute Care at Home patients is 6 days compared to 11 days in hospital. Over 1084 referrals have been received for the extended service in the Southern area.



Organising ourselves to deliver

To deliver care in a different way, it is clear that the way we plan and manage health and social care will also need to change. Therefore, in line with the recommendations of the Expert Panel's Report, we need to empower local providers and communities to work in partnership, including health and social care trusts, independent practitioners such as GPs and voluntary providers.

Embracing new models of care has the potential to harness the strengths of different parts of the system, across traditional organisational boundaries, across sectors and beyond what is traditionally considered to be the health and social care sector.

Working together, they will be expected to plan integrated and continuous local care for the populations they serve. I will set the outcomes we expect them to deliver, and the frameworks within which they need to operate, and hold them to account accordingly. For the first time, they will have the autonomy to make rapid and sustainable changes to improve services and address health inequalities in their area.

Where services are highly specialised, they will be planned and delivered on a region-wide basis. Building on the programme of work currently underway with Department of Health counterparts in Dublin, we will continue to explore opportunities to plan and deliver services on an all-island basis.

The recent consultation on HSC structures supported the need to reduce bureaucracy and put in place a more effective streamlined mechanism for how we plan health and social care services.

Starting now, we will work with the wider HSC system to design the new partnership approaches to the planning and management of HSC services, which moves away from competition towards collaboration, integration and improvement.



PRIMARY PERCUTANEOUS CORONARY INTERVENTION (pPCI)

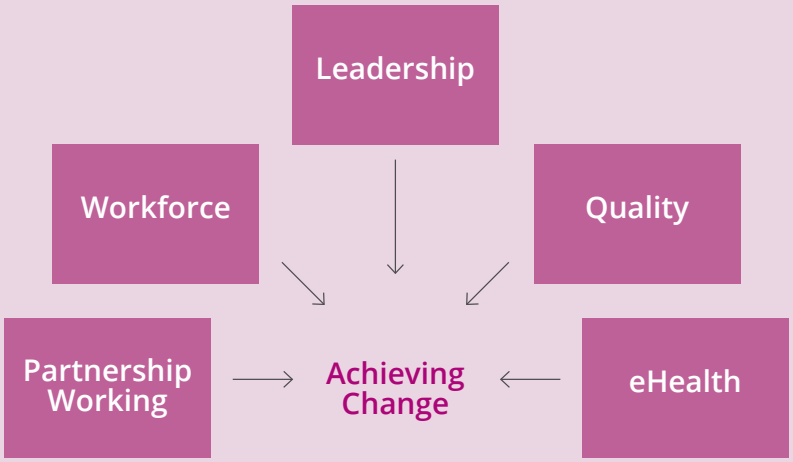
This service, based in Belfast and in Derry, means that patients having a particular type of heart attack are taken from anywhere across the North straight to a specialised centre which can undertake this life saving procedure on a 24/7 basis.

On average a total of 66 pPCI procedures are being carried out per month and from May 2016, Donegal patients have access to the Derry based service.

4 THE APPROACH

How we plan, design, support and implement service transformation is as important as the changes we wish to make.

Only by taking the right approach will these changes be the best ones for our population as a whole, and be sustainable in the long run.



Partnership Working

With people who use and deliver services

Our Health and Social Care system belongs to all of us and we all bring valuable insights to how it can improve. We must work in partnership - patients, service users, families, staff and politicians - in doing so we can co-produce lasting change which benefits us all. Everyone who uses and delivers our health and social care services must be treated with respect, listened to and supported to work as real partners within the HSC system.

Building on the good practice which already exists in the HSC, such as the Mental Health Recovery Colleges, we will work collaboratively in the spirit of openness and trust to deliver agreed outcomes.

When we embark on a change to our system or services, all relevant individuals or groups will be brought together, including those who use and those who deliver our services. A clear terms of reference will be developed collaboratively, ensuring all parties are clear about the task at hand, and how we will work together.

We will adopt creative and innovative ways to maximise involvement. All views and opinions will be received with equal merit. In the past the system has been criticised for delays in bringing forward change, we will support teams to work at pace.

Co-production will empower patients, service users and staff to:

- **design the system** as whole to ensure there is a focus on keeping our population well in the first place and ensuring that when people need support and help they receive safe and high quality care;
- work together to **develop and expand specific pathways of care and HSC services** which are designed around people and their needs, including setting outcomes to measure impact;
- be partners in **the care they receive** with a focus on increased self-management and choice, especially for those with long-term conditions.

A move to this model will not happen overnight. However, I am fully committed to this approach and will support this new way of working across the HSC. In order to start this process in November I will embark on a period of engagement about my proposals for the model of health and care for the future.

I am making a commitment that the design of new and reconfigured services will be taken forward on the basis of co-production and co-design.

We will strengthen the capacity of both those who use our services and those who deliver them to bring about positive change for and by themselves. This includes continued investment in initiatives such as Expert-by-Experience programmes, which provides training and development for users who work with the HSC to improve our services. We will also train staff to support the continued roll-out of the Quality 2020 Attributes Framework.

In addition, I intend to maximise the patient voice across our system, and align it much more closely to the quality improvement, and inspection and regulation. I also want to hear the voice of staff particularly those on the ground closest to those who use our services. In early 2017, I will consult and design a new feedback platform open to all those who both use and deliver our services. This will enable users and staff to tell us what matters to them in terms of their health and social care and to raise issues in as timely a manner as possible, so that they can be addressed early before they escalate to a complaint.

Co-production - a new approach to the design and development of mental health services

An example of how co-production can make a big impact on our services is the design and delivery of Mental Health Recovery Colleges. This is an innovative model that assists individuals in their personal and collective journey of recovery. This recovery focussed approach creates opportunities for those with lived experience to contribute as volunteers and in paid roles. These peer educators assist those with mental health problems to discover personal talents and develop life skills which can help them enter the labour market.

A number of people with lived experience have and continue to be developed to become peer educators and are now making a contribution to care delivery. Over 236 sessions of peer education have been delivered.

An alternative ladder of participation



With other providers

Partnership with other providers of care and other service providers is key to improving and safeguarding social, emotional and physical wellbeing. Health and social care has a strong tradition of working with other professions and sectors including the voluntary, community, criminal justice, education, housing and private sectors. These partnerships will be maintained and strengthened to maximise the impact we can make on improving people's health, social wellbeing and quality of life, as well as making the best use of resources.

Improving Quality and Safety

In the design and delivery of health and social care, quality and safety will always be a fundamental priority. The Expert Panel said "any system that aspires to be world class must take a strong position on quality improvement, with the patient and service user represented as part of this".

It is clear to me that, in order to achieve our ambition for health and social care, we need to establish an infrastructure capable of supporting, enabling and driving the improvements we seek, with people at its heart. There needs to be a greater alignment between quality improvement, partnership with those who use our services, and how we regulate those services.

Like many healthcare systems, there has been a gradual increase in improvement capability across our health and social care service. One example is the Regional Mortality and Morbidity Review System, which supports the review of all hospital deaths by multidisciplinary 'frontline' teams to identify learning to improve the quality and safety of care. The system is well embedded in two Trusts at present and will be fully embedded across all Trusts by April 2017. Another example is the Medicines Optimisation Quality Framework which is supporting improvement by scaling up good practices for the appropriate, safe and effective use of medicines across health and social care.

We now need to fully integrate quality improvement into the work of every HSC organisation and provide real support for local and regional improvement work. That will mean improving our capacity to foster local innovation and to implement what works at scale. It also requires us to be able to proactively detect hazards in care settings and implement solutions to reduce risk before harm occurs. Developing the science of improvement can be done at the same time as making improvements.

To deliver a sustainable and world class service into the future will require of all of us to work together very differently. We need an infrastructure that makes this possible.

For that reason, I intend to establish an Improvement Institute that will better align existing resources to enable improvement in our system of care. These include resources currently devoted to patient safety, regulation, evidence gathering, data analytics, information and, critically, those with experience of using our services. My aim is to establish a strong and integrated infrastructure to support improvement wherever it needs to happen across our system of care. This aim will only be achieved with the support and engagement of all leaders across the HSC system.

I have asked my Department to convene a group of local clinicians, professionals and service users with experience in improvement to advise on the design of that infrastructure. This will not be a new HSC organisation but will align existing resources and functions. The design work will be complete by February 2017 and I expect the Institute to begin to test how it will operate by May 2017.

Investing in our Workforce

The Expert Panel has re-affirmed that effective workforce engagement and planning are key enablers to HSC transformation. I believe the far-reaching transformation journey we are about to embark on needs the commitment and engagement of workers across the HSC at every grade if it is to succeed. I am confident that working together we can succeed.

The increasing pressure on services has contributed to difficulties in attracting and retaining experienced staff and the vacancy rate in a range of disciplines continues to grow. These factors have led to an escalation in the costs of maintaining safe service provision through the use of expensive agency and locum staff, as well as longer hospital stays than necessary.

Clearly, this is unsustainable and workforce planning cannot continue to be used simply as an exercise to ensure that existing rotas are filled. It has to be a vehicle for supporting the implementation of a new and sustainable model of care. It has to take account of increasing demand as a result of demographic trends, be informed by robust and accurate workforce information and analysis, and map to the new configuration of services in secondary care and the increased focus on primary care. It also has to address the factors that enhance the attractiveness of key jobs, such as domiciliary care.

However, effective workforce planning is only one aspect of what is needed. We want to ensure that we are harnessing the skills and experience of the 72,000 individuals working in the wider HSC family.

As stated earlier, I want the HSC to be an employer of choice, leading by example and investing in the health and wellbeing of its staff. We will explore ways to build on and consolidate the health and wellbeing services we provide for our staff.

I recognise the fears and anxieties about job security, role and job location that any change process will create. Based on their lived experience, HSC staff at all grades are all too well aware of the unintended day to day impact on their own teams of previous change initiatives. Too many of these experiences to date have not been positive.

I am determined that the unique store of knowledge, commitment and public service ethos that the HSC workforce represents will be listened to, engaged and nurtured at all levels. It is the single most important resource we have to achieve lasting change.

In collaboration with stakeholders, we are committed to ensuring a Workforce Strategy is developed by spring 2017 which will cover all aspects of the HSC workforce, including retention and recruitment; opportunities for introducing new job roles and of reskilling and upskilling initiatives. This will require investment but we are convinced that investment in every area of our workforce is critical in delivering this new model of sustainable care.

But it is clear that some action needs to be taken now to address current workforce challenges. Therefore, we will continue to invest in training by expanding GP and nurse training places. I have asked for a number of areas to be looked at in detail, including the appointment of a Nursing and Midwifery Task group which will report within 12 months with recommendations for how we can maximise the contribution nursing and midwifery can make to improved outcomes for the population.

The forthcoming Reform of Adult Social Care and Support will consider the nature, size and skills of the social care workforce needed to deliver social care in the future. I will consider carefully the findings of the Domiciliary Care Workforce Review, which is due to be completed by the end of 2016. I am committed to taking steps to improve the recruitment and retention of this critically important group of staff.

Leadership and Culture

If we are to develop a culture of quality improvement and partnership working, this must be underpinned by a new approach to collective and system leadership. We are fortunate to have some of the most capable, committed and enthusiastic people making up our health and social care workforce. Many leading edge research and reports provide evidence that having continuous learning cultures and team working in health and social care organisations is crucial to ensuring safe high quality care.

Rather than concentrating power at the top, I want all those working in health and social care to feel able to effect change and improvement in care. This means developing leadership at all levels, a truly collective leadership model. I will flatten and remove unnecessary hierarchy, eliminating those policies which inhibit innovation and improvement. If we are to move towards a model of care powered by multidisciplinary teams, we need to empower all teams to deliver care, not micro-manage them. Working in partnership with our staff, I believe this is achievable.

This will require a major programme of cultural change and it will not happen overnight. But we need to start now.

As part of this we need to enhance our clinical leadership. The Expert Panel said that change *"will be more successful if… implemented in a setting which encourages clinical and professional engagement"*. I want to see our structures have more professionals directly engaged in the management and leadership of our services, effecting the change supported by skilled and able managers.

I have recently re-established the Strategic Health Partnership Forum and see this as an important contribution to the development of a new culture of partnership, involvement and listening.

Over the next 6 months, an HSC-wide Leadership Strategy will be developed to support this aim. Resources will be directed over the next 3 years and beyond to develop the right staff and leaders, with the skills, behaviours and values that will be so crucial in developing the compassionate, collaborative and high performing culture we seek.

eHealth and Care

Making better use of technology and data is essential if we are to move to a model focussed on service users, on improving the health and wellbeing of the population and on getting beyond organisational and professional silos. I am determined to realise the potential and opportunities presented by modern information technology to improve outcomes for service users and free up time for front line staff. To do so, co-production must underpin our approach, and we must learn the lessons and build on the experience of current and past HSC IT initiatives.

We will expand the range of information and interaction available to citizens, service users and those providing services both online and through apps. This will include building a new patient portal which will allow secure online access to their own health and care information where service users want this. This new patient portal will be in place for dementia patients next year and rolled out across the North by 2021.

To ensure our staff can focus on supporting individuals, the right information must be available to the right professionals, at the time they need it. Our award-winning approach to sharing information across different IT systems (the Electronic Care Record) has significantly changed the way care is delivered and improved safety. However, we still have too many different systems across the HSC making it difficult to join up data and focus on the service user.

We are currently assessing the best way to achieve a much more consolidated and common patient and user record, with fewer separate IT systems. This will be a major undertaking. We will aim to liberate time for care by equipping our community based workforce with new technology that will increase the time that doctors, nurses, therapists and social workers have to spend with patients. If we can realise a 15-minute increase in care time by reducing bureaucracy this equates to over 1,000 additional care professionals working with service users. These initiatives will also allow more staff in the HSC to work remotely, saving travel to and from hospitals, care centres and offices.

Moving to a more consolidated health record across the North will allow us to make better use of information about our population - designing new ways to intervene early and support people in managing their conditions. A programme of work to improve our use of health analytics, focussed on dementia patients, will start in 2017.

5 THE ACTIONS

In this document I have set out my commitment to change but I recognise that much work is needed to develop, design and deliver the building blocks that will enable sustained improvement. I am committed to achieving the change required using a process of co-production.

The task is challenging and will take sustained and incremental effort over the next ten years to achieve real transformation.

But we start now. In the next section I have set out my actions for the next 12 months. These will be taken forward to make a positive and ambitious start towards stabilisation, reconfiguration and transformation.

As I have said, to deliver real and meaningful change will require an extension of the political goodwill and cooperation given to the Expert Panel. Moreover significant investment will be required. I believe this shared investment will not only improve people's health and wellbeing but have a positive impact on every aspect of their lives.

I fully believe that it is only by working together we can deliver a world class health and social care system.

Stabilisation

1	Develop a comprehensive approach for **addressing waiting lists** which takes account of the ongoing work of the Health and Social Care Board, as well as the recommendations from the Expert Panel.	*January 2017*
2	To improve access and resilience, and support the development of new models of care, make **significant investment in primary care** to ensure there is a multidisciplinary team focussed on the patient and with the right mix of skills. This will be supported by: - increased GP training places; - continued investment in Practice Based Pharmacists; - ensuring every GP practice has a named District Nurse, Health Visitor and Social Worker to work with; - supporting the development of new roles such as Physician Associates and Advanced Nurse Practitioners; and - further roll-out of the AskMyGP system. Bring forward a public consultation on the role of GP Federation and whether they should become HSC bodies.	*March 2017*
3	Bring forward proposals relating to the extension of placement options for **Looked After Children**.	*October 2017*
4	Following the completion and evaluation of a pilot project, roll-out access to the electronic care record (NIECR) to **community pharmacists** and establish a pilot to test access to the record for **independent optometrists.**	*October 2017*
5	Begin development of a new framework to fully realise the potential of **community pharmacy services** to support better health outcomes from medicines and prevent illness.	*November 2016*

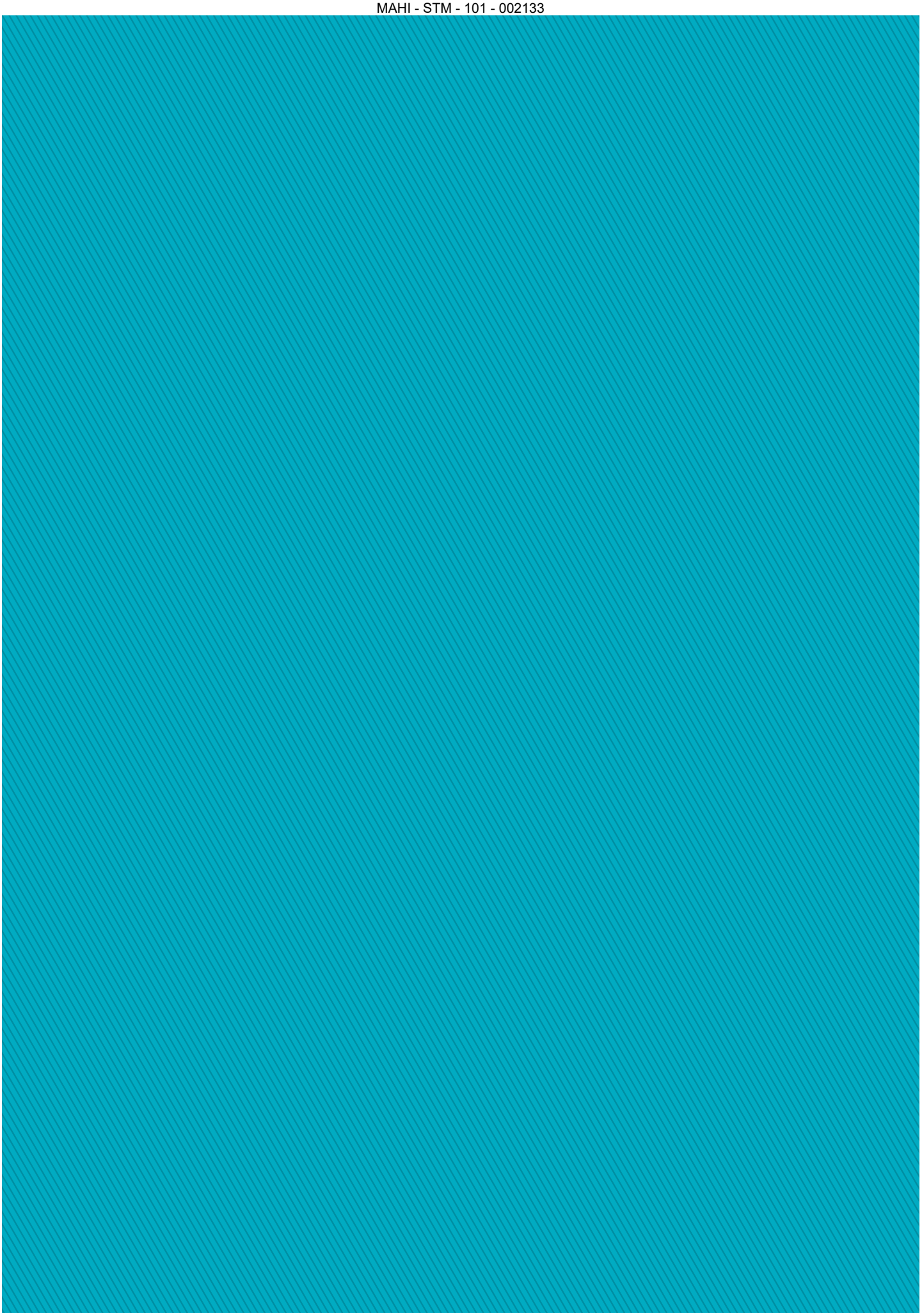
Reconfiguration and service change

6	Embark on a consultation on the criteria set out in the Expert Panel Report and start a programme of **service configuration reviews**. These will be clinically led, working in partnership with those that use the services.	*November 2016*
7	As part of this process, my immediate priorities are: • following extensive review and engagement, launch a public consultation on proposals to modernise and transform **Pathology** services designed to improve service and workforce sustainability ensuring a high quality pathology service for the future; — *November 2016* • move forward with the implementation of the new **Diabetes** Strategic Framework, which has been, and will continue to be, developed through partnership with patients and their representative groups; — *November 2016* • launch and commence implementation of the **Paediatric Strategies** (2016-2026) designed to modernise and further improve the standard of treatment and care provided in hospital and community settings, and palliative and end of life care for children and their families; and — *November 2016* • launch a public consultation on proposals to develop sustainable **Stroke** services and further improve the standard of treatment and care provided to stroke patients. — *February 2017* • following a recent review, launch a public consultation on the configuration of **Imaging** services, taking account of advances in technology, demographics and demands, and looking to both national and international best practice; — *February 2017*	
8	Bring forward proposals for the location and service specification for **Elective Care Centres**, and **Assessment and Treatment Centres.**	*October 2017*
9	Develop design for new structures and approaches to support the **reform of planning and administration** of the HSC	*March 2017*
10	Identify current **innovative HSC projects** at the local level and develop a rolling programme and implementation plan to scale up these projects across the region.	*April 2017*

Transformation

11	Embark on a **period of engagement** with staff and service users to build a collective view of how our health and social care services should be configured in the future, and encourage a much wider public debate.	*November 2016*
12	Establish and seek members for a **transformation oversight structure** with membership drawn from within and outwith the HSC.	*November 2016*
13	Consult on proposals for the reform of **adult social care and support**, to consider different approaches to ensuring the long-term sustainability of the adult social care system.	*April 2017*
14	Consult on proposals for and complete design of a **new user feedback platform** open to all those who both use and deliver our services.	*October 2017*
15	Complete the initial design work for the **Improvement Institute.**	*February 2017*
16	Develop a **Workforce Strategy** covering all aspects of the HSC workforce, including retention and recruitment; opportunities for introducing new job roles; and upskilling initiatives.	*May 2017*
17	Develop a **HSC-wide Leadership Strategy** to consider a 5 year approach and plan for development of collective leadership behaviours across our system.	*May 2017*
18	Expand the range of information and interaction available to citizens online and development of a **patient portal** for dementia patients.	*October 2017*





NICE National Institute for Health and Care Excellence

NICE quality standard

Learning disability: identifying and managing mental health problems

Quality standard

Published: 10 January 2017
www.nice.org.uk/guidance/qs142

Contents

Quality statements 5
Quality statement 1: Annual health check 6
Quality statement 6
Rationale 6
Quality measures 6
What the quality statement means for different audiences 7
Source guidance 8
Definitions of terms used in this quality statement 8
Equality and diversity considerations 9
Quality statement 2: Assessment by a professional with relevant expertise 10
Quality statement 10
Rationale 10
Quality measures 10
What the quality statement means for different audiences 11
Source guidance 12
Definition of terms used in this quality statement 12
Equality and diversity considerations 12
Quality statement 3: Key worker 14
Quality statement 14
Rationale 14
Quality measures 14
What the quality statement means for different audiences 15
Source guidance 15
Definitions of terms used in this quality statement 16
Equality and diversity considerations 17
Quality statement 4: Tailoring psychological interventions 18
Quality statement 18

Rationale 18
Quality measures 18
What the quality statement means for different audiences 19
Source guidance 19
Quality statement 5: Annually documenting the reasons for continuing antipsychotic drugs 21
Quality statement 21
Rationale 21
Quality measures 21
What the quality statement means for different audiences 22
Source guidance 23
Equality and diversity considerations 23
About this quality standard 24
Improving outcomes 24
Resource impact 25
Diversity, equality and language 25

This standard is based on NG54 and NG11.

This standard should be read in conjunction with QS159 and QS101.

Quality statements

Statement 1 Young people and adults with a learning disability have an annual health check that includes a review of mental health problems.

Statement 2 People with a learning disability who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Statement 3 People with a learning disability and a serious mental illness have a key worker to coordinate their care.

Statement 4 People with learning and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Statement 5 People with a learning disability who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

NICE has developed guidance quality standards on patient experience in adult NHS services and service user experience in adult mental health services (see the NICE pathways on patient experience in adult NHS services and service user experience in adult mental health services) which should be considered alongside these quality statements.

A full list of NICE quality standards is available from the quality standards topic library.

Quality statement 1: Annual health check

Quality statement

Young people and adults with a learning disability have an annual health check that includes a review of mental health problems.

Rationale

Annual health checks for young people and adults with a learning disability can be used to identify and monitor mental health problems. Young people and adults with a learning disability and mental health needs may have difficulty explaining their health problems, so checking for issues and regularly monitoring needs is important to ensure that these are not missed.

Quality measures

Structure

Evidence of local arrangements to ensure that young people and adults with a learning disability have an annual health check that includes a review of mental health problems.

Data source: Local data collection.

Process

a) Proportion of young people with a learning disability who have an annual health check that includes a review of mental health problems.

Numerator – the number in the denominator who have had an annual health check that includes a review of mental health problems.

Denominator – the number of young people with a learning disability.

Data source: Local data collection.

b) Proportion of adults with a learning disability who have an annual health check that includes a review of mental health problems.

Numerator – the number in the denominator who have had an annual health check that includes a review of mental health problems.

Denominator – the number of adults with a learning disability.

Data source: Local data collection.

Outcome

a) Identification of mental health needs in young people and adults with a learning disability.

Data source:Local data collection.

b) Identification of physical health needs in young people and adults with a learning disability.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (enhanced GP services) ensure that young people and adults with a learning disability have an annual health check that includes a review of mental health problems, and that a family member, carer or care worker is involved (as appropriate).

Healthcare professionals (such as GPs) conduct annual health checks that include reviews of mental health problems for young people and adults with a learning disability, and involve a family member, carer or care worker (as appropriate).

Commissioners (clinical commissioning groups) ensure that general practices are signed up to provide annual health checks that prioritise a review of physical and mental health,

for young people and adults with a learning disability.

Young people and adults with a learning disability have an annual health check that includes a review of their mental and physical health. This includes:

- identifying potential new problems
- looking at all the treatments they are having, to see if they are having any difficulties (for example with going to therapy sessions)
- reviewing the medications they are taking to see if they have had side effects, any difficulties taking medication or any other problems
- agreeing a care plan with the healthcare professional for managing any physical health and mental health problems.

If they want, the person may take a family member or carer with them.

Source guidance

- Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.6.3
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (2015) NICE guideline NG11, recommendation 1.2.1

Definitions of terms used in this quality statement

Young people

Aged 13–17 years.

[Mental health problems in people with learning disabilities (2016) NICE guideline NG54]

Annual health check

This should involve the person with a learning disability and a family member, carer, care

worker, GP or social care practitioner (as appropriate) who knows them. It should include:

- a review of any known or suspected mental health problems and how they may be linked to any physical health problems
- a physical health review, including assessment for the conditions and impairments that are common in people with a learning disability
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence for both mental health and physical health conditions
- an agreed and shared care plan for managing any physical health and mental health problems (including pain).

[Adapted from mental health problems in people with learning disabilities (NICE guideline NG54), recommendation 1.6.3; and challenging behaviour and learning disabilities (NICE guideline NG11), recommendation 1.2.1]

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with a learning disability. They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

Quality statement 2: Assessment by a professional with relevant expertise

Quality statement

People with a learning disability who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Rationale

The mental health assessment should be conducted by a professional with expertise in mental health problems in people with learning disabilities. This ensures that the assessment and subsequent care is effective and tailored to the person's individual needs and circumstances, and makes reasonable adjustments to take account of their learning disability.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability who need a mental health assessment and are referred to a professional with expertise in mental health problems in people with learning disabilities.

Numerator – the number in the denominator who are referred to a professional with

expertise in mental health problems in people with learning disabilities.

Denominator – the number of people with a learning disability who need a mental health assessment.

Data source: Local data collection.

b) Proportion of people with a learning disability who are referred for a mental health assessment and are assessed by a professional with expertise in mental health problems in people with learning disabilities.

Numerator – the number in the denominator who are assessed by a professional with expertise in mental health problems in people with learning disabilities.

Denominator – the number of people with a learning disability who are referred for a mental health assessment.

Data source: Local data collection.

Outcome

Identification of mental health problems in people with a learning disability.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (secondary care providers, mental health services and specialist learning disabilities services) ensure that people with a learning disability who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Health and social care practitioners with expertise in mental health problems in people with learning disabilities conduct mental health assessments for people with a learning disability. At the assessment, the professional completes a formal mental health assessment questionnaire.

Commissioners (clinical commissioning groups, NHS England and local authorities) commission services that ensure that people with a learning disability who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

People with a learning disabilitywho need a mental health assessment are referred to a professional who has the skills to do this for people with learning disabilities and mental health problems. If possible, this should be carried out in a place familiar to the person, with any family members, carers, care workers or others that they want to involve. If needed, staff should help the person with learning disabilities to prepare for the assessment.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.8.1

Definition of terms used in this quality statement

Mental health assessment

The assessment should include a review of the person's previous history (both physical and mental health) and personal circumstances. This is essential when assessing the person's mental health problem and developing a mental health care plan. A formal assessment questionnaire should be completed as part of the assessment.

[Adapted from mental health problems in people with learning disabilities (NICE guideline NG54), recommendations 1.8.1 and 1.8.6]

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with learning disabilities when conducting a mental health assessment. They should make reasonable adjustments for people accessing mental health services, and provide support if needed for people who have limited or no speech or who have difficulty with English.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

Quality statement 3: Key worker

Quality statement

People with a learning disability and a serious mental illness have a key worker to coordinate their care.

Rationale

Appointing a key worker would improve care coordination and help services to communicate clearly with people with a learning disability and their family members and carers.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people with a learning disability and a serious mental illness have a key worker to coordinate their care.

Data source: Local data collection.

Process

Proportion of people with a learning disability and a serious mental illness who have a key worker to coordinate their care.

Numerator – the number in the denominator who have a key worker to coordinate their care.

Denominator – the number of people with a learning disability and a serious mental illness.

Data source: Local data collection.

Outcomes

Patient and carer satisfaction with their key worker's coordination of care.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (primary, secondary and social care services that provide care for people with learning disabilities and mental health problems) ensure that people with a learning disability and a serious mental illness have a key worker to coordinate all aspects of care.

Key workers coordinate all aspects of care and communication for the person, their family members and carers, and the services that are involved. They should maintain regular contact with the person and their family members and carers and specify this in the care plan.

Commissioners (clinical commissioning groups, NHS England and local authorities) commission services that provide a key worker for each person with a learning disability and a serious mental illness. The key worker should coordinate all aspects of care and communication.

People with a learning disability and a serious mental illness have a key worker who acts as the main contact for them and their family members and carers. The key worker makes sure that all staff involved are working together, and that the care plan is being followed and is helping. They ensure that any assessments, care and treatments are explained clearly to the person with a learning disability.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.2.8

Definitions of terms used in this quality statement

Serious mental illness

A diagnosis of:

- severe depression or anxiety that is impacting heavily on the person's functioning
- psychosis
- schizophrenia
- bipolar disorder
- an eating disorder
- personality disorder
- schizoaffective disorder.

[Mental health problems in people with learning disabilities (NICE guideline NG54) and expert consensus]

Key worker

A key worker (also known as a care or case coordinator, or a Care Programme Approach care coordinator) is the central point of contact for the person with a learning disability, their family members and carers, and the services involved in their care. They are responsible for helping the person and their family members and carers to access services and for coordinating the involvement of different services. They ensure clear communication between all people and services and have an overall view of the person's needs and the requirements of their care plan. They ensure that services communicate regularly with the person and their family members and carers, in a suitable format.

[Adapted from mental health problems in people with learning disabilities (NICE guideline NG54)]

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with a learning disability. They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

Quality statement 4: Tailoring psychological interventions

Quality statement

People with a learning disability and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Rationale

Children, young people and adults with a learning disability are at higher risk of mental health problems than the general population. Standard evidence-based psychological interventions are not designed to take account of the cognitive, communication or social impairments associated with learning disabilities. People with a learning disability can have a broad range of difficulties, so the care setting and interventions need to be adapted and tailored to each person's preferences, level of understanding, and strengths and needs.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Process

Proportion of people with a learning disability and mental health problems who are receiving psychological interventions that are tailored to their preferences, level of understanding, and strengths and needs.

Numerator – the number in the denominator who receive psychological interventions that

are tailored to their preferences, level of understanding, and strengths and needs.

Denominator – the number of people with a learning disability and mental health problems who are receiving psychological interventions.

Data source: Local data collection.

Outcome

Quality of life of people with a learning disability and mental health problems and their family members and carers.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (secondary care providers, mental health services and specialist learning disabilities services) ensure that people with a learning disability and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Health and social care practitioners tailor psychological interventions for people with a learning disability and mental health problems, to match their preferences, level of understanding, and strengths and needs.

Commissioners (clinical commissioning groups, NHS England and local authorities) commission services that ensure that psychological interventions for people with a learning disability and mental health problems are tailored to match their preferences, level of understanding, and strengths and needs.

People with a learning disability and a mental health problem have access to psychological ('talking') therapies that are designed around their needs.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and

management (2016) NICE guideline NG54, recommendations 1.9.1–1.9.4, 1.9.8 and 1.9.9

Quality statement 5: Annually documenting the reasons for continuing antipsychotic drugs

Quality statement

People with a learning disability who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Rationale

People with a learning disability who are taking medication for a mental health problem would benefit from closer monitoring and a clear rationale for their treatment plan, such as an annual record of the reasons for continuing prescriptions. People with a learning disability are often given long courses of medication. This is not always helpful, and regular review and agreed shared care protocols are necessary to avoid this.

Effective use of medication to prevent and manage mental health problems is likely to improve the quality of life of people with a learning disability and their family members and carers, and reduce costs and inappropriate prescribing.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Data source: Local data collection.

Process

Proportion of people with a learning disability who are taking antipsychotic drugs that are not reduced or stopped and who have annual documentation on reasons for continuing this prescription.

Numerator – the number in the denominator who have annual documentation on reasons for continuing this prescription.

Denominator – the number of people with a learning disability who are taking antipsychotic drugs that are not reduced or stopped.

Data source: Local data collection.

Outcome

a) Antipsychotic medication prescribing rates for people with a learning disability.

Data source:Local data collection.

b) Quality of life of people with a learning disability and their family members and carers.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (secondary care providers) ensure that people with a learning disability who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Healthcare professionals (clinicians) annually document the reasons for continuing prescriptions for people with a learning disability who are taking antipsychotic drugs that are not reduced or stopped.

Commissioners (NHS England) commission services that ensure that people with a learning disability who are taking antipsychotic drugs that are not reduced or stopped

have annual documentation on reasons for continuing this prescription.

People with a learning disability who are taking antipsychotic drugs (medication to help with psychosis) that are not reduced or stopped have a review of their prescription and the reasons for continuing it recorded every year.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.10.8

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with a learning disability. They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Information about how NICE quality standards are developed is available from the NICE website.

See quality standard advisory committees on the website for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the quality standard's webpage.

This quality standard has been incorporated into the NICE pathways on challenging behaviour and learning disabilities and mental health problems in people with learning disabilities.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- identification of mental health needs in young people and adults with a learning disability
- identification of physical health needs in young people and adults with a learning disability
- experience of primary care and secondary care for people with a learning disability
- experience of mental health services for people with a learning disability
- quality of life of people with a learning disability and their family members and carers.

It is also expected to support delivery of the Department of Health's outcome frameworks:

- Adult social care outcomes framework 2015–16
- NHS outcomes framework 2016–17
- Public health outcomes framework for England, 2016–19.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact products for the source guidance to help estimate local costs:

- baseline assessment tool for the NICE guideline on mental health problems in people with a learning disability.
- resource impact report and template for the NICE guideline on mental health problems in people with a learning disability.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local

context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- British Association of Art Therapists
- British Psychological Society (BPS)
- College of Mental Health Pharmacy
- Royal College of General Practitioners (RCGP)

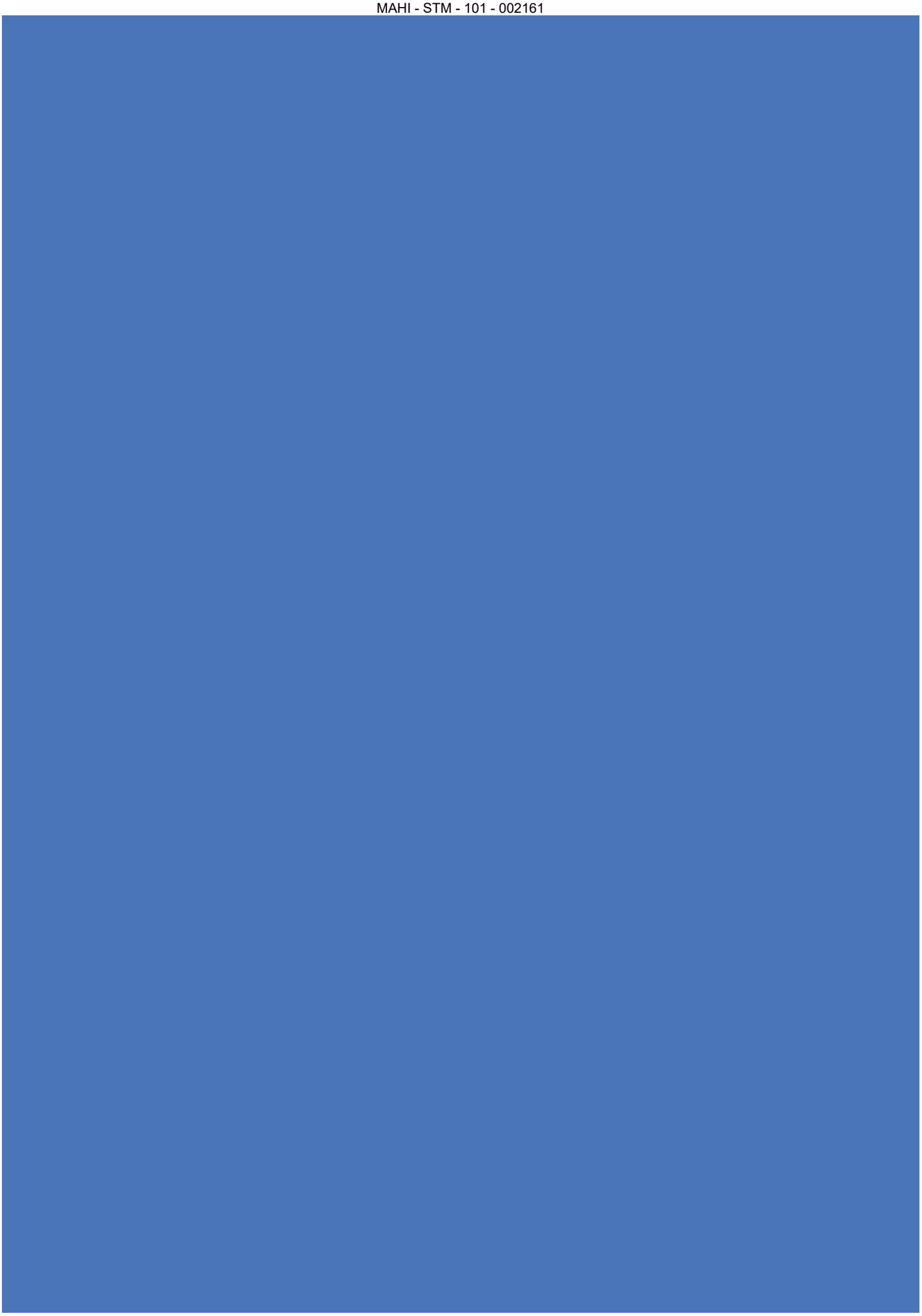
POWER TO PEOPLE

Proposals to reboot adult care & support in N.I.

Expert Advisory Panel on Adult Care and Support

DES KELLY & JOHN KENNEDY





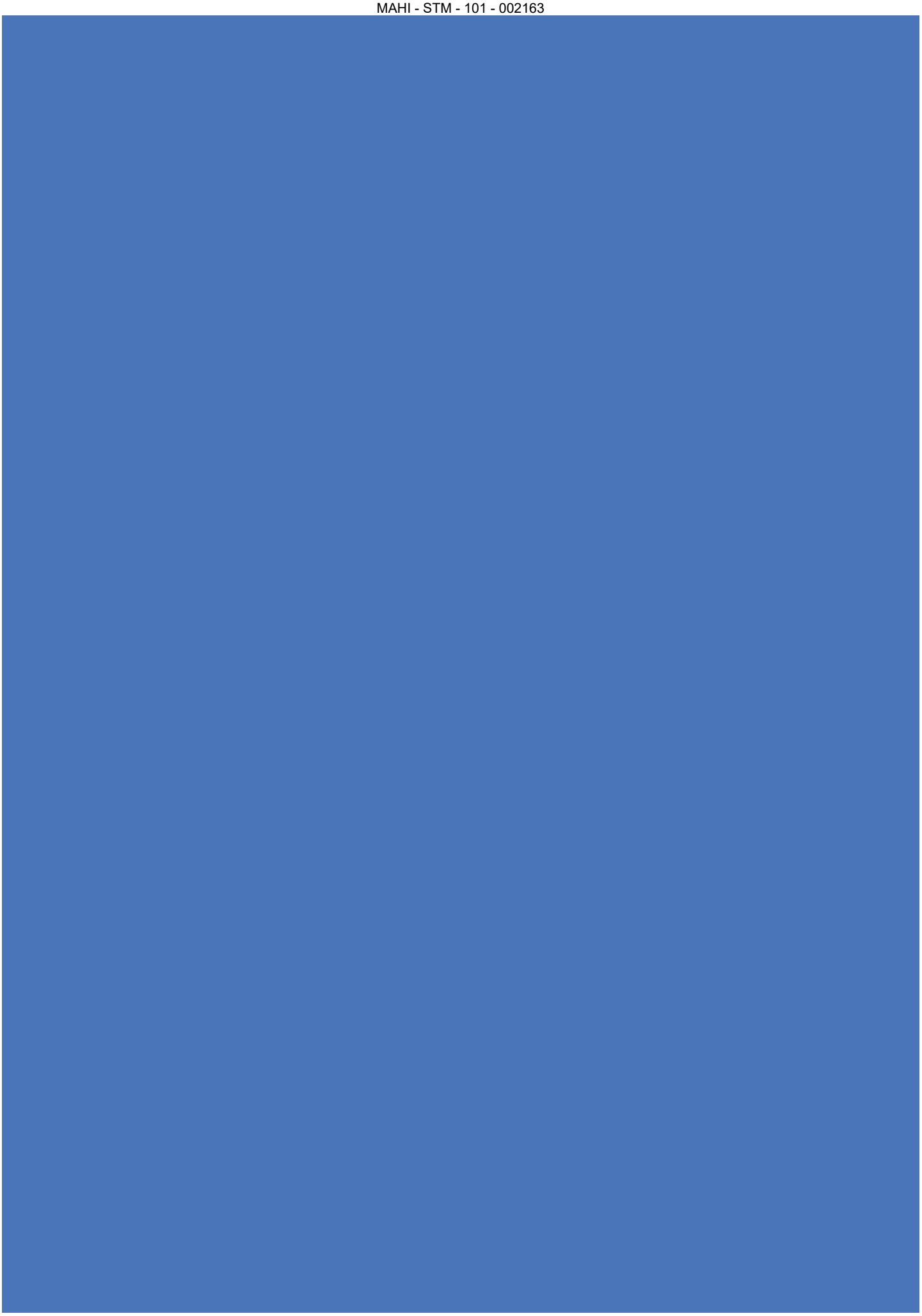
CONTENTS

Acknowledgments 3

1. Introduction 5
2. The Value of Social Care 13
3. The Citizen at the Heart 25
4. Family Carers - Vital Partners for Social Care 35
5. Building Resilient Communities 41
6. The Professional Workforce in Social Care 51
7. The 'Market' for Care 61
8. System Alignment - Making Integration Meaningful 71
9. Towards a New Concordat 83

List of Proposals 89

Expert Advisory Panel on Adult Care and Support
Supporting Annex 93



ACKNOWLEDGMENTS

We met a lot of people representing a wide range of different interests in the relatively short period to develop our Proposals Paper on the future of adult care and support in Northern Ireland. (A full list of individuals and organisations can be found in the supporting annex.) Given that our review follows a somewhat well-worn path it would have been entirely understandable to have faced ambivalence or cynicism. The experience was quite the reverse. We found people keen to express their views, share their knowledge and learning, and to challenge established ways of thinking and working. We note in our report a striking consensus about the shortfalls of the current system and a shared understanding of the need to do things differently.

We would like to thank all those that contributed to our work: responding to the call for evidence, through interviews and meetings, or hosting a visit in order for us to see care and support services and share in the learning.

We have had some spirited, and stimulating, discussions about adult care and support. People have been generous with their time, engaging enthusiastically and tolerating the many questions we asked. The level of engagement at the workshops used to test our thinking was particularly encouraging.

Transforming proposals into actions needs to build on this commitment to change through public engagement and we do not underestimate the scale of the task.

The team at the Department of Health ensured that our time was used efficiently and made the task more manageable. We have much appreciated the assistance of Dean Looney, Taryn McKeen and Ruth Todd (thankfully chocolate biscuits kept us all going at times!)

The hospitality we have experienced in Northern Ireland has been wonderful – so many scones! It is our sincere hope that this Proposals Paper really is the start of sustainable change for adult care and support.

A big 'thank you' to everyone concerned.

Des Kelly and John Kennedy

“Be radical!”

STAKEHOLDER COMMENT

1 INTRODUCTION

The scope and context of the review

This review is part of the wider Reform of Adult Care and Support project in Northern Ireland which involves three stages:

- The initial **consultation on 'Who Cares? The Future of Adult Care and Support in NI'** to build the consensus for change (September 2012 – March 2013);
- The development of a **Proposals Paper** (this report) which was undertaken between December 2016 and May 2017, and subsequent policy consultation document which is expected to be produced in 2018; and
- A **Final Strategy** setting out future direction and funding reforms that will be required.

As set out in the terms of reference (see the supporting annex) this review covers care and support for all adults: older people, people with physical, sensory or learning disabilities, and those experiencing mental distress. The care and support services they receive are primarily the responsibility of the Department of Health. However, services provided by other government departments that can support people including housing, transport, health and education are also touched on in the report. This is a considerable task particularly in the timescale!



Of course, the Expert Advisory Panel recognises that there are significant differences between the needs of people who receive adult care and support services and the specialist provision designed to support them. For example, a young person with a learning disability experiencing the transition to adult services, a person with mental ill-health moving from a long-stay hospital setting to supported living or someone living with dementia in a care home will have very different needs and receive different services under the care and support umbrella. But we also firmly believe that our need for care and support should not define us. We are all different as individuals more

than we are different because of our age, abilities or care and health needs. We are ourselves because of who we are and we will argue in this paper that who we are as people should be the starting point for a transformed adult care and support system. One that recognises, and celebrates, our ambitions and contribution. One that values who we are regardless of our age, gender, ability, sexuality or ethnicity; one that focusses on us as people and one based on our individual unique value and human rights.

In reviewing adult care and support in Northern Ireland we have witnessed considerable consensus on what is wrong with the current system and a strong shared understanding of the problems. A substantial proportion of the evidence received reinforced this premise. However, in this Proposals Paper we want to focus positively on the future rather than restate the shortfalls of the past.

It is important that our paper is considered within the wider Department of Health reform programme emerging from 'Health and Wellbeing 2026: Delivering Together'. While the time constraints have restricted detailed analysis, the Expert Advisory Panel have sought to set out clearly the principles which we believe should both underpin, and guide, the transformation process to reform adult care and support services in Northern Ireland. It is our view that, as the full force of continued public spending constraints combine with changing demographics and rising demand and expectations, the context for adult care and support will be forced to change. It is happening already
- a system collapsing in slow-motion.



An unassailable case for reform

More than once during this review we have been encouraged to be radical in our proposals. The challenges are great and arguably the solutions have been resisted for some decades. **We believe that there is now no choice but to be radical.** A mixture of incremental adjustments is no longer sufficient to keep an unsustainable system working.

It is the view of the Expert Advisory Panel that fundamental reform of adult care and support is required to avoid a total collapse of the system with all the implications this would have for those in need. This requires both leadership and ownership across the whole system of care and support. Furthermore, we argue within this report that a 'pick and mix' approach to the proposals is not appropriate. Systematic reform of the whole system of adult care and support is necessary to achieve the ambitious commitment in Delivering Together to tackling the pressing issues facing the social care and health system in Northern Ireland. Of course, Northern Ireland is not alone in

these challenges. The same pressures and the pressing need for reform are true for most developed countries. In the course of this review we have formed the view that there is an appetite for changing the way in which adult care and support is organised and delivered in Northern Ireland, with an evident commitment to make the changes that are needed. In our concluding section we turn to the idea of a Concordat as the means of stimulating a discussion with the public about the future of care and support and how it should be funded.

The scale and scope of this review, and the time available to complete it, have meant that our proposals cannot be fine grained and detailed. Although some detail was specified in response to the Call for Evidence we are mindful that substantial further work will be necessary, particularly for the proposals to be developed into actions. In addition, it is our view that it is not appropriate that the proposals are seen to be overly prescriptive. The policy consultation from the Department of Health that will follow this review paper, together with the public response, engagement and discussions, obviously need to be a part of shaping the proposals into steps for action that fundamentally change the way that services are operated and delivered. We have endeavoured to distill the key things we have learned about what people say is wrong with the current system to create a set of proposals that can be used to give greater clarity and priority to transforming adult care and support. If it was easy, obvious or painless to deliver the change that is necessary to the adult care and support system, arguably it would have been done already. **The leadership challenge of making care services fit for the 21st century is significant.**

Our proposals are an attempt to synthesise the excellent examples of innovation and creativity we have seen in order to address the shortfalls that have been raised with us. We believe that the proposals, in themselves, could be the very drivers of transformational change. It is our abiding hope that the proposals included in this paper can form the basis of discussions with the widest interests as a 'social movement for change' in the way adult care and support in Northern Ireland is organised, delivered and funded. Furthermore, that perceptions of its purpose and value are similarly transformed.

During the period of this review we have met with in excess of 100 people: they include people receiving care and support, their carers and families, social care staff, voluntary organisations, independent care providers, commissioners, regulators, policy makers, trade union representatives, and a range of care and health professionals. We are hugely grateful for the generosity with which we were received.

The Call for Evidence

A Call for Evidence was launched on 5 December 2016 at the beginning of our work, and ran for six weeks until 23 January 2017. This was intended to provide an opportunity for stakeholders to share examples and evidence as to how care and support can be improved to meet growing demand and changing expectations, and to provide suggestions as to how the care and support system can be sustainably funded to meet those needs.

We received 46 separate submissions to the Call for Evidence, from a range of organisations and some individuals, and as many papers again in supplementary evidence. Some of the people we met continued to submit comments and information throughout the time we

were working on the review. The quality of evidence received was very high, and it provided a sound basis for us to begin our work.

During the Call for Evidence we also met with a range of stakeholders and visited some innovative services around Northern Ireland. We were impressed by everyone we met, by their willingness to engage, their hospitality, and their readiness for change. The conversations we had, the people we met and the services we visited, have all played a part in shaping our thinking during the completion of the review.

Engaging with stakeholders

Throughout the period of the review, the Expert Advisory Panel has worked with service users and carers through the Adult Care and Support Reference Group, facilitated by the Patient Client Council. We met with the group in February 2017, when we presented our early findings following the Call for Evidence. We met with them again in April 2017 as we worked to finalise this Proposals Paper, and the views shared and suggestions made were valuable and have greatly helped to shape our final report.

We also held three stakeholder workshops (in Craigavon, Derry and Belfast) in early March 2017 which were designed to test our thinking around the key themes of:

- choice, control and community engagement;
- building capacity and sustainability;
- the workforce for adult social care.

Over 130 people attended the workshops, with some choosing to participate in more than one and others writing in with further comments after the events. There was a high level of engagement across the many interests represented at the workshops. There appeared to be a recognition that the current structure of social care, in terms of commissioning on the one side and providing on the other, was significantly out of step with the demands and expectations now being made of it. Crucially too, the definition of adult social care is considered to be drawn far too narrowly.

Further detail on the response to the Call for Evidence, including meetings with stakeholders and visits to services, is provided in the supporting annex provided alongside this report.

The structure of the Proposals Paper

The scope of this review covers all adult care and support. We have sought to write the report with this in mind whilst acknowledging that there are inevitable important differences between people with different needs, personal histories and family circumstances. Being true to the principle of individual support which has the person, as citizen, at the centre is more important than 'client' classifications that group people's needs according to their age or to a specific condition.

The following sections consider the areas in need of reform. Each section analyses a key theme pertinent to the effective delivery of adult care and support, although we avoid detailed policy tinkering to concentrate more on trying to describe and articulate the essential principles for our proposals. We believe that the principles are relevant to all adult groups receiving care and support, although we are mindful that specific policy will need to be agreed to ensure that individuals receive services that are appropriate to their specific needs for which more detail will be necessary. We do not underestimate the leadership that will be required to take forward our proposals and develop a framework for implementation.

Section 2 – The value of social care
The nature and importance of adult care and support and the contribution it makes to personal wellbeing, health services, society and the economy is outlined in this section. The key themes that have been raised with us as evidence to the review are introduced. Why we believe social care needs to be elevated to a far higher status in both government priorities as well as in the minds of citizens, families and communities is discussed.



Section 3 – The citizen at the heart
Here we set out our thinking in relation to a human rights approach to care and support. Putting people, rather than structures and systems, at the centre of our interests. We explore ways in which self directed support could become the organising norm for adult care and support services.

Section 4 – Family carers – vital partners for social care
This section acknowledges the significant contribution made by family, friends and other informal carers to the health, well-being and human rights of adults with support needs. Currently, they may be seen as the bedrock of care, as their contribution is the principal way that most people experience care. It is vital that they are treated as partners.

Section 5 – Building resilient communities
People live in homes and communities, not in social care systems. Here we consider how an asset-based community approach could be fundamental in underpinning the structure of a transformed approach to care and support with a crucial role for social workers.

Section 6 – The Professional Workforce in social care
Whilst we believe that adult social care is, and should be, much more than 'paid' and formalised services, these will always be required. The people who care for us may be doing it for a living but they are people too. In this section we outline how the workforce should be supported and valued.

Section 7 – The 'market' for care and support
Much has been said and reported to us in relation to the inadequacies and dysfunction of the social care 'market'. It doesn't function in the way we need it to do. In this section we set out what might be done so that an effective and responsive market can be sustained and thrive.

Section 8 – System alignment - making integration meaningful
The fragmented arrangements that are a common feature of adult social care services as it relates to health, housing and other disciplines have long been seen as problematic. Policy exhortations to bring about a joined-up response and partnership working have pointed to the benefits of achieving more integrated working. In this section we discuss the need for the various systems relevant to adult care and support to be properly aligned.

Section 9 – Towards a new Concordat
In the final section we summarise our thoughts and set out the underpinning principles of a new Concordat. This is envisaged as a new settlement between individuals and the State with a recognition that rights are balanced by risks and responsibilities on both sides.



From reviewing to action

Whilst the review has been welcomed, the responses to the Call for Evidence encouraging and the discussions positive, concerns were raised with the Expert Advisory Panel on the seemingly slow progress of change: "plenty of reviews and lots of evidence but no action". This statement echoes the comments made in Professor Bengoa's report 'Systems, not Structures' which rather compellingly refers to "review fatigue".

We sincerely hope that this paper will not be read as 'just another report' but that it will help in encouraging the radical rethink or 'reboot' we believe is necessary to challenge the current approaches, attitudes and established ways of delivering adult care and support. In this way it can **embolden a genuine public movement for change and transformation.**

> We need a system of care where the individual and their family are in control of the nature of the social care provided, giving them realistic choice.

NI SOCIAL CARE COUNCIL

2 THE VALUE OF SOCIAL CARE

This section sets out the nature and the importance of adult care and support and the contribution it can make to personal wellbeing, health and society in general. It introduces the key themes that have been raised with us as evidence to this review and explored in discussions with many different people with an interest in the care and support system in Northern Ireland.



Social care is personal ... and about all of us

A good system of social care can transform lives - it's that simple. Not just for those who receive social care services but their families, friends and communities too.

And yet it is something of a puzzle that our attempts to create the kind of system we want – services that are responsive to individual need – have become tangled with the 'task' of delivering social care. The processes of assessing, organising and managing appears to have become ever more complex. The process of providing personal care and support has, in turn, become an activity so often characterised by risk assessments, policies and procedures, rules and regulations. Efforts to safeguard and protect the rights and independence of individuals in need of support has led to an 'industry' of inputs and processes which threaten to overshadow, or subvert, the very outcomes they seek to enable. **The notions of wellbeing and quality of life can so easily get lost in the structures and architecture of a managerial system.**

In undertaking this review the Expert Advisory Panel have been struck by the many different ways in which discussions, with a wide range of different people in Northern Ireland, have emphasised a need for a renewed focus on the individual citizen at the heart of care and support services. We warmly welcome this approach.

Social care is personal. It starts with the individual. To be truly personalised it means genuinely listening

to the people who receive care and support, their families and friends, to help them reach their goals and aspirations. It is vital therefore that they are actively involved at all levels of decision-making about how their needs are to be met. But care and support is also personal in the sense that we have a shared interest in knowing that there is a system of care and support should we, or any member of our family, ever be in need of such services.

Being clear about what is meant by adult social care

There are very many definitions for social care. The definition we have favoured for this Proposals Paper, because it is so firmly rooted in the values of human rights, is taken from the Social Care Institute for Excellence (SCIE) and was developed to define excellence for a report originally commissioned by the Care Quality Commission:

"Excellence in social care is rooted in a whole-hearted commitment to human rights, and a continuous practical application of that commitment in the way that people who use services are supported. People who use services are demonstrably placed at the heart of everything that an excellent service does."
(A definition of excellence for regulated adult social care services in England p4)

The definition adds:

"We have identified four essential elements of excellence. Three of these are about improvements in people's lives as a result of using the service. These outcomes are:

- Having choice and control over day-to-day and significant life decisions;
- Maintaining good relationships with family, partners, friends, staff and others;
- Spending time purposefully and enjoyably doing things that bring them pleasure and meaning.

The fourth element relates to the organisational and service factors which enable these outcomes to be achieved and sustained... The four elements interact with each other. They do not stand alone. Without choice and control, a person cannot spend their time in ways they would wish... An excellent service, therefore, will be one that recognises the interplay between these four elements, and which addresses them simultaneously." (2010, p5)

This fourth element is the service and its operational management that sets the standard and makes possible the outcomes defined by those using services. Throughout this report we typically refer to 'adult care and support' as a descriptor for the social care services for all groups of adults covered by our terms of reference.

Policy tensions within social care

Professor Jon Glasby from the University of Birmingham identifies a number of policy tensions[1] within adult social care in the third edition of his seminal introductory text:

- whether to involve people with experience of using services because they are 'customers' or as 'citizens' with a right to greater choice and control;
- whether to support informal carers, exploited by formal services, to acknowledge their needs and rights, or to focus on the needs of carers as a means of helping users and thus reduce demand on services;
- whether to support people with long-term conditions because they are citizens with the right to live independently, or as a means of reducing reliance on expensive hospital services;
- how best to promote more joined-up responses to need in a system that continues to assume that it is possible to distinguish between people who are sick and those that are frail and disabled.

These tensions were clearly evident during the discussions which have informed this review. As a consequence, we have sought to address the issues head on. Professor Glasby argues that in the past it was possible to do a little of each of the 'either-ors' listed above as a short term fix. To an extent, in England particularly, this has worked to prevent a complete collapse of the care system to date, although cracks and gaps have come to characterise a sector openly seen as in crisis.[2,3] According to Professor Glasby "the jury must remain out on the extent to which the current system can continue to contain these contradictions and tensions".

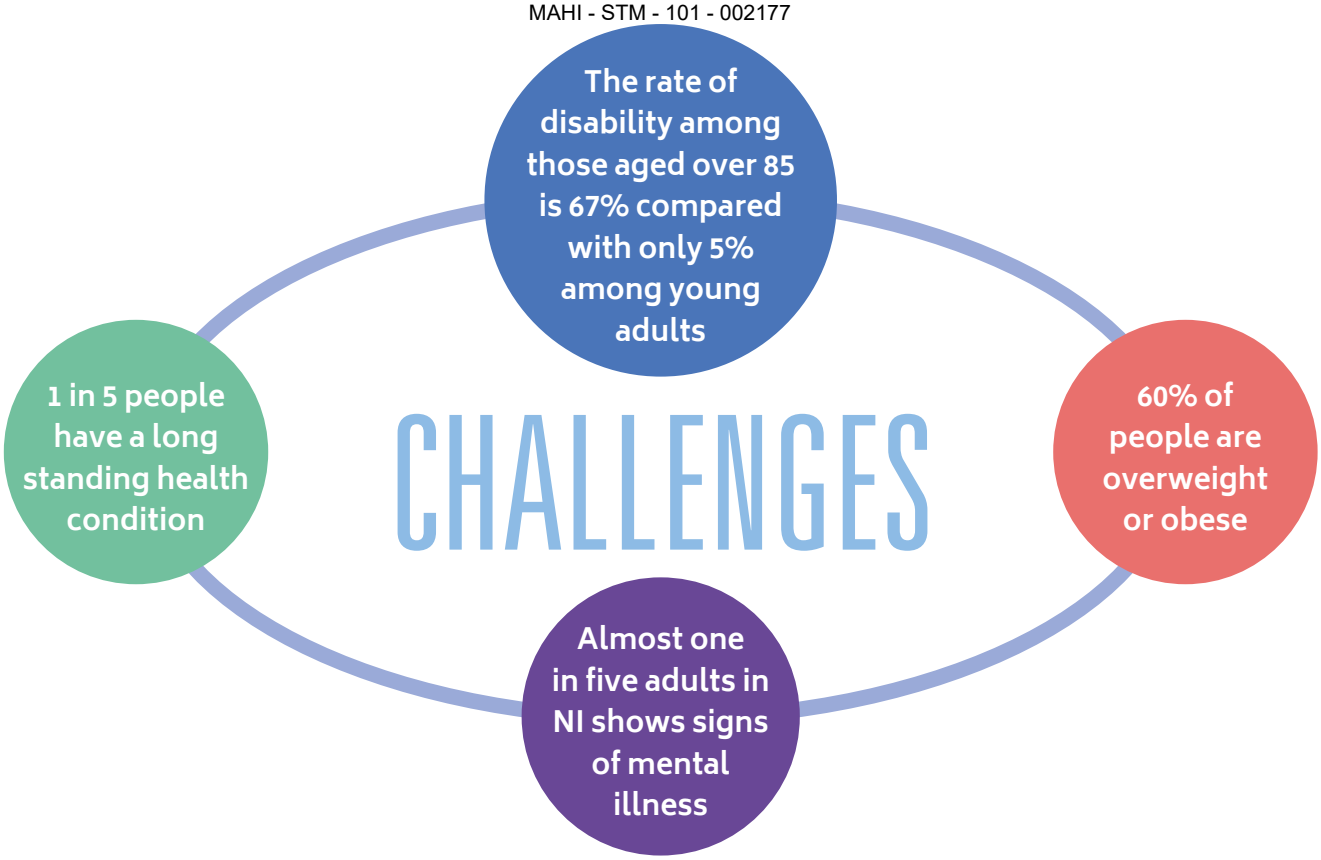
We have concluded that it is no longer sustainable to merely tinker at the edges of a broken system

It was suggested in one meeting with stakeholders that change might be forced on the care sector in Northern Ireland by the system "imploding". Arguably policy tensions have now reached a level where something will have to give. To repeat a phrase which has arisen many times during our discussions: "we need action, not another review and another report!"

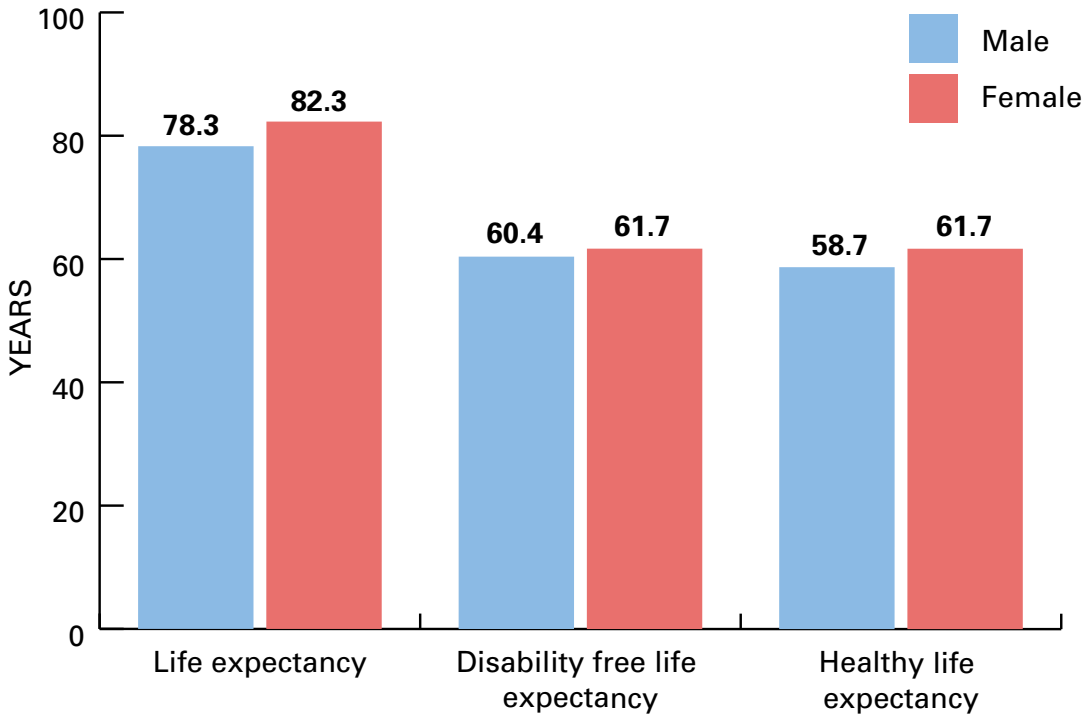
Demographics and changing life expectancy – again it's about us

Many reports precede this review including the recent report by the Expert Panel chaired by Professor Rafael Bengoa, 'Systems, Not Structures: Changing Health and Social Care (2016)', which set out some of the challenges already present in the current population:

1. Postscript to 'Understanding Health and Social Care', 2017, p181
2. Nuffield Trust 2016 'Social Care for Older People: Home Truths' Kings Fund
3. NAS, Mencap, Leonard Cheshire, Sense, Scope 2013 'The other care crisis: Making social care funding work for disabled adults in England'

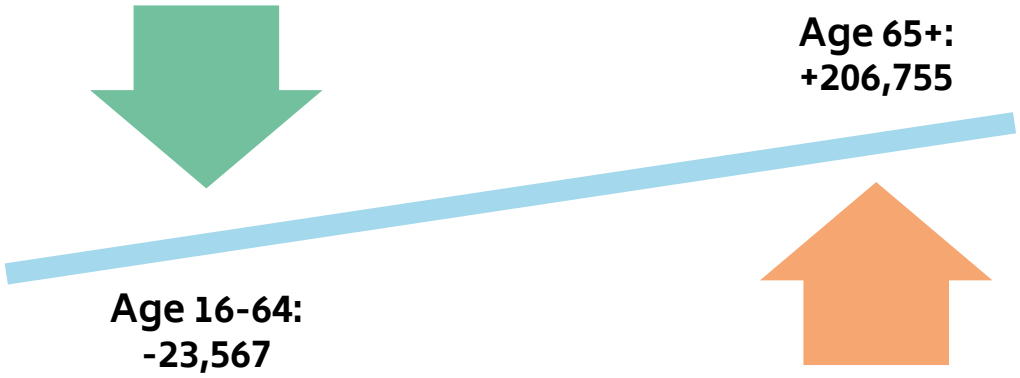


This means that many of us will face illness or disability in our lifetimes. As outlined in the diagram below, both men and women can expect to live approximately ¼ of their lives in ill-health or with a disability.[4]



4. 2016 (DoH) Health Inequalities Regional Report

The implications of this are all the starker when we consider how demographic change will impact on society: by 2039 our younger population will have decreased while our older population will have grown enormously.



NISRA (May 2016), Sub National 2014-Based Population Projections

It is important therefore to be alert to the fact this is not about 'them'. The likelihood that we will all be touched by the demand for social care for ourselves, within our families and communities is overwhelmingly clear - **it's about all of us!**

Social care is broad

The broad reach of adult social care means that it shares borders with many other disciplines that are important to personal wellbeing and quality of life. Yet too often adult social care is simply far too narrowly defined. Social care has an important relationship with health care services; this can be seen from the demands on GPs and Emergency Departments, which comes sharply into focus when people are unable to be discharged from hospital care. There are also similar overlaps with housing, education, work, leisure, transport and criminal justice services. There is a crucial element of interdependence, to these overlaps and relationships. Furthermore, social care is dynamic because circumstances change: people can improve, recover, or regain independence, just as they can experience an increased need for support. For these reasons it is vital that adult social care is acknowledged to be multifaceted, subject to and benefitting from multidisciplinary partnerships and relationships. Social care should not be seen as simply linear or one-way. Ideally social care is outcome-based - not simply about the 'processes' or the 'inputs'. An outcome-based focus to meeting needs acknowledges that wellbeing and quality of life as defined by people receiving care and support, and their carers, are paramount. Notwithstanding the fact that such aspirations are more easily said than done.

It is our view that the provision of social care has a crucial bearing on the sort of society we really want to be. **Social care should be recognised as a vital and positive part of the infrastructure of society and the economy.**

During the review discussions we have been urged to be radical in the approach to formulating proposals. Our sense is that this is a reaction to the overwhelming view that the current system of adult care and support is considered unfit for purpose and unsustainable in the longer term. A strong theme emerged from the Call for Evidence, and the discussions

we have had, that the inadequacies of the present system have either been ignored or periodically tinkered with but to little lasting effect. However, we see little benefit in re-analysing what may be seen as past failures of the care and support system. We are equally mindful that producing another report on adult social care will be of limited value unless it can be a genuine catalyst for transformational change. **It is our hope that the proposals will be used to stimulate a serious public debate about the future of adult care and support in Northern Ireland.**

If we have been in any way ambiguous we will have failed in this task. If our proposals are considered too subtle, we will have missed an important, timely opportunity to offer the radical options we believe are necessary to build a sustainable social care system for the future.

This Proposals Paper seeks to keep the individual as the central focus of attention. It starts therefore with the person and subsequent sections build on this fundamental principle in ways that refocus attention on their assets rather than their needs, rights rather than risks, and outcomes rather than processes.

Re-valuing social care

The question of the value placed on adult care and support by the public and, as a consequence, the status ascribed to the tasks and activities of social care has arisen many times during the course of this review. Public perceptions of social care differ significantly from that of health care. In part this may be because fewer people have direct experience of adult care and support services. As the impact of changing demographic trends is felt we might expect that this will change. More people might actually experience care and support services or at least become aware of the need for such services.

Being clear about the purpose of adult care and support as strongly rooted in improving wellbeing and quality of life for individuals is vital to challenging the views that people may have of care and support services. So too improving understanding of the need for a more individualised approach to meeting care and support needs. Quality of life is linked to personal relationships and networks of support as well as opportunities for development to enable people to fulfil their potential. The way in which care and support services are structured and delivered has an important part to play in promoting the value of person-centred, local models. Notwithstanding the need for greater responsiveness, flexibility and integration of services with more openness and transparency in the way they operate, care and support services are a lifeline for many people and their families.

It is plainly wrong to view social care only as a cost. The way in which social care services are integral to many other aspects of people's lives highlights the ways in which it contributes to society and the economy. Support services can enable people to be independent in so many different ways:

- to continue working, both in a paid capacity or as a volunteer;
- to provide informal care;
- to undertake education; and
- to help to keep people out of institutions and live in their own homes.

Harnessing the consensus for change

Throughout the discussions that have informed this review the Expert Advisory Panel have been struck by the overwhelming appetite for change. This experience mirrors the findings of the Bengoa Report 'Systems, not Structures' (2016). A strong sense has emerged of a social care system that no longer functions either effectively or efficiently. Care and support services have become reactive rather than proactive, and selectively reactive as well. This is the consequence of a variety of factors and forces.

In addition, there have been few incentives for the system to operate differently with too many obstacles to changing the status quo within social care or across the wider health and care systems. Thus, it is our conclusion that incremental adjustments at the margins are unlikely to have the necessary impact to make a meaningful difference, and that without radical transformation it will be all too easy for things to fall back into the familiar shape they have become.

> "We need to understand the wider role of social care, including its links with Councils, housing providers, voluntary sector, private sector and business."
>
> WORKSHOP COMMENT

We have been greatly encouraged by the consensus of opinion that to continue with a social care system that does the same things in the same ways is as nonsensical as it is unsustainable. Given we have met such a high degree of readiness for change **it is not unreasonable to ask why change hasn't already happened.** There is certainly plenty of analysis and opinion about what has led to the current situation and why the adult social care system is not working as well as it should. And yet for all the analysis there appears to be a paucity of data for some important aspects of adult social care which gets in the way of complete understanding. We have found that up-to-date information is patchy at best. In addition, the broadness of the interests together with the fact that the power for change is spread thinly across the system might explain how the system has so far resisted change.

Rising demand and rising expectations create additional pressures. Coming on top of a period of austerity in the public sector, it is not surprising that the strains on the adult care and support system are beginning to show. But the need for change is also about the transfer of power from professionals to citizens. We know this is hard for so many reasons. It is the view of the Expert Advisory Panel that this requires considerable leadership - political, professional and personal - assisted by a willingness to both encourage and facilitate new models and new ways of working. Again, **this is easy to say but difficult to do.**

The 'systems, not structures' line used as a title for the Bengoa report graphically illustrates the challenge of ensuring that the provision of health and care is properly organised and

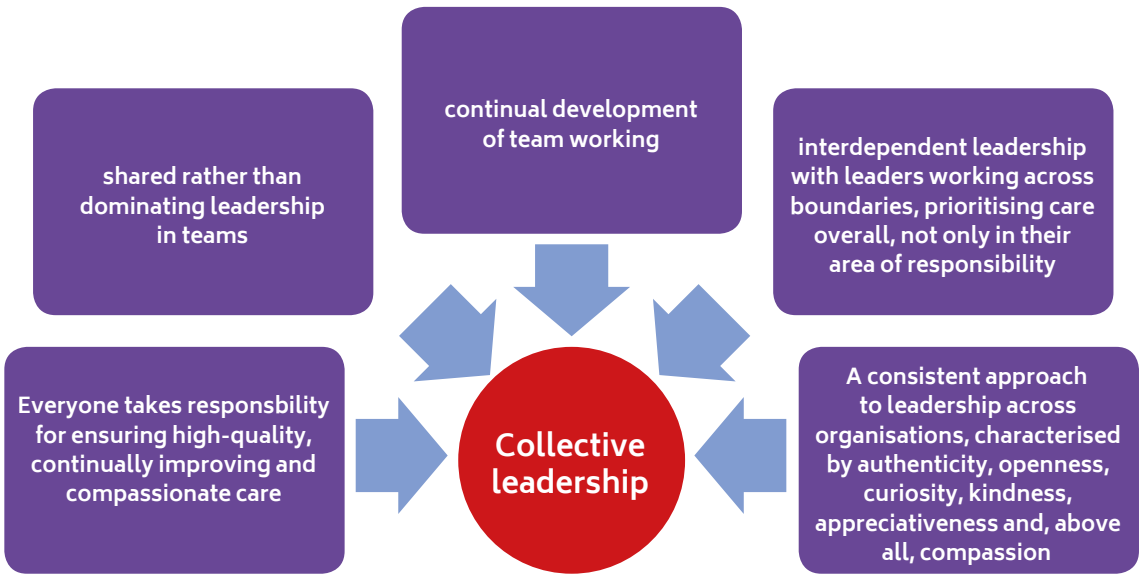
working effectively. It is clear that this applies equally well to describing the current shortfalls of adult care and support. There is also a recognition for that for many people more money, in itself, is not the answer.

The demographic and demand pressures facing Northern Ireland mean that resources, without reform, will merely delay the inevitable collapse of the social care system. Whole-systems change to transform and reconfigure health and social care was similarly a major theme argued by Professor Bengoa. The evidence provided to us and the discussion we have had with organisations and individuals has further highlighted this "unassailable case for reform".

Despite the apparently integrated structure of health and social care that exists in Northern Ireland, it is our view there is still insufficient joined-up working, and we consider this further in our section on systems alignment. **Unintentional barriers somehow seem to perpetuate the status quo of a silo mentality.** There is a need for far greater honesty and transparency with the public as well as between commissioners and providers. We consider this issue in more detail when we turn to the matter of shaping the market for adult care and support and the shared responsibilities of commissioning and providing services in section 7.

The leadership imperative

There is a political priority for the value of adult social care and its contribution to society to be clearly articulated and properly acknowledged. Building on the apparent consensus for change by setting out the vision, purpose and potential of adult care and support would be greatly beneficial. In part, this is about changing the perceptions about care and support. The contribution that social care services make to wellbeing for individuals, families and communities, and society in general, is so often taken for granted.



Leadership is about vision. But it is also about listening and involving and having the courage to take difficult decisions in making choices. Leadership in adult care and support needs to be set within a values framework, as social care leadership has many levels. And leadership in this context has to be about more than simply sharing power and control with people receiving services and carers – **fundamentally it's about the transfer of power.**

We see leadership and the specialist role of social work as a crucial linchpin to reframing adult care and support as professional activity. There is a leadership (as distinct from management) responsibility to set out clearly the steps necessary to create, implement and sustain change in the way that care and support services are shaped and operated. This is also about leadership at many levels, including at the frontline of adult care and support, as well as amongst carers and communities. The King's Fund identifies this as 'collective leadership': leadership of all, by all, for all.[5] The key elements of collective leadership are outlined in this diagram.

It will be the exercise of leadership to turn the lessons of the past into a vision for the future. To work collaboratively to break down the barriers that work so effectively to resist changes to the status quo. This will mean challenging, and dismantling, some firmly established interests.

We agree with the view put forward by Professor Bengoa's Panel that successful transformational change depends on:

- a balanced approach between a top/down and bottom/up approach;
- people not strategies, and relationships not systems;
- change being seen and accepted as everyone's business.

In 'Systems, Not Structures' Professor Bengoa argues that the process begins with developing a vision and creating the conditions for local improvement to facilitate change. This is a view which received widespread support at our workshop on workforce issues. At the same event there was also a strong bid to recognise that leadership is present, and required, at many different levels, including political and professional, alongside service user and carers.

> "We need radical leaders willing to take risks and push through real reform."
>
> WORKSHOP COMMENT

5. King's Fund - Caring to change: How compassionate leadership can stimulate innovation in health care

There is a considerable literature on professional leadership in social care to build preventative, person-centred and personalised approaches to meeting future demand, which we do not need to cover here. For example, the joint work of the Association of Directors of Adult Social Services (ADASS), Think Local, Act Personal (TLAP), the Local Government Association, Skills for Care and South Central Strategic Health Authority in England, to develop a programme of 'Leadership for Empowered and Healthy Communities'. Such literature consistently highlights the importance of values, professional capabilities and communication skills. The Expert Advisory Panel would like to see such attributes broadened in the 'community leadership' role of social workers to harness the energy and creativity of local communities, and we explore this along with the role of social work in the section on the workforce.

The Expert Advisory Panel therefore welcomes the commitment in 'Delivering Together' to develop a health and social care-wide leadership strategy. However, it is essential that alongside this the importance of leadership outside the formal health and social care system – service users, carers, communities, politicians – is fully recognised.

Steps to implementation

Implementing change will require a coordinated approach that mirrors the endeavour to keep the individual citizen at the centre of any system of support. Successful change will require partnership working which involves people receiving care and support services, their carers and communities along with professionals in the care system – both as commissioners and providers of services.

It is the view of the Expert Advisory Panel that the readiness for change seen in the submission of evidence and highlighted throughout discussions offers a hugely positive platform from which to formulate a strategy to implement transformational change. The significant benefit this could bring should not be underestimated.

Whilst progress towards new ways of arranging and delivering services rarely move in a linear fashion with a clear beginning and end, it can be greatly assisted by a recognition of the need for change and a shared understanding of the intended outcome. We are also struck by the potential benefit of making the most of the fact that Northern Ireland is of a size to bring about change to services across adult social care in ways that stimulate new models and new ways of working. **The promise of a 'revitalised' system that turns the current challenges into opportunities by making more of joining-up user-led community and formal services to act as an exemplar for positive action.**

Proposal One

The Expert Advisory Panel proposes that consensus on the need for, and direction of, transformational change is achieved and that the leadership responsibilities for the adult care and support system are made more explicit.

It is proposed that a cross-government initiative, led by the Department of Health, is undertaken to raise awareness of the purpose and value of adult care and support. The Panel also proposes that the Health and Social Care (HSC) Trusts, together with other key bodies in Northern Ireland, take a specific lead in promoting the positive contribution of adult care and support.

This initiative will need to involve all the key stakeholders. It will also benefit from specific discussion with the media to inform and shape the next stage of the consultation process.

> We need to change hearts and minds of professionals so they start to trust service users and carers.

WORKSHOP COMMENT

3 THE CITIZEN AT THE HEART

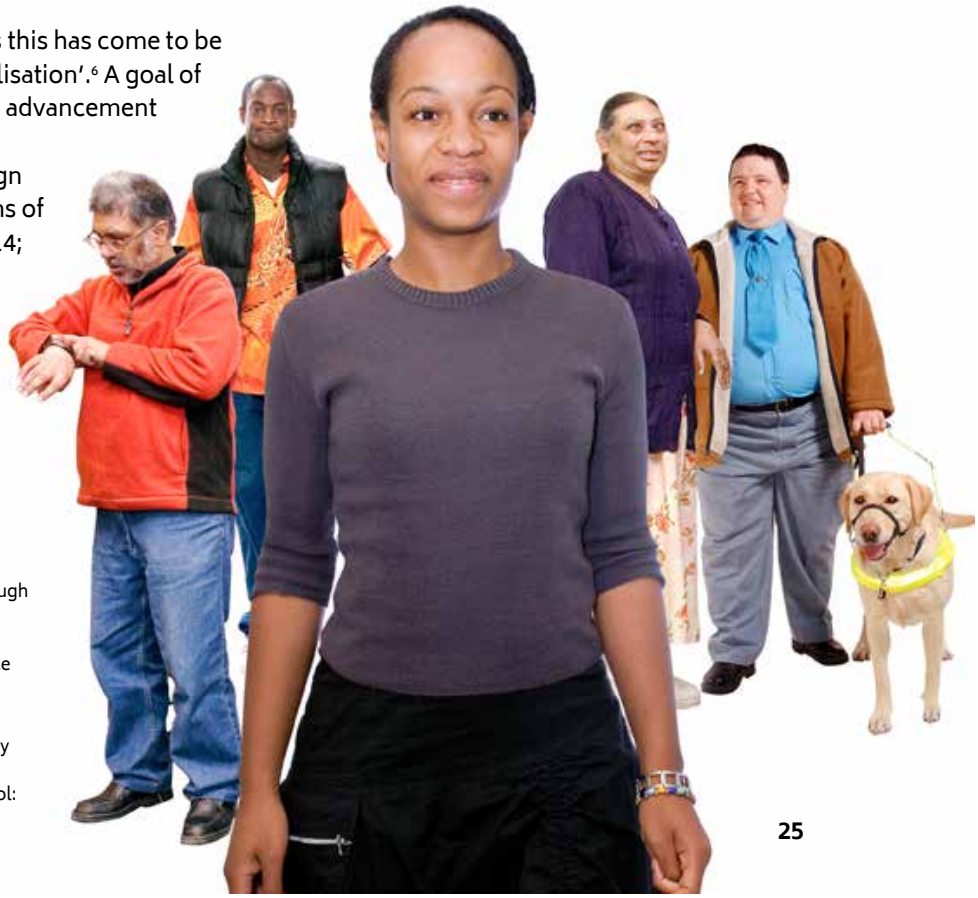
This section gives prominence to the primary tenet that the best starting point for determining a fair and equitable system of adult care and support is the individual citizen. It was identified as a major priority area in our Call for Evidence and we explore ways in which systems of self-directed support could become the norm in organising adult care and support services.

Truly person-centred – from rhetoric to reality

A renewed focus on the individual citizen is central to the concerns of this review.

A person-centred vision for adult care and support services, in whatever form they take, wherever they are offered, and whoever delivers them, is intended as a defining feature of this Proposals Paper. The Expert Advisory Panel wishes to emphasise at the outset the fundamental importance of a human rights approach in which people with care and support needs enjoy the same entitlements to quality of life and wellbeing as all other citizens.

In social care circles this has come to be defined as 'personalisation'.[6] A goal of which has been 'the advancement of citizenship' and attempts to "redesign professional systems of control"[7] (Duffy, 2014; see also Shaping Our Lives and Think Local Act Personal – the TLAP partnership).



6 Carr, S. (2010) Personalisation: A Rough Guide (revised edn), London: Social Care Institute for Excellence

7 Duffy, S. (2014) 'After Personalisation' in C. Needham and J. Glasby (eds) Debates in personalisation, Bristol: Policy Press

Social care (and health) services have responded to a growing 'consumerism' in public services, alongside rising expectations, with efforts to recognise the place and value of user-involvement. But progress is patchy at best and the extent to which such involvement has yet created real and sustainable change remains an open question. Arguably the voices of people receiving care and support (as well as carers) are getting louder but whether these voices are truly being heard, let alone acted upon, is still a moot point.

The Expert Advisory Panel has been impressed by the level of work that has been done to ensure that efforts to reform the system of adult care and support are, as much as possible, 'co-produced' with people who receive services and their carers. The formation of the Adult Care and Support Reference Group, facilitated by the Patient Client Council, and efforts to ensure that their concerns and views have properly informed the work of the review has been greatly valued. We know that the recommendations of the report from Professor Bengoa were shaped by consultation with patient and user groups and, we believe, it is every bit as important to the formulation of our proposals.

In the Call for Evidence three priority areas are relevant to the theme of the Citizen at the Heart of Services:

- in Priority Area Two: **'Supporting people to regain, retain and maintain their independence'**, the preference for a system valuing prevention and early intervention was noted. Growing evidence[8] shows that intervening early can significantly reduce the need for acute services at a later stage. Social care has an important part to play in rebalancing services. However, not all care and support needs can be prevented and therefore services are required which provide appropriate support and help restore capacity and independence. Forms of intermediate care such as rehabilitation and re-ablement are vital and can be invaluable when offered at the right time for the individual.
- in Priority Area Three: **'Supporting carers'**, attention was drawn to family changes alongside concerns that limited information and support is currently available for carers, which we will consider in the following section.
- in Priority Area Four: **'Choice and control'**, the changing expectations that people have of social care services were highlighted. People are understandably unwilling to accept the offer of a limited range of established services to meet a broad range of identified needs. An outcomes focus, as defined by the individual and those close to them, is of fundamental importance. Forms of self directed support, including Direct Payments and Personal Budgets designed to unlock new services and different ways of working with better outcomes, are therefore seen as having considerable potential.

What people say they want

"A life not a care package" was a comment made at one of the workshops and it chimes with statements that seek to give meaning to wellbeing and quality of life for people receiving care and support. **Promoting independence to maximise choice and control is easy to write into a mission statement but can be more challenging in the delivery of a social care service.**

8. (2010) PSSRU - The National Evaluation of Partnerships for Older People Projects
9. Think Local Act Personal (2012) - 'Making it Real: Marking progress towards personalised, community based support'

Considerable work has been done to champion user-led initiatives to harness the transformation potential of 'personalisation' as the key to modernisation of adult social care. In England, the 'Making it Real' framework[9] (published in 2012) developed by the Think Local Act Personal (TLAP) partnership, which includes a powerful National Co-production Advisory Group, sets out clear statements along with markers of progress. It is not a performance management tool but a way of measuring progress towards personalisation.

The framework is divided into six themes:

- Information and advice – having the information I need, when I need it;
- Active and supportive communities – keeping friends, family and place;
- Flexible and integrated support – my support, my own way;
- Workforce – my support staff;
- Risk enablement – feeling in control and safe;
- Personal Budgets and self-funding – my money.

Each of these themes is supported by accessible, practical, aspirational statements – the 'I statements'. The statements describe what people might say if personalisation was working well for them. In essence, such an approach is about enabling people to live an ordinary life and one which is not defined simply by personal care needs or the way that services are organised and delivered. The unique aspect of 'Making it Real' is the fact that provider and commissioning organisations are encouraged to publicly share the progress being made towards personalised, community-based support. Furthermore, National Voices, a coalition of charities that promote people being in control of their health and social care, have adopted the 'I Statement' approach[10] as the means to set out explicitly the patient benefits that integrated care is meant to achieve.

The HSC Trusts are in the process of rolling out Self Directed Support in Northern Ireland but progress has been acknowledged to have been slow. While there was support for the concept, a number of concerns about Self Directed Support were raised with us in our Call for Evidence and through meetings and the workshops. These include the level of personal budget, limited brokerage support and perceived administrative burden. If these concerns can be addressed, we believe that models of self directed support can play a key role in ensuring that the focus of support is indeed on "a life not a care package".

Shifting emphasis away from professionals – transferring power

On many occasions in the course of this review we have sought to ensure meaningful involvement of users and carers as well as frontline care staff in the review process. This has been echoed in discussions, visits and the workshop sessions. The Expert Advisory Panel strongly support the sentiment expressed in the phrase: "nothing about us without us" (used in the 2001 White Paper 'Valuing People'[11]).

10. National Voices (2013) A narrative for person-centred coordinated care, Leeds: NHSE
11. DH (2001) Valuing people: A new strategy for learning disability for the 21st century, London: TSO

In our meetings with the Adult Care and Support Reference Group we have sought to hold good to the principle that **successful reform of the system of adult care and support requires a genuine transfer of power** – as well as resources - and must not be undertaken as a 'top down' exercise. It will be better for being co-produced and will ensure appropriate buy-in, ownership and support. Partnerships at a local level can, and do, happen naturally. However, there is also a leadership responsibility for the HSC Trusts to facilitate local partnerships and partnership working. The earlier that users, carers and service providers are involved in such developments the better.

Personalisation, together with an emphasis on preventative services, brings a need for different service offers and, in turn, different relationships between those receiving the service, commissioners and those providing them. **This will only be possible if these relationships are truly collaborative.** Personalisation in the provision of social care should therefore be seen as fundamentally altering the way in which engagement is undertaken. Commissioners and providers working in partnership with citizens (as users and carers) is vital to drive change and innovation - neither party can effectively bring this about on their own.

For the avoidance of any doubt, we firmly support initiatives that make it possible to shift the emphasis from professionals to people receiving services, and away from acute or institutionalised services, although we are mindful that this will need to be negotiated and that some people may have additional safeguarding needs which will have to be addressed for this to be possible. In addition, decisions about services to provide support should be made as close as possible to the individual receiving care and support and offered and operated in flexible ways. Furthermore, the desirability of an outcome-based approach to the provision of social care is a fundamental principle we want to make explicit.

It is our view that the term 'outcome-based' in the social care context has become familiar before there is a proper understanding of what it actually means. The outcome to 'enhance quality of life', as outlined in the Adult Social Care Outcomes Toolkit (ASCOT) for example, is informed by domains including control, dignity, personal care, food and nutrition, safety, occupation, social participation and accommodation.[12] We are fortunate to have seen projects seeking to make a reality of outcome-based ways of working and putting this principle into practice in ways that show sufficient promise to be worthy of further investment, testing and evaluation. Services such as The Cedar Foundation's 'Inclusion Matters' and 'Inclusion Works' are good examples of a sustainable approach to social care that enables person-centred planning and promotes choice and independence.

12. "Details of the development of the Adult Social Care Outcomes Toolkit and methodology can be found on the Personal Social Services Research Unit website www.pssru.co.uk"

13. "Glasby, J and Littlechild, R (2016) Direct Payments and Personal Budgets: Putting personalisation into practice' (3rd edn) Bristol: Policy Press; see also SCIE Report 36: 'Enabling risk, ensuring safety: self-directed support and personal budgets' (2010); and the Health Foundation Evidence Scan on Personal Health Budgets, (September 2010)."

INCLUSION MATTERS

Cedar's Social and Community Networking Service supports people with disabilities living in towns, cities and rural locations across the 5 HSC Trust areas. The service aims to:

- **develop and maintain effective partnerships within the local community;**
- **work with participants to develop individual action plans to increase their involvement in the local community;**
- **identify and support participants to actively engage with local social inclusion and community networking opportunities;**
- **support participants to identify and implement support systems which will enable them to overcome barriers to inclusion;**
- **motivate and empower participants to socially engage in their local community;**
- **promote peer support to heighten the social and community engagement of participants and the sustainability of activities.**

Evaluation of the service found that it is sustainable, low cost and effective, costing around £3 per hour, and it is proving to be sustainable in the long term, with service users perceiving it as producing permanent change in their lives (based on external evaluation by Alison Wightman and Inclusion NI).

Enhancing choice and control whilst balancing risks

The concept of self directed support, including direct payments and personal budgets, has become synonymous with personalisation. Developed to enable people to receive a pot of money rather than a commissioned service, they are intended also to unlock new services and different ways of working with better outcomes as defined by the individual. There is a growing literature on different forms of self directed or 'consumer-directed care'.[13] While Direct Payments and Personal Budgets have become familiar concepts across the countries of the U.K. (and elsewhere) there are many different variations of the model. Personal Budgets or direct funding models can now be found in many parts of the world including, for example, in France, The Netherlands, Sweden, New Zealand and Australia. Although evaluations of the impact based on international case studies are somewhat limited because of the difficulties of comparisons across different welfare systems and legislation, there appears to be a growing acceptance that models of self directed support have become a mainstream feature of social care practice. This approach was enshrined in the 2014 Care Act introduced in England, while the Scottish Government, with the support of key stakeholders, have put in place legislation, a national implementation plan and made significant investment to embed self-directed support as the approach to social care with The Social Care (Self directed Support) (Scotland) Act 2013.

Clearly self directed approaches can have considerable potential although, for a variety of reasons, models have been rather slow to develop and are yet to realise the ambitious aspirations that early pioneers had of them.

We make reference to the issue of risk at several points in this paper. It was suggested to us that there is a tendency of a **risk averse culture** around care and support in Northern Ireland. In the time we have had to undertake this review we were not able to determine whether this is true or whether the attitudes to risk held by different stakeholders in the system in Northern Ireland are any different to that found elsewhere within the UK. We have sought to understand the extent to which the attitudes to risk in Northern Ireland are different and whether concerns about risk are used unreasonably to deny services or as a reason against change. It is evident that they can have a disproportionately stifling effect on enabling people to get the support they want. Fear of blame, and the consequences, and a lack of trust may in this way contribute to restricting choice and control for individuals. We acknowledge that it is important to understand the extent of the challenge that developing a person-centred approach giving greater control to individuals receiving care and support can inevitably bring. Safeguards clearly need to be in place to protect people and avoid neglect. Rights need to be balanced by responsibilities to manage risk.

In response to our Call for Evidence one service user wrote:

"Society is increasingly risk averse. In terms of care this sometimes means that there is a focus by professionals on safety concerns, which can conflict with an individual's wish to live independently. This balance between safety and autonomy can be a difficult one to strike. I feel strongly that while safety issues should be given due consideration, they should not automatically assume paramount importance. A person's care should be considered in the broader context of social and psychological needs as well as physical safety, and service users should, of course, be involved in decisions about their care at all times."

We support the spirit of this comment that people may need assistance to exercise informed choices to enable them to reach their goals and outcomes in ways that do not compromise their need for safety.

There may also be a need for brokerage and advocacy to make this real for some individuals. We see an important role for social work in leading such change. In a system underpinned by a vision of person-centred and community-based intervention to support people, the primary role of adult care and support might therefore be redefined to encourage a much greater emphasis on both prevention and enablement to promote independence and enhance wellbeing.

14. World Health Organization (May 2016) Assistive technology factsheet
15. Carretero, S (2015) 'Technology-enabled services for older people living at home independently: lessons for public long-term care authorities in the EU member states'.
16. Social Research Centre and Ulster University, (2008) "Evaluation of Impact of Assistive Technology at Ardkeen and Hillmount Court Supported Living Options, Belfast"

MY LIFE PORTAL – SELF DIRECTED SUPPORT IN ABERDEEN

The SDS Team in Aberdeen has developed a simple online tool to help people source information about SDS and support services, goods and activities offered by local organisations and service providers. The My Life site allows all local providers to promote their goods, activities and services, as well as giving people easy access to the most up-to-date information on what is available in their area. This will help people make decisions on how best to spend their personal budget to meet their needs.

For more information see https://aberdeencity.mylifeportal.co.uk/home

In our view there is sufficient commitment to self directed support as an approach, and evidence of its effectiveness, to justify further development to put the person receiving care and support firmly in control and proliferate an expansion of the model across social care services. There is scope to further develop models of self directed support to establish new models of supporting people and new ways of working. We propose that mechanisms to stimulate such models are further developed and facilitated.

The place of technology in care and support

A wide range of factors can contribute to supporting people and enabling their independence to be protected. Housing and transport are perhaps the most obvious examples. **Technology similarly has huge potential.** So much so that it is commonplace for reports to reference the vital contribution of various forms of assistive technology, including telecare and telehealth, designed to enhance independence. Whilst the use of technology has become familiar in so many aspects of our lives, it has been somewhat slow to develop in the provision of adult social care. Work by the World Health Organisation on assistive technology[14] highlights the benefits of forms of assistive technology and the problems associated with the lack of policy coordination or integration in many countries. A paper by Dr S Carretero[15] includes analysis of good practice in technology-enabled services across different countries to draw out lessons and recommendations for long term care.

There has been sporadic use of new technologies in adult social care in Northern Ireland. For example, we witnessed its successful use in Meadowvale supported living settings for people with brain injuries, but such an example is far from being the norm in social care practice. Evaluations of this type of technology underline the huge potential benefits it can bring to people, vastly improving their independence and consequently their quality of life.[16] But technology doesn't always have to be so complex, or expensive, as the systems used in bespoke supported living units. We have heard of a number of examples of simple, cost effective solutions making a big difference to individuals – whether that is by helping them to connect socially to others, or allowing them to be monitored in their own home rather than in a hospital bed. Often, the challenge is making these technologies more widely available, and encouraging service users and care providers to use them. Sometimes fear or accessibility can be an issue, so there is a need to both promote the benefits of using technology, and invest in information, advice and infrastructure to make adopting new technological solutions possible.

Making self directed support the norm

In this section we have placed paramount emphasis on the individual citizen at the heart of any system of adult care and support. We see this as absolutely vital to a person-centred/ relationship-centred (and community-oriented) vision of future service options. It is the view of the Expert Advisory Panel that there is sufficient evidence of the value of self directed approaches and improved outcomes to justify investing in their development and expansion. We would like to see prominence given to self directed models in order to ensure they become the initial means by which all adult care and support services are determined and provided. **We want to see individuals given greater consumer sovereignty as a means of changing commissioning for adult care and support services.**

In the sections that follow we build on this notion of the individual citizen at the heart of services to better understand needs in the context of available family support, community resources, as well as the personal commissioning of more formal social care services, such as domiciliary care and care home provision or primary health care. The foundation to the whole-system approach we are describing is the human rights we all enjoy and which should be experienced as a continuum of seamless support services.

Proposal Two

The Expert Advisory Panel proposes that models of self directed support become the norm in order to empower citizens with effective demand. Further priority should be given to how Self Directed Support funds could be used as catalysts to create and shape a diverse market of care and support provision, and we propose that mechanisms to stimulate such models are facilitated as a matter of priority.

> The social care model of the future needs to be based on promoting independence, empowering choice and enabling integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities open to everyone else.

ASSOCIATION FOR REAL CHANGE

> “A public awareness campaign looking at what caring is and the spectrum of carers there are is vitally important.”

CARERS COALITION

4 FAMILY CARERS - VITAL PARTNERS FOR SOCIAL CARE

This section acknowledges the significant contribution made by family, friends and other informal carers to the health, wellbeing and human rights of adults with support needs as well as to the adult care and support system as a whole. Currently, they may be seen as the bedrock of care as their contribution is the primary way that most people experience care and support.

Partners in adult social care

There are nearly 214,000 informal carers in Northern Ireland. This means that almost 12% of the Northern Ireland population carries out some informal caring.[17]

Carers NI estimate that informal carers (aged over 16) are providing at least 2.4million hours of unpaid care every week, and suggest that, if that care was provided by a home help on the minimum wage, it could cost the government more than £16million a week in wages alone.[18]

40% of carers provide more than 20 hours of care per week. More than a quarter provide over 50 hours.

(Source: Census 2011)



17. Census 2011
18. Carers NI submission to Call for Evidence, referencing "Who Cares for Carers (2016) Detail Data"

The report, 'The Human Rights of Carers in Northern Ireland[19] (2014) by the Northern Ireland Human Rights Commission states:

"Caring can be rewarding and fulfilling as well as demanding. What is important is the need for recognition of the role being played and that support that should be available and easy to access. Too often, obtaining support can simply be a further additional struggle to overcome.

Carers are not a homogenous group. Carers can be all ages from children to the very elderly who are looking after family members. Each carer is an individual who has his or her own story to tell and particular needs." (p1)

During the course of our evidence gathering, the Expert Advisory Panel heard from carers groups and individuals and it is impossible not to be humbled by the scale and generosity of their love and commitment. Not just to their own nearest and dearest but often as support to others also in caring roles. We have heard how hard and lonely the caring role can be. Although every caring situation is different, because families and neighbourhoods are different, we heard similar concerns from carers in many varying situations. **They often feel out of sight, undervalued and neglected.**

For many, although they may want to care, it can have a significant impact on their own lives. At one of our workshops a carer commented: "for some caring is a lifelong commitment". It can have a bearing on their ability to remain working or can lead to feelings of loneliness and isolation which can result in a detrimental effect on their own physical and mental health and their wellbeing. We also heard that in some instances carers feel taken for granted, they feel that it's just assumed that they will just carry on with it. It is clear that too often family carers do not feel that they are treated as partners in care and part of a team of support for an individual.

In our view we need to find a way of supporting, understanding and valuing the carers role more explicitly and honestly. **Considering the immense contribution carers make, we neglect or exploit them at our peril.** Despite the inevitable challenges that providing care and support can bring, we have been surprised at the reasonableness of the requests made by carers. Access to the right information at the right time is a key wish, as is the availability of appropriate short term breaks so that carers can have regular respite from the role. The main request though is to be acknowledged and recognised and truly seen as a real part of the adult care and support system.

Many carers undoubtedly offer care willingly because of love, affection or a sense of duty to the person needing support. However, there is a great deal of evidence that even when this is the case, the inadequacies of care available to the person with care needs combined with a lack of support and attention to the rights and needs of carers, often results in a situation that is detrimental to the carer in a number of ways. The research and information briefing paper to the Northern Ireland Assembly in 2016, Carers: Legislation, Policy and Practice[20], draws attention to the negative impact on carers' physical and mental health; the detriment to their social integration and inclusion; the financial difficulties and loss of income many experience; difficulties in relation to work, career and education. The paper also points out that during the past two decades, across the whole of the UK, legislation has been introduced which addresses carers' rights. It is argued, however, that such legislation in

Northern Ireland has lagged behind that in the rest of the UK to the detriment of the rights and opportunities of carers.

The Human Rights Commission report referenced earlier makes a total of 15 strongly worded recommendations, including that raising awareness amongst carers of the availability of support should be a priority and takes a rights-based approach to ensuring policies and practices value the contribution of carers. Sadly, the evidence to our review suggests that little real progress has yet been made in achieving the ambitious aims of the Commission's report. It is therefore the view of the Expert Advisory Panel that new legal provisions are needed to ensure that carers in Northern Ireland at least have the rights accorded to carers in England by the Care Act 2014.[21]

The recommendations made in the report remain valid in our view, and are still required, as carers are the bedrock of our adult care and support system. **We must look at ways to strengthen their rights and to better support them.** There can be little doubt that family, or informal carers, already contribute the largest share to supporting people and this takes no account of the very many people who remain unknown to the system and who probably wouldn't actually define themselves as 'carers' or to having any specific support needs. Most care and support takes place in private. It's a personal thing and for many carers the term 'care' probably does not adequately describe what they do. Their contribution to personal wellbeing, quality of life and health is absolutely vital therefore and deserves to be fully acknowledged as an essential part of the adult care and support system and, when necessary, appropriately supported by services. They provide care and support to as wide a range of adults and children with different needs as might be defined by the term 'adult social care' - often 24 hours a day and 7 days a week. **If the regular care and support they provide was withdrawn there can be little doubt that the system of adult social care would collapse.**

Indeed Carers NI estimate that carers save the government some £4.6 bn every year.[22] This reflects similar findings by Carers UK[23] which demonstrates the substantial contribution made by family carers.

Bringing a legal status to carer rights

The logic of this approach is to make explicit the rights of carers alongside rights for people receiving care and support. It is the view of the Expert Advisory Panel that the protections that form a part of the Care Act introduced in England should apply in Northern Ireland. We were concerned to be informed that there is currently no specific, binding requirement for the HSC Trusts to provide support to family carers.

19. Northern Ireland Human Rights Commission (2014) The Human Rights of Carers in Northern Ireland
20. Carers: Legislation, policy and practice (2016)
21. Care Act 2014 - http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted
22. Valuing Carers 2015 – the rising value of carers' support [2015] University of Sheffield, University of Leeds and CIRCLE,
23. Carers UK Valuing Carers 2015 – the rising value of carers support

Appreciation, education and information

It is not in any way unusual for carers to lack essential information about matters that can have a significant impact on their lives. Although there is now a body of evidence to inform the emergence of carers as a policy priority and a series of initiatives designed to develop more and better support, the gains have been slow, piecemeal and hard-won.[24] As recently as 2016, Carers UK[25] was highlighting the fact that 1 in 5 (22%) of carers say they received "little or no helpful information or advice and felt they did not know where to go for support with caring." As the majority of social care and support is provided by informal carers, ignoring them or taking them for granted, may have serious consequences both for them and the people they support. Such a lack of appreciation of the contribution of carers denies the impact that it can have on their own lives: physical and mental health, the loss of social contact, being unable to work, lost opportunities for promotion or income, a finding starkly emphasised in Carers UK's report State of caring 2016.

Enabling carers to continue to offer support is essential to the future sustainability of the adult social care system. The Expert Advisory Panel supports the need for carer-friendly initiatives as articulated by Carers UK[26].

It is an obvious point to make that carers need to be able to have a life beyond their caring role. They may need the help of their communities and the HSC Trusts to make this possible. Through information, and education, the boundaries between social care, public health and healthcare need to be softened. All parts of the adult care and support system need to work together to establish clear and coherent 'care pathways'. Professional assessment of need should be about mapping assets rather than simply rationing access to resources. A single point of access for services was raised by carers in our discussions. The stress felt by family carers, including the understandable concerns on the part of ageing parents of adults with disabilities, remains a key theme. It is important to have awareness of the implications for those ageing without family to support them if required. This is a particular concern in Northern Ireland where there is a higher proportion of older people with a learning disability living in the family home being cared for by an ageing family carer than elsewhere in the UK and Ireland.[27]

The Expert Advisory Panel are mindful that issues of safety and risk may be as pressing for carers as for professionals in the adult social care system. Clearly it will be necessary to fully involve carers in discussions about risk and safeguards. A focus on person-centred ways of promoting independence and the transfer of power from professionals needs to take account of the unique role of family carers.

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24. See for example Clements, L (2015) Carers and their rights – the law relating to carers 4th edn, London: Carers UK and Carers UK (2016) State of Caring 2016
25. Carers UK (2016) State of Caring 2016
26. Carers UK and partners (2016) Building carer friendly communities: Research report for carers week 2016 London: Carers UK
27. Providing support to people with a learning disability transitioning into older age. NI Assembly

> it is imperative that policy makers and commissioners in social care recognise that accessible, person-centred short breaks are in very short supply in NI.

POSITIVE FUTURES

Proposal Three

The Expert Advisory Panel proposes that the rights of family carers are put on a legal footing and that a strategy to bring them into the heart of transformation of adult care and support is adopted.

“We challenge government to invest in communities to develop innovative projects.”

MID AND EAST ANTRIM
AGEWELL PARTNERSHIP

5 BUILDING RESILIENT COMMUNITIES

In this section we consider the importance of community for adult care and support arrangements and the networks surrounding individuals. Models of best practice in developing resilient communities clearly need to be further scaled and spread.

Care and support in a changing society

The scope of our review is to consider how the system of adult care and support can be transformed in Northern Ireland to meet the needs of society in the 21st Century. So often when we think of adult care and support we focus on professional care and support services such as domiciliary care, care homes, supported living, day centres and perhaps some primary health care services. Is this really where we should start? The fact is, the majority of us will not require any of these professional care services, at any time in our lives. Age or frailty or disability does not, of itself, result in needs which require professional care services. Only a small proportion of older people, for example, currently receive a domiciliary care package or are living in a care home. Indeed, less than 7% of our over 65 population receive domiciliary care, while less than 4% are in a residential or nursing home.[28] This does not mean however that those without current care needs will never have a need for care and support at some point in the future.



Equally, care needs are experienced differently by everyone. Some of us require care and support throughout our lives supporting us to be as connected and as independent as we can be. Such support enables us to lead fulfilling lives. Whether we

28. Calculations based on NISRA 2015 mid-year population estimates (NISRA), Statistics on Community Care for Adults in NI 2015-2016 (DoH), and Domiciliary Care for Adults in NI 2016 (DoH)

have a learning disability, physical impairment or experience mental distress we may need varying degrees of care, changing throughout our lives. But each one of us is an individual, each has particular choices and expectations, hopes and aspirations. Too often though, when support is offered it is too generic and not personal enough for us or our families – it is not sufficiently personalised to meet our particular needs or requirements.

Of course the overwhelming majority of care and support is provided informally within families and the communities where we live. It is the nature of things that we rely on interdependence in this way to live independently.

As we outlined in section 2, the future of our changing society means that many more of us will live longer lives despite ill health or disability. Conditions previously untreatable can now be managed and younger disabled people can also expect to live longer and more fulfilled lives than previous generations. These are things to be celebrated - living longer is a good thing. However, this may mean that, in the future, many more of us will be informal carers. It seems likely that carers will always be the biggest and most essential part of any adult care and support system, as they have always been. They are the 'bedrock' of the care and support system as we discussed in the previous section.

Resilient, capable communities

Notions of community cohesion, engagement and empowerment have long featured as a strand of social work and social policy. Assisting people to come together to improve the lives of everyone in the community has similarly informed many policy initiatives. Variously, efforts have been made to transfer power to communities/neighbourhoods and encourage people to play a more active part in local life or social enterprises to assume responsibility for the provision of services. Such endeavour has an important role in the development of resilient and capable communities. **After all, care and support is local.**

The Expert Advisory Panel have visited and heard of many excellent examples of neighbourhood-based networks of support during the course of this review. We have been impressed with one particular project, based in north Belfast which is Creative Local Action Responses and Engagement (CLARE). CLARE takes an asset-based approach asking: "what would you like to achieve?" and "what outcomes do you want for yourself?". They then work closely with the person to identify their assets and any existing connections. Who is important to me? What do I like doing? What makes me happy? How do I keep myself well? A feature of this approach is to have 'conversations' with people as part of a less formalised approach to assessment. This contributes to providing the means by which people can direct, and be involved with, the design of their own network of support.

The approach is one of finding out about the person and then connecting them whether that be to a voluntary group for social engagement, clinical services for health management or supporting carers and family networks. Crucially it mobilises the assets in a family and neighbourhood around the person to help them achieve what they want.

It starts with the person and their strengths (as we argued in section 2) and then makes what there is around them fit around them better. What they endeavour to resist is working in ways that make the person fit into the structures of the existing system. Crucially too, this

CLARE CIC (Creative Local Action Responses and Engagement) is a community interest company created in response to a series of community conversations, stakeholder meetings and innovative thinking from a community about how social care and health care could be designed and delivered differently. It began in Mount Vernon in north Belfast and quickly became a north Belfast wide project. CLARE accepts referrals from the Belfast HSC Trust and a small GP pilot to engage with people at an early stage of concern, in order to provide advice and address potential increased social isolation and decreasing health. They do this by the CLARE social worker meeting the service user and jointly completing an in-depth Living Plan that looks at all aspects of the person's life and seeks to help them, through the use of Community Champions and voluntary groups, to achieve desired goals.

Some of the positive outcomes achieved in the two year period of November 2014 to November 2016 include:

- **219 referrals were received across Integrated Care Teams, Allied Health Professionals, Hospitals & GP Practices;**
- **144 interventions were requested to address social isolation and 142 to promote improved physical/ mental wellbeing;**
- **196 connections were made to supporting organisations;**
- **69 Community Champions were recruited;**
- **Over 1800 Hours of meaningful volunteering were delivered.**

approach allows the person themselves to reciprocate. It's not just about what someone needs but about what they can give too. Evidence suggests that people, irrespective of their needs, appreciate being able to give as well as receive, and it's good for us.[29]

CLARE is not the only community based approach we've seen or read about, for example, Living Well (Moyle)[30], Mid and East Antrim Agewell Partnership[31] and Community Circles (England).[32] All these models have slightly different methods, but fundamentally they all strive to move away from a 'medical model', dominated by a deficit approach to age and disability and thereby move to a more people-orientated, relationship-centred way of working. This involves looking first and foremost at what someone wants and then builds a support circle around them which enhances any networks that already exist. They all focus on the little things, that 'little bit of help'.

They also greatly enhance the importance of the social - having company, having something worthwhile to do, staying in touch with friends and interests - which are as important to our health and wellbeing as keeping hospital appointments (although they can help with that too).

29. 'A Better Life: Valuing Our Later Years', JRF (2013)
30. https://vimeo.com/193514696
31. https://www.meaap.co.uk/
32. http://community-circles.co.uk

The Living Well scheme aims to improve prevention and resilience amongst older people with multiple long-term conditions by providing low-level support to day-to-day living and utilising asset-based resources to promote empowerment and wellbeing.

The process begins with a conversation between the person and the voluntary sector coordinator, who helps them to identify their goals and coordinate a management plan. Trained volunteers provide support to build social networks around the individual to help them become better connected to their community, be more physically and socially active and subsequently have better health outcomes. Practical support, navigation and coordination are provided in order to boost self-confidence and self-reliance, leading to reduced adult social care spend and primary/community health benefits.

The following outcomes are based on the first 325 older people on Cornwall's Living Well Programme:

- **27% reduction in A&E attendances;**
- **37% reduction in non-elective admissions;**
- **20% average improvement in wellbeing;**
- **20% of people supported to become a volunteer;**
- **8% reduction in social care costs.**

This approach is now being piloted in the Moyle area.

Of course being well includes being able to access appropriate medical and professional services when needed, for example: speech therapists, occupational therapists or physiotherapy. However, people's experience of the system suggests it is often too compartmented and that people can slip below the radar until crisis occurs. The community approach which gives people a 'navigator' can help to ensure that people are guided and assisted to get what they need from the care and support system.

Outcomes for these approaches look very promising. People report higher levels of engagement, connectedness and satisfaction. These projects demonstrate how communities and neighbourhoods, with the right connections, with the right catalyst, are ready and able to mobilise as a fundamental and significant part of an innovative care and support system.

Community approaches can also help address specific needs within groups in ways that can benefit everyone. Initiatives such as "age-friendly cities"[33] and "'dementia friendly communities"[34] are good examples of mobilising wider communities of interests.

Belfast was the first city in Northern Ireland to join the World Health Organisation's Global Network of Age-friendly Cities.

An age-friendly city is one in which organisations work together to make sure the quality of life for people is enhanced as they age.

Belfast is part of the Healthy Ageing Strategic Partnership (HASP), which developed an Age Friendly Plan 2014-2017.

See: http://www.belfastcity.gov.uk/community/Seniors/age-friendly-belfast.aspx

We have also seen excellent examples of community enterprises that offer work and learning opportunities for disabled people. Acceptable Enterprise in Larne, for example, is a thriving operation consisting of a packaging and internet sales centre, café and market garden. The scheme offers a social meeting hub with employment based on a fair business model. The role of employment and volunteering can also be a part of a solution for people's needs or indeed something that they engage with; just because you need support yourself doesn't mean you can't give too.

Stimulating greater connectedness

Whilst we have acknowledged the importance of family carers as the foundation of social care, they do not work in isolation. They are part of communities and neighbourhoods. Arguably we haven't always been good at connecting up. We have witnessed excellent examples of neighbourhood-based projects which have the potential to turn the adult care and support system on its head.

The current model of social care, typified by struggling on and coping until a crisis occurs, is undoubtedly a deficit-defined model. It is highly reactive. There is a growing body of evidence, for example, that loneliness and isolation are very bad for our health.[35] Older people, disabled people, people with mental health problems and carers can be at risk of becoming isolated with serious impacts on their health and wellbeing. An approach that focuses strongly on early intervention and prevention would therefore be good for us, in avoiding or postponing the need for higher levels of care, and in time would also have a positive impact on the demand for acute services.

Prevention, or a focus on wellbeing, should be the primary aim of the care and support system. Despite this, our system is currently focused almost entirely on 'Failure Demand' defined as demand caused by a failure to do something or do something right for the customer. Or in other terms the failure to support carers, provide early intervention and promote prevention simply creates more demand in the high cost part of the system. It's not just about money either, it's miserable for the people concerned. The Department of Health social work strategy[36] Improving and Safeguarding Social Wellbeing: A Strategy for Social Work in NI 2012-2022, acknowledges this approach and the significant change that is necessary to "reflect the shift in power between those who receive services and those who provide them". The strategy describes social workers as "occupying a space between the individual and society". **A professional leadership role within communities which this review fully supports.**

33. http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf
34. http://www.dementiaaction.org.uk/joint_work/dementia_friendly_communities
35. http://www.campaigntoendloneliness.org/threat-to-health/
36. Improving and Safeguarding Social Wellbeing: A Strategy for Social Work in Northern Ireland 2012-2022

The Social Work Strategy describes it in the following way:

"Using community development approaches and working alongside other agencies and organisations, social workers can help to build stronger, self-reliant communities and effective working relationships that promote people's rights, challenge inequalities and improve local supports." (p38)

It would be wonderful to see this happening in all communities throughout Northern Ireland and we believe that if it was, adult care and support services would already be transformed.

From margin to mainstream

Why do these and other such initiatives seem to stay merely as 'projects' or pilots? What prevents them from spreading and becoming mainstream? Arguably the existing system is too rigid and its structures dominate the ways in which adult social care tends to be arranged and delivered. Resources - people and money - are typically sucked into doing what we've always done which means we end up dealing with yet another crisis. There is no impetus therefore to invest in a longer term plan. **We have to work out how to make a fundamental shift away from a crisis dominated system into a long-term solution focusing on prevention and early intervention in which care and support is based initially around people and their communities.**



The Expert Advisory Panel acknowledges that there will always be a need for more formalised systems of care and support, such as domiciliary care and care homes, in order to meet the needs of some people at certain times. Nevertheless we need to define much more closely what they are for and why they are being used. With a focus on low level support arguably the 'demand failure' can be stemmed and controlled. Such an approach would see greater integration of informal care and support, community connectedness and, in turn, a more focused, purposeful domiciliary care and care home provision.

Engaging with communities to enable them to mobilise their resources to help create networks of support for individuals should be seen as an important part of a range of ways of promoting independence and valuing interdependence. It also greatly increases opportunities to intervene early. And not just in terms of health needs but also in combating loneliness and in supporting carers.

In our view there are two key drivers that need to be considered to empower communities. The first concerns ways in which self directed support could effectively be used to enable demand from individuals, suitably supported, to design and create the support arrangements that best address their needs. The second is whether a mechanism is needed to put resources back into communities to help underpin any voluntary services or community assets. We believe this merits further exploration. This could be designed around a 'rebate' arrangement funded, for example, from demonstrated reductions in hospital admissions, speedy hospital discharges, reductions in missed clinical appointments and delayed or avoided care home admissions.

Local government already makes a vital contribution to creating healthy, safe, sustainable places and thriving communities, and the new duty on local councils to make arrangements for community planning could be pivotal in supporting communities to become more resilient and responsive to their citizens' needs.

Community Planning offers huge potential to strengthen collaboration between the wide range of organisations operating in their areas and their communities to shape and deliver improved services and outcomes for the benefit of local people, for example through:

- Better use of local knowledge, skills and assets;
- Improving connections between services, and improving access and participation, for example, to support people to lead more independent, engaged and socially connected lives;
- Securing multi – partner focused, place based initiatives (for example, in relation to mental health, early intervention, Age Friendly communities);
- Developing a more joined up approach with a focus on community health and wellbeing.

COMMUNITY PLANNING

Community Planning aims to improve the connection between all the tiers of Government and wider society through partnership working to jointly deliver better outcomes for everyone. Community plans identify long-term priorities for improving the social, economic and environmental well-being of districts and the people who live there.

> "There needs to be a shift from reactive to preventative."

WORKSHOP COMMENT

Although we haven't been able to explore this concept in detail, we feel that the work being undertaken as part of 'Delivering Together' on the expansion of community development offers a tremendous opportunity to align relevant policy initiatives and build greater momentum around community resilience, co-production and capacity creation. **We would like to see the reform of adult care and support fully aligned with the community planning agenda of local councils.**

We consider in section 7 the 'market' for adult care and support services, noting that the current mechanisms have not been successful in creating or enabling a mixed economy of service provision. We reflect where the market sovereignty is and where we believe it should be. But a move to a more community-based approach to adult care and support also has a part to play. It will require a conscious bias towards promoting and developing a much broader and dynamic approach from commissioners. This may mean building into procurement procedures the means to stimulate parts of the market, such as the community and voluntary sector, that have not yet been adequately developed.

Community support will not be able to support everyone or be appropriate in all situations. Neither are we suggesting that all communities can meet every need. Some people, and some needs, will still require formal systems of intervention and professional support. However, if the keystone of a transformed adult care and support system were to be individuals empowered by their own purchasing power and supported by a navigator, then this could become the impetus for radical change.

> "Community Navigators and Information and Support Volunteers act as a bridge between existing care, community and voluntary services, to help older people access necessary information, advice, advocacy, community services and social engagement opportunities."
>
> AGE NI

Proposal Four

The Expert Advisory Panel proposes that neighbourhood based, preventative and citizen-focused community support models are encouraged and enabled. This should include the concept of a social worker-led Community Navigator role with such models available to every locality in Northern Ireland.

Proposal Five

The Expert Advisory Panel proposes that the reform of adult care and support is fully aligned with the Community Planning responsibility of local councils. This should include consideration to the development of a more diverse range of funding vehicles, such as Social Impact Bonds to create incentives and capacity in the development of resilient communities.

> We need to make social care a career of choice.

WORKSHOP COMMENT

6 THE PROFESSIONAL WORKFORCE IN SOCIAL CARE

In this section we consider the issue of 'professional care'. We argue that the current system of commissioning and providing professional care and support has led to a form of exploitation which in turn impacts on quality, recruitment and retention and the overall sustainability of the workforce. Addressing the perception of adult social care as unskilled work can only be achieved by raising the status of professional care. This means setting, and paying, a professional rate for the work they do. Making the social care sector a more attractive place to work will widen the recruitment pool ensuring a skilled, capable, consistent and more effective workforce.



Adult social care – not just a job

Approximately 28,000 people in Northern Ireland are registered social care workers, with approximately 12,000 of those working in domiciliary care. The Northern Ireland Social Care Council (NISCC) estimates that 75% of the workforce is employed by the independent sector with the remaining 25% employed by the HSC Trusts. Notwithstanding ongoing issues with recruitment and retention – in England, Skills for Care[37] have indicated that up to 10% of existing posts in the social care sector are vacant –NISCC estimates that an additional 1,400 care workers are needed every year in Northern Ireland to meet growing demand.[38]

Very many of those people who work in social care choose to do so because they want to 'make a difference' to people's lives – **it's not just a job.** Research undertaken in England, but which we believe has equal relevance for Northern Ireland,[39] surprisingly found that over 50% of the respondents

37. https://www.nmds-sc-online.org.uk
38. Northern Ireland Social Care Council submission to Call for Evidence
39. National Skills Academy (2012) Who Cares?

had been working in the care sector for more than 15 years and only 14% for less than 5 years. Although we know that recruitment and retention are major challenges for the social care sector, this finding does challenge the view that it might seem to be dominated by a transient workforce where workers move for a few pence on their hourly wage rate. In fact, there was a strong sense of social care as professional work, with good career progression opportunities. From this survey, it was clear that **staff working in social care felt 'unfairly maligned' due to low pay, public perceptions of care work and care workers and what is seen as a constant diet of bad news in the media.** It is compounded by the fact that there is no obvious sector champion speaking in support of care workers, and is at odds with the passion most care workers have for supporting people receiving care and support.

A changing workforce?

These negative perceptions are clearly having an impact. The State of the Adult Social Care Sector and Workforce in England 2016[40] report highlights a changing picture of the social care workforce. The workforce is growing in line with the increase in the population aged over 65. Almost 150,000 new starters to the sector were recorded in 2016. However, the turnover rate has increased to almost 30% on average, with domiciliary care workers typically featuring amongst the highest turnover rates. The turnover (or 'churn') is particularly skewed towards the newer entrants to the workforce so that much of the turnover is due to workers leaving within 12 to 24 months of joining the sector.[41] The core group of workers, those who've been in the sector for some time, are ageing with an average age of 43 and over a fifth aged over 55. So an experienced workforce is being slowly replaced by a more transient cohort with lots of churn. This is a bleak picture in terms of ensuring an experienced, skilled and consistent workforce, to meet our care needs in the future. It is clear that there is a significant cohort of the labour market who would, if adequately valued and respected, actively choose to work in the social care workforce, but the sector isn't able to attract them or if it does, isn't able to retain them. It seems that precisely when we need to be building our social care workforce we are making the care sector less and less attractive.

This situation is unsustainable, given the projected demand for care and the rightful growing expectations of the kindness, skill and humanity from care workers that we expect. Care work is highly skilled. Induction and basic training does not make you a skilled and effective care worker; **experience is a career-long journey.**

We expect a lot from social care workers

Some of us, but by no means all of us, will in the course of our lives need assistance to meet care and support needs. And some of this support will require professional care workers. This could be for a multitude of reasons. It may be because of disability or frailty as a consequence of illness or ageing. It may be that our family and community are no longer able to support us, to the extent that our needs demand, or indeed we may not have family close by and able, or willing, to help. Indeed, it may be that we want to move out of the family home and live a more independent life. We may need regular help in our home or indeed we may need to

40. https://www.nmds-sc-online.org.uk

41. The annual workforce survey undertaken by the National Care Forum has consistently estimated that around 40% of staff leave within 12 months and close to 60% within 24 months.

move to a care home or supported living scheme to receive the necessary care and support. We would, and should, expect that the care we receive is just as good, just as kind, and just as caring as we would expect from our own kith and kin. **We expect an awful lot from our social care workforce.**

We have spoken about the need to put more priority and resources into supporting informal carers and how we need to invest in our communities too, but it is our view that there will always be a need for professional care within any care and support system. Domiciliary care, alongside care homes, will always be part of a spectrum of provision to meet people's care and support needs. It is vital therefore that there is adequate investment in the sector to ensure that the workforce is appropriately rewarded, particularly as social care workers are critical to the transformation of care. A low paid, high turnover and undervalued workforce is a poor way to ensure the quality of care we demand.

Inevitable exploitation?

If caring for the most frail and vulnerable people in society is so important, why do we treat those who do it with such scant respect and recognition? Why do we appear to value them so little? They receive amongst the lowest wages in the labour market, typically the minimum wage. We expect them to provide some of the most exquisite and intimate care to our frailest and most vulnerable fellow citizens and yet we have a system that expects that they can get someone up, out of bed, washed and dressed in 15 minutes! They are required to be kind and empathetic, patient and sympathetic, motivated and resilient, skilled and much more besides. We expect them to be able to build relationships, and to listen and respond openly and honestly. We expect them to deal with people's pain, distress, discomfort and, in some instances, to support people with end-of-life care needs.

Care work is highly skilled. To be good at it you need a high degree of emotional intelligence, negotiating skills, and kindness in spades. Yet we surround care workers in a mire of paperwork, suspicion and when they get things wrong we pillory them. **To put it bluntly: we 'exploit' them.** It is our view that we are at risk of colluding in a disingenuous 'group think' that makes us believe that we can expect the highest of standards whilst simultaneously saying that working in social care has no more value than other minimum wage jobs. Given that the vast majority of care workers are women, and that the majority of care is given to older people, this is a deeply sexist and ageist position to have reached.

A recent report by the Office of National Statistics[42] which analyses suicide rates by occupation in England, points to worryingly high suicide rates amongst care workers. While we do not know the precise reasons for this apparent trend, the potential vulnerability of care workers in this respect needs to be seriously borne in mind.

It appears that a rather strange situation of parallel worlds has been created for social care. Social care in Northern Ireland is largely commissioned by the HSC Trusts from for-profit and voluntary sector providers. The independent sector now provides 100% of nursing home care, 83% of residential care and 62% of domiciliary care. But there is

42. Suicide by occupation, England: 2011 to 2015 (Office of National Statistics)
See also: http://www.bbc.co.uk/news/uk-39560735

still a significant proportion of care that is provided by HSC Trusts.[43] In the public sector, wages (and conditions) for care work are fairer, whilst in the private and voluntary sector, pay is often at minimum wage rates and service conditions have been eroded. Given that the majority of paid care work is now provided in the private and voluntary sector, there is clearly an imbalance. It also makes the divide between social care (largely provided by the independent sector) and health care (largely provided in the public sector) uneven in ways which can undermine career development and stability. It also hinders attempts at effective integration as the gulf in perceived value is so stark. Why has this situation arisen? Again there is some odd thinking. Under the guise of saying, 'we can reduce the cost of care by outsourcing to the independent sector because they are more efficient', we've actually created a commissioning model that forces providers to compete almost exclusively on price. Such that we get a 'race to the bottom'. By far the largest cost for any care provider is the cost of staff. The only way a provider can effectively keep the price of their services low is through pressing down on wages and staff costs. **And in our view there is collusion with this impoverishment in the way that care and support services are commissioned.**

Improving the status of care work

Obviously pay is important. Care workers need to be paid a decent wage, at the least the Living Wage, for the essential work they do. But, across the whole of the UK, only 91 care organisations are, as yet, accredited Living Wage employers. To put that in context, Northern Ireland alone has almost 1,000 registered providers of day, domiciliary, residential and nursing home care.

Crucially, the care sector should be raised above the bottom of the pay market to enhance its ability to attract the best people across a much wider pool than it currently does. The care sector shouldn't have to be in direct competition with supermarkets, pubs and such like for its workforce. It needs to be seen as of higher national strategic importance.

Pay though is not the only thing that needs to change.

The status of care work also needs to be improved. It is an essential, skilled and professional occupation and we need to ensure that the best people are attracted to working in it, developing their career and skills, and staying in the workforce. We have to improve their pay, but we also need an effective workforce plan. **The national registration of care workers in Northern Ireland gives an opportunity to raise the status of care work to that of a recognised profession.**

Registration in itself might not appear, at first sight, to be much but it is a vital connector of the workforce. Registered status can improve the professional regard for care workers, improve communications and information around training and development, which, in turn can inform an effective workforce development strategy. Professional registration could potentially form the basis from which to develop a membership base for a representative organisation for social care workers. Creating a professional body for social care workers may be an effective way of raising the status of care work. A body setting and maintaining professional standards requiring continuing development and training would give a

43. Systems, Not Structures: Changing Health and Social Care, Expert Panel Report, October 2016

professional voice in the design and evolution of a transforming care and support system. In this paper we argue for the need to refocus our social care system to start with the person, their families and communities. We've said that most of us will never need 'paid for' care but that for some of us paid for care will be needed and it needs to be delivered by valued, well-supported and skilled people.

The Economic benefit

Too often we categorise paying for care as a drain on resources, a pressure on budgets. **Should we not take a higher level view and start to consider the macroeconomic benefits of a better paid care workforce?** It's a big workforce and is likely to get bigger as we have noted already. Social care could provide good jobs and fulfilling long-term careers that are vital to society. If care workers were better paid and their conditions were fair, they would pay more in tax and receive less in benefits. They also spend their money, in the main, in their local economies on local goods and services. The majority of care workers live within a few miles of their workplace. The workforce is broadly geographically spread, or more accurately, where there are people, there will need to be care workers. Spending on care workers pay has an economic multiplier effect which is reasonably equally distributed across communities. For example, even a relatively small care home, say 40 beds, will have a significant payroll of around £750,000 p.a., much of which is spent in the local economy. Similar economic dynamics are true for a small domiciliary care provider. And, in some areas, a social care service may be the biggest employer and therefore an even more significant contributor to that area's economy.

Although raising the pay of the care workforce will increase costs, there are mitigations, in addition to the macroeconomic benefits indicated above. A sector more able to recruit, and crucially, retain its workforce, will see savings in recruitment cost, induction training and evidence from organisations that have increased their pay offer have shown a decrease in absence and agency staff costs.

A recent analysis by the Ulster University suggests that the adult social care sector:

- **Supports 41,000 jobs directly (not including Personal Assistants employed with Direct Payments) with Gross Value Added of £332m;**
- **An additional 30,657 jobs are indirectly supported (e.g. through the supply chain) with a GVA of £247m; and**
- **The sector impacts on a further 30,038 jobs through the purchase of goods and services by those directly or indirectly employed in the sector.**

Source: 'Assessing the Economic Value of the Adult Social Care Sector in NI', Ulster University Economic Policy Centre

In 2013, the Joseph Rowntree Foundation became the first care provider in the UK to pay the Living Wage. Staff turnover fell by 50% in the first year.

Source: 'Why we became a living wage employer', Rafferty, S.

RAGLAN PROJECT, MONMOUTHSHIRE

- The Raglan Project is a pilot project looking at how to deliver a high standard of relationship-based home care to people with dementia;
- Staff are given freedom to decide for themselves how the relationship and care should be managed, with decisions supported rather than controlled by management;
- Evidence suggests this approach results in better outcomes both for service users and staff who have higher morale, health, wellbeing and job satisfaction.

WELLBEING TEAMS

- Based on Dutch Buurtzorg model;
- Focuses on creating small, neighbourhood self-managed teams including community circle connectors to promote independence;
- Staff experience is improved through small teams, paid at or above the National Living Wage, supported by coaches who focus on fostering reliability, kindness, trust and creativity;
- This approach is affordable through reduced layers of hierarchy made possible by the self managed approach.

CARE AND SHARE ASSOCIATES (CASA)

- CASA was established in 2004 as an employee-owned provider of domiciliary care;
- This approach taps into people's natural creativity and commitment, by giving them a stake in the business;
- Built on a culture of positive long-term impact, both on the business and across the wider community. This unique approach can be seen in practice in a number of ways, from creating a Social Care Academy, the employment of employee engagement leads, and the 'voice' employees have in its governance structure;
- CASA believes that, because employees are also the owners, they achieve the highest quality care and low staff turnover, making the business more successful.

Getting the most from the skills and capacity of the care workforce

The current model of professional care arguably does not maximise the potential of the workforce. It is highly managed and bureaucratic. Low paid staff race around to get to 15 minute visits having to 'clock on' and 'off'. It is very task-based and highly impersonal. A recent commentator[44] said that the business model of the domiciliary care sector seems more akin to a parcel delivery service than a model designed to create kindness, relationships and give good care. It is the view of the Expert Advisory Panel that commissioners need to be more creative in their thinking and learn from innovative approaches elsewhere such as those outlined opposite.

This kind of self-directed management approach has the potential to improve people's lives, empower staff and reduce costs. Introducing a more human and relationship-centred ethos into social care would be the antidote to the current managerial, vertical and industrial ethos which seems so often to be dominant in the care sector.

Leadership throughout the workforce - freeing the potential

Nurturing leadership throughout the professional care system is essential. If transformation of adult care and support in Northern Ireland is to be successful, then leadership at all levels requires nourishment and permissions. New models of care are likely to require flatter structures and a deliberate move away from a command-and-control management style. In our view, they also need the right people, appropriately rewarded, supported and with a sense of being valued and listened to.

Quality in social care is a function of the people who engage in it, not the structures designed to contain it. The structures impose significant administrative and bureaucratic burdens on managers and care workers. Not only do the structures take up their time, but they also distract their priorities. They take them away from the relationships they are trying to build simply to feed the system's demands. A report commissioned by the Joseph Rowntree Foundation in 2014 highlighted how excessive paperwork demands impact negatively on priorities and relationships.[45] Although the work focused on care homes, the same issues apply to all parts of the care and support system.

As we have noted elsewhere in this report, social care is broad and, as a consequence, so is the workforce. The care and support sector includes care workers and a wide range of other support staff, often with an equally wide range of job titles. However, there are very many other occupations employed within the care sector: social workers, nurses and occupational therapists, to name a few. Leaders, or as more often referred to in social care, managers, are the cornerstone of quality care and support. **The single biggest factor in the quality of a care service or care home is the quality of its manager.** The leaders in social care also need to be supported better too. We received evidence from My Home Life NI on a programme of supportive development that helps leaders in care settings to negotiate the complex, and often conflicting, emotional stresses of their work. Helping them to gather perspective, seek solutions and protect themselves from the very real risk of burnout.

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44. Interview with Geoff Mark: https://soundcloud.com/helensanderson/conversations-with-commissioners
45. https://www.jrf.org.uk/report/excessive-paperwork-care-homes-undermining-care-older-people

Back to the future

In the view of the Expert Advisory Panel the social care workforce has been neglected and exploited. Furthermore, we believe that an effective and sustainable social care workforce strategy is an essential part of the transformation of adult care and support services. The workforce should be redefined as one of primary strategic importance, not just to the care sector in Northern Ireland, but to the whole economy and wellbeing of society.

Our proposals suggest that the workforce be 'consolidated' as a professional workforce for social care in Northern Ireland. We propose that a movement towards equalisation of pay and conditions across the care sector should be pursued. Common induction standards should be developed and a national training and development programme put in place. The aim, to create a national professional workforce with equal status and professional standards across all parts of the professional care market. A workforce that can attract the right people in the future and offer a fulfilling and rewarding career. **Such a workforce would drive up standards, enable truly citizen-led approaches and help raise the status of social care generally.**

The aim of the transformation of adult care and support in Northern Ireland should be to focus on community-based prevention maximising the wellbeing of citizens, with citizens in control. Professional paid care and support will continue to have a vital place, but in a broader, and more diverse, market of care provision. We envisage an important leadership role for social workers in communities. And social care would have the primary purpose of providing care and support to those whose needs cannot be met in other ways, or when specialist skills are required. When we do need professional social care, it is absolutely vital that a suitably skilled, competent, motivated, supported and valued paid workforce is available to provide it. And to be sustainable that the leadership within the social care sector – at every level - is similarly skilled and confident.

> "The quality and sustainability of services must be enhanced through providing adequate terms and conditions of employment."
>
> UNISON

Proposal Six

The Expert Advisory Panel proposes that the care and support sector should be, at least, a Living Wage sector as a first step to recognising it as a professional workforce. In the longer term the vision should be to equalise pay and conditions across the social care workforce.

Proposal Seven

The Expert Advisory Panel proposes that the Northern Ireland Social Care Council (NISCC) leads efforts to elevate the status of the social care workforce, through registration and the development of a shared induction, training and career development standards. That the NISCC further considers the representation of the social care workforce in the development of a professional body to ensure that the voice of frontline staff is effectively heard in the transformation of care strategy.

> “The standard of service delivery is more important than the sector that provides it.”

WORKSHOP COMMENT

7 THE 'MARKET' FOR CARE

In this section we pose the questions: What is the purpose of social care? How should the market for professional social care be managed? And finally: How can consumer sovereignty be used to extend and diversify the whole social care market?

The purpose of social care

During the course of our evidence gathering and talking to people, a question keeps recurring. 'What is social care for? What do we want it to do?' Which then leads to the question 'Is it currently doing what we want and need it to do?' The answer to this question has invariably been a resounding no. The current 'market' of adult care and support is widely considered to be broken and no longer fit for purpose, it is failing to deliver for us and falls short in so many ways.



As we argued in section 2, social care is, and should be, very broad. But there is a tendency for it to be defined narrowly as domiciliary care or care homes - professional social care as we've come to term it. Shouldn't care and support really be seen as much wider? Surely it should include the network most of us have around us which enables us to have a good quality of life despite our need for care and support? This requires us to be able to access a wide variety of services and support, not just for physical care but also for emotional, intellectual and social needs.

Much of the formal social care provision has changed very little in the last 25 years with domiciliary care and care homes continuing to be most people's experience of care and support. Standards have developed of course and the type of provider has changed as there has been a significant shift from the statutory to the private sector. However most of the care services are much the same services as they have always been.

Why is that? Why, if the population's needs, expectations and aspirations have changed so much, is the so-called

'market' for social care still offering the same services and doing much the same things? If the media was run in this way, we might still be watching the same three channels on a black and white analogue TV!

Creating a sustainable market for social care

We have argued in other parts of this paper for interpretations of adult care and support to be expanded into a much wider, broader, community-centred and asset-based approach to individuals and their support networks. One in which prevention and wellbeing are the primary focus, together with reablement and the promotion of independence. We do believe, however, that there will always be a need for paid professional care and support services.

So what is the purpose of professional social care? We are arguing that social care, in terms of paid professional care and support, supplements that which might otherwise be offered by family, friends or through a network of community support. Social care is likely to be provided by registered and regulated care providers.

In the view of the Expert Advisory Panel professional social care will always be a part of the adult care and support system. However, the Panel also believes that it must be of good quality, well-supported and viable. In earlier sections we have made the case for widening and broadening what we mean by social care, by putting the citizen at the heart and by empowering and enabling communities. We have also argued that **good professional social care cannot be achieved through a minimum wage workforce afforded little status** and built on a business model unsuited to endeavour based on personal relationships.

Our proposals will make professional social care more expensive. However, we believe that the combination of measures we have outlined in this paper, in which wider opportunities and services would become available, mean that limited resources would be more effectively utilised within the whole social care system.

What is the social care market for and what is it intended to deliver? The system of purchaser and provider heralded by the changes to community care more than 25 years ago sought to introduce competition around quality and price. This was intended to result in consumer choice, in other words a choice of services and provider. In reality there isn't one 'market' as such. More often it is effectively a collection of smaller markets based on geography. When people need professional social care it is often at a point of crisis, a distress purchase because existing support cannot be continued or can no longer cope. But if you live in Dungannon would you scour the whole market for a care home? Or a domiciliary provider? No, you want the local care home to be a good standard so you can be near your family and friends. We don't really want to be shopping around for the best care home. We actually want our local care home (or domiciliary care provider) to be consistently good and all of the time. We also don't want it to be so fragile that it is a good standard today but not so six months later. It's an obvious point, but care and support is not the same as the restaurant market. You can't easily move to another care home or swap your domiciliary provider. Which begs the question is a model of a competitive market actually appropriate to social care?

Is it really a 'market' in the conventional sense? Is it consumer-led? The language used around social care is enlightening. We tend to talk of 'service users' rather than 'customers' or 'clients'. There are 'commissioners' rather than 'agents' or 'brokers'. This is not the language of market power being with the consumer or customer. In Northern Ireland a substantial majority of professional care and support is funded by the HSC Trusts with a significantly smaller proportion of people paying for their own care. This means, effectively, that many care providers see themselves as having only one customer: the Trusts. Not a monopoly but a monopsony. At least most of the time because once demand outstrips supply then the tables can turn and up and down we go!

Over and over the Expert Advisory Panel has heard the same concerns and they come from all sides – providers, commissioners and crucially from people themselves. The most common concerns were:

- There is very **little choice**. It's either domiciliary care or a care home and in some places the market has so failed that there isn't a willing provider to give a service.
- The market can be **unresponsive to individual needs** and wants. There is a failure to acknowledge that everyone is different with different needs and different situation.
- Some **relationships in the system are experienced as adversarial** or competitive. People don't find this helpful. Commissioning a service from a provider, issuing a contract and a service specification and then walking away isn't helpful.

The culture around care and support services needs to be one of everyone's 'skin in the game', appreciative enquiry and mutual support. It shouldn't be that each part is just thinking in terms of its own activity or budget but also what can it do to make some other part of the system work better. All parts engaged in care and support should therefore be aligned and we consider this issue in section 8.

The market as it stands only appears to have one actual competitive dynamic: the squeeze on cost. And providers compete almost entirely on price. This has led to a professional social care provision based on minimum wages, poor working conditions and financially fragile providers. This is not the context in which to expect to encourage confident, skilled, safe and kind professional care and support to be everyone's experience every time.

And what of quality?

We heard from the regulator (The Regulation and Quality Improvement Authority - RQIA) and from individuals about the sense of quality in the professional social care sector. Responses from individuals were mixed, some having positive experiences and some less so. RQIA reported on variability but not a significant difference between independent and statutory care provision. RQIA haven't adopted the ratings approach as in England. Their view is that the aim of the whole system is to ensure that all care is good and that, whilst poor standards of care must be challenged, their experience is that, in the main, providers work positively and openly with them to improve services when they are failing. The underlying causes of poor care are often, but not always, exacerbated by inadequate resources and or severe difficulties in recruiting adequate numbers of suitable staff. This is an issue that we would hope to improve with the proposals made on pay rates, workforce development and a more open and honest commissioning model. Achieving quality

consistently in professional social care cannot ever be achieved through regulation in isolation. Many other factors are important. The engineering underpinning the sector needs to be sufficiently robust too.

Capacity and planning in professional social care

We have heard that the demand and supply of professional care and support services are not well aligned. Some parts of Northern Ireland are well supplied whilst other have a significant shortfall of supply. Both situations bring problems. If there is over supply, then price competition creates a 'race to the bottom', with consequences for quality and longer-term sustainability. Where there is under supply, providers can use their power to drive up prices, thereby holding the customer to ransom. In either scenario people can't access the services they need, when they need it and at the quality they require. There is no mechanism for the planning of supply. It appears crucial to us that there is a capacity strategy that uses data on projected demand to inform and implement the planning of the supply of professional social care services. Leaving supply simply to the vagaries of the market creates uncertainties, leading to market power imbalances with consequent regular local demand and supply crises. Added to which continuing to commission the same services perpetuates an imperfect market, with little scope for innovation or the development of new models or different ways of working.

A sustainable and functional professional social care market

There is a lack of honesty and transparency created by an arms-length commissioning system which is unsuited for the imperfect market that exists in care and support services. It is not the same as procuring stationery or roads maintenance. Care and support involves supporting a human environment and culture that encourages relationships and kindness. The market we create needs to recognise this. Commissioners and providers should be honest about the true costs of care and agree a funding tariff that sustains a properly paid and valued workforce, one that underpins a quality and professional sector. Recognition also needs to be made of the need for a sustainable return, whether to a private provider or a voluntary one. The responsibility is on both sides. Commissioners and providers both need to be honest about costs and transparent about priorities. In our view the care sector is not the right place for a 'profit maximisation' business model, rather a 'profit with purpose' approach.

> “It is our strongly held view that treating people as equal citizens means that they should assume responsibilities for their support, including the funding for same.”

POSITIVE FUTURES

Adult care and support is not free at the point of delivery, unlike the NHS. **In our view the current charging arrangements in Northern Ireland are unfair and create unintended consequences.** It does not feel equitable that, if you need the support of a care home, and have sufficient funds, you have to pay the whole cost, whilst someone with the same assets and income can receive domiciliary care for no cost. In the end there is an 'opportunity cost' for every Pound spent by the State. The 'opportunity cost' is what you can't now pay for because you've spent it on something else. By giving free domiciliary care to people who could afford to contribute simply means you have less available for those who can't or to invest in new services.

The Expert Advisory Panel proposes that three mechanisms are considered:

1. **Establish a 'true rate for care'**. The finances of a domiciliary care agency or care home are not unduly complex. It should be straightforward, with the required degree of openness and honesty, to agree a true rate which recognises the need for a properly paid and valued workforce and a sustainable return for the purposes of investment.

2. Charging arrangements should be based on the **principle that where a person can afford to contribute to the cost of a service they should do so**. This principle should be applied consistently and equitably across all adult social care services, including care homes and domiciliary care.

3. **Establish a market regulation mechanism** with a market oversight role for RQIA to ensure that, in return for a 'fair price', the Living Wage is paid to staff, there is investment in quality and that excess profit is not taken. This could take the form of a market regulator, able to scrutinise procurement arrangements, fees, charges and profits for care provision or extending the remit of RQIA to include market oversight as exists for larger care providers for the Care Quality Commission in England. [46]

This should allow the commissioners to be able to demonstrate adequate resources are being provided to ensure that quality can be delivered and that they are receiving value for money. The citizen would receive financial assistance in accordance with their identified needs and according to their ability to contribute. It would also allow good providers to be able to deliver the quality expected of them and to make a reasonable return on their investment.

During the course of this review the question has frequently been raised with us in relation to the current balance of private (for-profit), statutory or voluntary (not-for-profit) care providers. Concerns were expressed as to the lack of a mixed economy of care provision as evidenced, for example, by 100% of nursing homes now being in the private sector. It is our view that the current market mechanism of relying only on price has been the primary cause of this imbalance. A more open and honest market management, as we've described above, would, we believe, allow a range of providers to come into the market. A concentration on any one type of provider, or business model, will create the sort of imbalance that is now evident in Northern Ireland with potentially negative unintended consequences.

46. www.cqc.org.uk/guidance-providers/market-oversight-corporate-providers/market-oversight

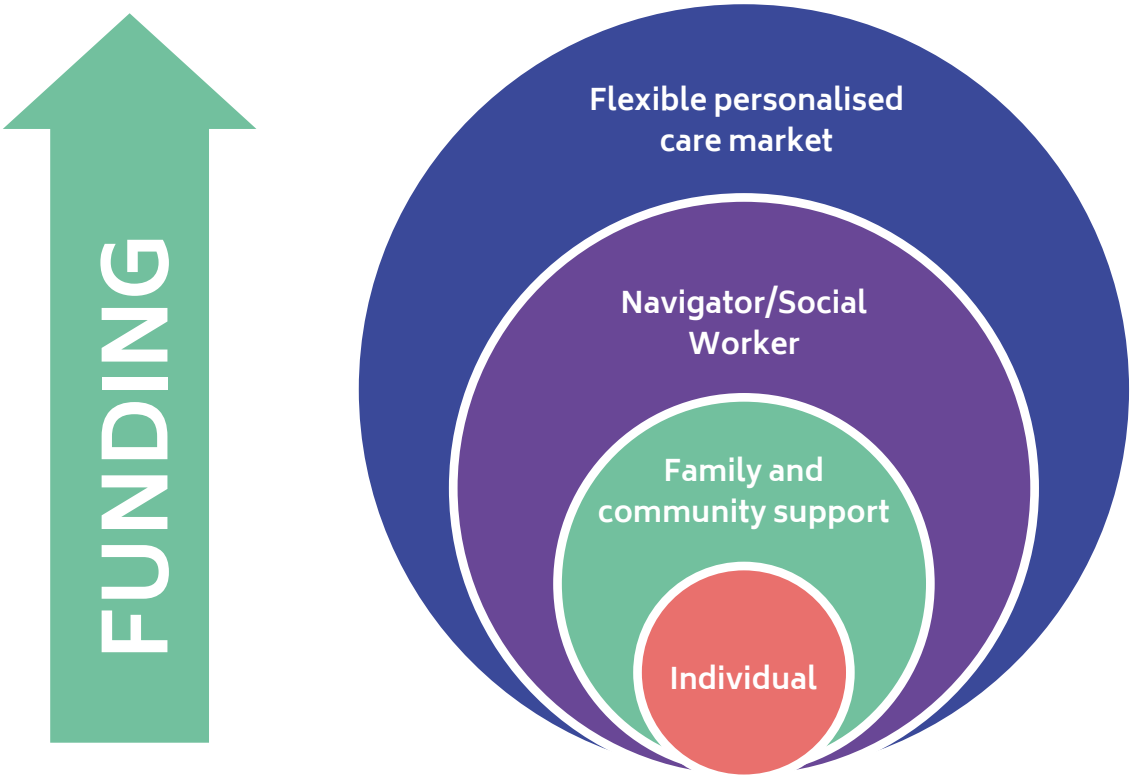
As part of the transformation of adult care and support a conscious bias is required to draw voluntary, community and social enterprise providers into a broader and more diverse social care system. Consideration of different business models such as cooperatives as well as different funding models, for example social investment finance, may be helpful.

SOCIAL IMPACT BONDS

Social Impact Bonds are a way of funding new innovative services: Investors agree to provide money upfront for a new service, and get paid back a premium if and when a set of agreed outcomes are delivered. In this way social impact bonds can enable both value for money and improved services.

Injecting diversity into the market

Arguably market power is in the wrong place. The adult care and support system tends to operate with 'commissioner sovereignty', sometimes 'provider sovereignty' but rarely with true 'consumer sovereignty'. This makes for different relationship dynamics between the people receiving the service and their families, those providing care and support and the commissioner of the service than is usual in other service sectors. It is our view that the system of adult care and support needs to be more focused on developing, encouraging and spreading a far greater variety of interventions, supports and services that can currently be accessed flexibly and individually at a community level.



The system should start with the person, together with family and community assets, supported by a navigator/ empowerer/social worker (see section 5). This can help create a flexible and personalised social care market by giving the individual the knowledge of the services best suited to meeting their needs. But they will need the power too, including the money to spend, either on quality professional care services or indeed on whatever they need to maintain their wellbeing as they define it.

> "We must agree a new risk paradigm; one which recognises and embraces the need for positive risk-taking and learns from mistakes, rather than points a finger of blame"
>
> POSITIVE FUTURES

Taking a truly rights based approach means that, because each individual experiences their challenges differently and has different circumstances and relationships, they are the ones who are best placed to direct their care and support. In order to stimulate a diverse and responsive market in care and support services, the consumer needs to have both knowledge in terms of their own needs and information about what is available. They also need to have control of the spending power.

We have heard concerns in relation to the risks posed by this kind of approach. The creation of a community support system based on navigators would enable people to use their consumer power effectively in meeting their needs as defined by themselves. The evidence presented to us, and the discussions we have had, has drawn attention to a view that attitudes to risk can often stifle and restrict people's choices. **Such an approach to risk fails to encourage people to be involved in defining risk for themselves.**

The allocation of money should be based on a measure of outcomes and not simply the cost of specific services, in other words an hour a day of domiciliary care defined from an assessment of deficit. The notion of outcomes came up quite a lot in our discussions.

Clearly a SMART method of establishing desired outcomes and measuring progress is required. We therefore welcome and support the incorporation of the ASCOT tool within the roll out of Self Directed Support in Northern Ireland. In capturing information about an individual's social care related quality of life, it will enable the evaluation of service user and carer outcomes.

In this section we have considered using Self Directed Support as the primary default method of creating effective demand to shape the market. We've also spoken of how commissioning by HSC Trusts should change. We know that this will raise questions. To be clear, we see the Commissioner and State role as one of establishing true cost for care in domiciliary care, care homes, and so on, so they are transparent and sustainable. This would be overseen by a market regulator to ensure providers adhere to the principles of the pricing model - **a level playing field.** The consumer can then have confidence that they are getting a fair price. It may be in some circumstance that the HSC Trusts do need to directly commission some services for some types of service or for certain people as a self-directed support model becomes established and effective.

Proposal Eight

The Expert Advisory Panel proposes that commissioners and care providers work collaboratively and openly together to develop and introduce a framework based on an agreed true cost of care which includes agreement of a 'sustainable return' for providers. This should recognise the workforce considerations set out in Proposals 6 and 7.

Proposal Nine

The Expert Advisory Panel proposes that the Department of Health should ensure that charging arrangements should be based on the principle that where a person can afford to contribute to the cost of a service they should do so. This principle should be applied consistently and equitably across all adult social care models.

Proposal Ten

The Expert Advisory Panel proposes that the HSC Trusts make explicit their commitment to a process for planning the supply of care and support services and which involve all stakeholders early in developing the strategic vision for future provision.

Proposal Eleven

The Expert Advisory Panel proposes that the Department of Health considers whether additional powers should be given to the Regulation and Quality Improvement Authority to regulate the professional care market. In particular assuring adherence by care providers to the principles in Proposal 8 including the oversight of a fair and agreed return.

Proposal Twelve

The Expert Advisory Panel proposes that HSC Trusts are enabled to more effectively discharge market shaping responsibilities. In this way, requirements to facilitate self-directed support and encourage community based models of intervention alongside formal systems of care and support can be monitored.

> “Make every contact count – focus on early intervention and prevention.”

WORKSHOP COMMENT

8 SYSTEM ALIGNMENT - MAKING INTEGRATION MEANINGFUL

Fragmented arrangements are a common feature of adult social care services as it relates to health, housing and other disciplines and has long been seen as problematic. This section is concerned with the joining up of services in a seamless way to maximise the effectiveness of the system as a whole, and improve the experience of individuals receiving care and support.

Integrated structures but not integrated systems?

The word "integration" has come up time and time again in response to our Call for Evidence and in our discussions. The Expert Advisory Panel have been told by many that Northern Ireland, through the HSC Trusts, has an integrated health and social care system. Clearly there is an integrated structure. The question is whether the structure results in closer partnership working that really brings a joined-up experience to those that use the system. It has been suggested to us that, despite the integrated structure, a lack of connectivity still exists and continues to bedevil the system. Integration does not appear to be working for people in need.



In particular, concerns focused on the impact of working in silos:

- Everyone is doing the job they have been asked to do but at **arms-length from the rest of the system;**
- There are **too many points of contact** with too many gatekeepers for referral. This means people often have their needs managed 'in parts' e.g. GP is managing medication, nurse is managing dressings, social worker overseeing care package, with no one place/person/provider looking at the whole picture;
- People don't receive the **right service or expertise at the right time** to get the best outcome;
- Barriers to a more aligned approach are created by such **factors as attitudes, budgets and professional status**. The structures behind services define how they are delivered, not the individuals in need.

Somehow we need to align everyone to work together in the same endeavour. How health and social care services can work seamlessly together has therefore been a recurring theme during this review. It has been said more than once to us that it's as if health and care are different countries - they share a willingness and desire to work together for the best, but they have different languages, different cultures and a different set of ideas as to what they are trying to achieve. Discussion about integrating health and care (and, more recently, housing) has been going on for years and yet it stubbornly refuses to be a reality for many of those at the receiving end of services. Thus the structural integration of health and social care in Northern Ireland does not appear to be delivering an integrated experience for people. It might be said: 'they may live in the same house, but it is definitely separate bedrooms'.

Barriers to alignment

Another issue which arose in our discussions was that of wariness and even mistrust between parts of the care and support system. This is potentially a significant barrier to greater alignment. It seems to be particularly true between the statutory and independent sector. In our view, the suspicion that profit is the only motive for some care providers hinders close and effective working between the HSC Trusts and independent care operators. Perceptions of a lack of mutual esteem can undermine relations between health and social care. These attitudes fetter open and honest working which can be detrimental to the system working well. **Only when all parts of the system are working seamlessly together, with parity of esteem, will the full potential of the adult care and support sector be realised.**

One of the major causes of the current demand crisis in acute health is the failure to successfully negotiate the interface of frail older people with acute hospital care. Too many present at Emergency Departments when it isn't the best solution or could have been prevented. As a consequence, too many people lose function in hospital (even after only a few days) making it even more difficult to appropriately discharge them. Too many people end up in hospital to die.

Whilst doctors and consultants may wish to consider the whole person, the structure of a hospital doesn't enable them to address the entirety of a person's needs. The same is often true for GPs. Ten minute appointments may be sufficient for diagnosing a condition

or making a referral but are unlikely to be adequate for a meaningful conversation about an individual's circumstances and their specific needs. We believe the situation could be significantly improved by considering some key relationships. The illustrations below are not exhaustive but we hope that they will give a flavour of the kinds of changes to how the system could work which may address the crucial issue of effective interfaces for integration.

SOCIAL PRESCRIBING

A Social Prescribing model is being piloted in the Western HSC Trust area. This model is provided by Bogside & Brandywell Healthy Living Centre who have employed a member of staff to act as a dedicated link to connect case work and navigate older people who are picked up through a screening process in local GP practices. Those suffering with anxiety related mental health problems, loneliness, long term health conditions with related debility and social isolation are supported to access a range of programmes aimed at improving their health and wellbeing.

Source: WHSCT response to Call for Evidence

Healthy communities

Primary care is perhaps inevitably the entry point into the health and care system for most people. It is relevant therefore to considerations about the future of adult care and support and strategic priorities. Ensuring people stay fit and healthy for longer requires a programme to promote prevention and early intervention initiatives alongside community planning to address health inequalities. Such imperatives appear to be emerging as collective aspirations for the system.[47]

Our references to the provision of primary care are necessarily cursory, although we are clear that they are fundamental to understanding ways to improve the alignment of care and health systems. The first point of call for a person experiencing difficulties with their health and wellbeing is likely to be their GP. If GPs were connected into a community navigator scheme (see section 5) then the options available to them would be greatly enhanced. This would give GPs a much bigger 'prescription pad' enabling them to refer to community connectors on issues like loneliness and isolation.

The implications of closer integration between care and health is evident in many different ways. An example is that of the points at which primary care and care homes relate to each other. We were informed that the care provider Four Seasons Health Care had completed analysis of admissions to hospital via 999 calls from its care homes in the last quarter of 2016. Of the 247 episodes, 40% were related to an undiagnosed and generally unwell category where medical practitioners were unavailable or declined to see their patient, directing care home staff to call 999. In their submission to us Four Seasons suggest a comprehensive review of primary medical care services to care homes is required.

47. See: Northern Ireland Confederation for Health and Social Care 'One Voice – Time for Change' (May 2016)

Hospitals, care homes and domiciliary care

Obviously care homes (including nursing homes) are not hospitals and neither they should be. Care homes are where people live, and in the best ones people can live well despite complex needs. They can offer a certain amount of medical management and nursing care to support people with considerable needs and frailty, but they have neither the confidence nor the skills and knowledge to do it well without significant medical support.

Hospitals are not places where people live. They are where we go to be fixed. They can do a certain amount of 'social care' but they have neither the design or the resources to do it well. It is the view of the Expert Advisory Panel that the relationship between hospitals and care homes should be much closer and mutually supportive. Ideally, each hospital should view the care homes on their patch as extensions of themselves, though not the same as themselves. Closer working relations could reduce admissions from care home to hospital but also create smooth pathways for quicker effective discharge. Closer working and planning together, for example at end-of-life, could bring more of the strengths and expertise of the hospital to the care home and vice versa. Offering a better experience for individuals and reducing stress and pressure on the system as a whole.

Frail older people need a different pathway through hospital. All too often they arrive in hospital and their existing care and support (whether it be from a care home or domiciliary care) vanishes. A way of extending social care into the hospital should be enabled to improve people's experience and to speed their transition back home – whether that is their own home or in a care home setting.

If hospitals and the care homes in the same locality or community designed together, with say ambulance services, alternative pathways could be created to reduce unplanned admissions from both care homes and the community. Care homes, if properly integrated and supported, could provide an alternative to hospital admission and most definitely be a place for early discharge and rehabilitation. But not if they continue to be held at arm's length.

However, **we don't believe you can just commission intermediate care, you have to co-create it.** Research carried out in Kent County Council[48] showed that, of older people placed in standard residential care beds on a short term basis, around 80% remained there for the rest of their lives. When people with similar needs were placed in an intermediate care bed where there was a focus on helping people's recovery, over 80% returned home. "It was not the assessed needs that made the difference but the offer that was available to the patients at the point of discharge".[49]

This approach requires a real commitment to working together, on a daily basis, knowing each other's pressures and strengths, working as a whole system, not just a collection of separate parts. You may, for example, have an excellent hospital close to an excellent care home, but if the interface between them isn't excellent then huge potential is unrealised. Some examples are outlined on the next page:

48. http://www.local.gov.uk/documents/10180/11779/LGA+Adult+Social+Care+Efficiency+Programme

49. "Six Steps to Managing Demand in Adult Social Care – A Performance Management Approach", John Bolton and Philip Provenzano, March 2017

WCS CASTLE BROOK

South Warwickshire NHS Foundation Trust now works with WCS Care in its Castle Brook Care Home. Having provided a therapy-led care model in a dedicated unit at Warwick hospital, the Trust recognised that patients would benefit if they received care in an out of hospital environment. The aim of the new service, delivered in Castle Brook, is to provide patients with additional short term support and therapy that will help them return home from hospital as independently as possible.

Source: http://www.swft.nhs.uk/news/additional-therapy-help-patients-return-home

WINDSOR CARE HOME & INTERMEDIATE CARE CENTRE (FOUR SEASONS HEALTH CARE)

This is a 39 bedded home in South Belfast, located centrally between 3 main acute hospitals and a multidisciplinary allied healthcare professional hub. This home had a falling number of services user numbers in the frail elderly category, which was less than half of its budgeted occupancy. This reduction in occupancy created the capacity to develop a new Intermediate Unit for a new service of discharge assessment beds. Using Four Seasons Health Care Intermediate Care Framework a review was conducted of the physical environment, styling, staffing levels and training requirements. Staffing levels in the Intermediate Unit were enhanced and are supported by a clinical lead post to quality assure care delivery, and provides a daily link to the Belfast HSC Trust staff. The rehabilitation care delivery is supported by a full multidisciplinary team of care managers, social workers, physiotherapists, occupational therapists and rehab assistants. There is medical cover supplied by a daily GP visit and consultant screening at the point of hospital referral. In the first 5 weeks there were 15 admissions which meant that the unit was fully occupied, with no readmissions to hospital.

Source: Four Seasons Health Care - submission to Call for Evidence

> “There is a need to advance models of integrated care (social and health) such as co-located multi-disciplinary teams that act as professional hubs... The interface between professions and improved communication pathways lead to enhanced outcomes for the individual.”

NORTHERN IRELAND PRACTICE AND EDUCATION COUNCIL

ENHANCED HEALTH IN CARE HOMES

NHS England have identified a number of interventions that the health system could do to support care homes, which in turn helps care homes to support hospitals. Across England, six vanguards are working to improve the quality of life, healthcare and planning for people living in care homes. Within these six vanguard areas, care homes are working closely with the NHS, local authorities, the voluntary sector, carers and families to optimise the health of their residents.

'The Framework for Enhanced Health in Care Homes (EHCH) - Sept 2016' outlines what the whole system can do to help:

- **Enhanced Primary Care Input**
  - **Individual health professional assigned to each care home. e.g. GP, prescribing nurse:**
  - **Regular expert medication reviews;**
  - **Hydration and nutrition support;**
  - **Out of hours emergency video link;**
- **One point of access for MDT support e.g. OT's, Speech Therapy etc;**
- **Reablement and rehabilitation;**
- **End of life and dementia care;**
- **Joined up commissioning and collaboration between health and social care;**
- **Workforce:**
  - **Joint training and supervision;**
  - **Joint workforce planning;**
- **Data, IT and technology.**

For further information see: https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/care-homes-sites/

An example of one of NHS England 'Enhanced Health in Care Homes' vanguard sites is a 24 hour video link between care homes and Airedale Hospital in Keighley, Yorkshire. The care home can access directly a team of triage nurses located in the hospital. The service enables care staff to receive immediate advice and support. The care homes have reported an increase in confidence and particularly feel much more supported in terms of decision making and accessing emergency services.[50]

Effective and accessible Multi-Disciplinary Teams (MDTs)

We heard evidence from a number of professional bodies representing health specialties lamenting that their skills and expertise aren't being maximised, often because the needs of the person were not being matched to the specialty. Evidence was given of the potential for improved outcomes for individuals and savings to the system if expertise and need could be brought together in a well matched and timely fashion.

We believe this could be better achieved by having flatter 'one point of contact' MDTs aligned to neighbourhoods and strongly connected to GPs and Community Navigators. For

example, there is evidence of the effectiveness of interventions by speech and language therapy in the prevention of aspiration pneumonia in the older population, which, if untreated, causes high hospitalisation rates, serious morbidity and often death (Welte et al 2012). [51]

"The Royal College of Speech and Language Therapists consider that full multidisciplinary community based respiratory management services urgently need to be configured....
SLTs could make a significant contribution to self management of conditions and appropriate diagnosis, for example, working alongside nursing colleagues in elderly community care teams could significantly reduce the number of hospital admissions and improve wellbeing, leading to greater independence".

Source: RCSLT response to Call for Evidence

Lack of alignment for those in transition between programmes of care

The lack of alignment for people in transition between programmes of care and support came up time and again in our discussions and visits. We heard the concern often and in different contexts. The frustration felt when a person is catagorised according to who they are and not according to their needs. People find this hard to understand and it definitely feels like it is done to 'align' with structures, especially budgets, and not appropriately for need. Examples included when a person with learning disability reaches a certain age and is transferred to 'older people's services' when their needs relate to their learning disability rather than their age. Or a disabled child moving from children's services to adult services. We had strong representations that transitions need to be planned and overlapping for a time; "feathered" so that there are no hard cut-offs.

Housing and social care

Despite the fact that during our visits we saw some excellent examples of housing based support schemes for older people, learning disabled people and those experiencing mental distress, the Expert Advisory Panel were surprised at the lack of scale of specialist housing in Northern Ireland. We took evidence from housing associations who informed us they were ready and willing to develop more specialist housing for a variety of different needs. However, we gained the impression that **housing tended to be viewed as a peripheral activity in relation to adult care and support.** Except for a few innovative examples of provision it was somewhat under the radar of the adult care and support system.

Evidence from our visits and from our experience of specialist housing would demonstrate that housing can be an essential part of a response to supporting disabled people and older people, in their own homes and remaining close to their own communities. Extra care, retirement villages, and forms of supported housing combine the benefits of maintaining your 'own front door' with preventative intervention and improved outcomes for people.[52]

50. https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/care-homes-sites/airedale/
51. RCSLT response to Call for Evidence
52. Collaborative Research between Aston Research Centre for Health Ageing and the ExtraCare Charitable Trust (2015) Aston University

Of course everyone will make different choices and many people will choose to remain in their own home for as long as possible, but evidence from the rest of the UK and around the world points to well-designed specialist housing as being a positive choice for many and that it has demonstrably positive role to helping people maintain their independence and wellbeing.[53]

The Cedar Foundation, for example, supports over 55 individuals with physical disabilities, acquired brain injury and learning disabilities in four supported living projects using SMART technology across Belfast and Lisburn. Individuals live in single or twin occupancy apartments which are enabled with a range of assistive technology to support independent environmental control such as access to property, opening windows, closing blinds and managing heating. These services have been independently evaluated and demonstrated to have a significant positive impact on the functional independence of the tenants living there. In one evaluation[54], researchers found that tenants particularly valued that they were able to have their own personal space (many had previously lived in residential care) and that the housing model had given them much greater choice and control over their lives, which in turn had enhanced their personal confidence. This growth in confidence was also reported to have had a positive effect on other areas of their lives, including social and community inclusion and feelings of personal contentment.



Specialist housing can also be engaged as a hub within communities to provide access to social events, information and advice, thus providing an 'asset' for a connected community. Specialist housing is of course only one aspect of housing provision. It has long been the case that in the absence

Shared Lives is a service that provides family-based support for older people and people with disabilities. It enables people to experience ordinary family and community life and receive personal care outside more traditional care settings.

Central to the ethos of Shared Lives is the matching process which offers service users the opportunity to be matched to a Shared Lives carer in the community based on their interests and preferences. This offers a level of personalisation and choice not often available with other services.

There are four Shared Lives schemes in Northern Ireland, which are regulated by RQIA with annual inspections. The schemes support over 300 service users thanks to nearly 190 Shared Lives carers. Evidence suggests Shared Lives costs less than other forms of care: on average £26,000 a year less for people with learning disabilities, according to a detailed independent cost comparison carried out in three areas by Social Finance. These are tangible savings and do not include savings associated with better outcomes and the associated evidence of less use of health and crisis services.

Source: (http://www.communitycatalysts.co.uk/social-finance-investing-in-shared-lives-july-2013/)

of suitable accommodation, people often cannot be supported in their own homes. It is clear that better housing which was 'life-long' fully accessible would enable people to live independently and thus remain in their own communities, with or without formal care or family support. Strategies to develop standards for lifetime housing as well as lifetime neighbourhoods are now well established[55] if not yet implemented. Unfortunately, new developments in specialist housing seem to have considerably slowed in Northern Ireland. The reasons for this are twofold. There appears to be a lack of a positive recognition of the contribution of housing as part of aligned social care strategy and there is a lack of funding. **We believe that the role of housing as an integral part of an aligned care and support system is a core area which requires significantly greater attention and encouragement.**

Of course housing based options are not only achieved through new bricks and mortar. Shared Lives[56], for example, connects young and older people with support needs to families and carers providing a community based option.

53. Housing, prevention and early intervention at work: a summary of the evidence base (2011) Housing LIN Viewpoint
54. Evaluation of Impact of Assistive Technology at Ardkeen and Hillmount Court, Supported Living Options, Belfast, Social Research Centre/Ulster University 2008
55. Department for Communities and Local Government (2008) Delivering Lifetime Homes, Lifetime Communities – a national strategy for housing in an ageing society; Lifetime Neighbourhoods (2011) for a summary of literature and case examples
56. Information on Shared Lives http://sharedlivessw.org.uk/what-is-shared-lives/

Towards a collaborative accountable care system

In the Bengoa report much was said about creating an 'accountable care system' (p4). We believe that the same principles outlined in 'Systems, Not Structures' should extend to adult care and support. How connected each part is, how well the interfaces work is just as, if not more important, than what each of the parts do. The interfaces need to be softer, more diffuse and more collaborative. All parts of the care and health system need to become accountable, jointly and severally.

> "for the reform within adult care and support to be a success, partnership working... must move from the fringes of the system to become part of the system's core business. [It]... must be encouraged, supported and facilitated, including through the allocation of resources."
>
> UNISON

Proposal Thirteen

The Expert Advisory Panel proposes that the Department of Health oversees the introduction of a whole-systems approach to facilitating joint working between commissioners, health services and care providers which include a clear mechanism for involving people receiving services and carers within all the HSC Trusts.

Proposal Fourteen

The Expert Advisory Panel proposes that the HSC Trusts promote a collaborative, rather than competitive, ethos which fully involves all key stakeholders in the care and support system.

Proposal Fifteen

The Expert Advisory Panel proposes that the Department of Health and the HSC works more closely with the Department for Communities and NI Housing Executive around future strategies for specialist and supported housing to ensure more effective alignment between housing and social care.

> “Housing providers and Health and Social care have to work hand in hand.”

INDIVIDUAL

> We need culture change and a change in public attitudes –there is a need for a wider conversation to set the context for change.

WORKSHOP COMMENT

TOWARDS A NEW CONCORDAT

Our concluding section turns to the proposed Concordat as the means of stimulating a discussion with the public about the future of adult care and support. This new settlement between the citizen and the state is offered as the most effective way to build public understanding of the purpose of adult social care and recognition of its value. It would also clarify personal responsibility and enable proper consideration of risks. Through greater awareness a shared vision can be agreed and the steps to implementing change can be put in place.

Care and support fit for the 21st Century

Throughout this review the Expert Advisory Panel has sought to make the case for transforming the way that the adult care and support system operates. This is the reason the Proposals Paper was commissioned and in the final section we summarise the key themes we have covered.

In our view the transformation of adult care and support means at the very least:

- Placing the individual citizen at the heart of the system;
- Being clear about the purpose of adult care and support;
- Starting from an asset-based approach with an emphasis on earlier intervention, prevention and planning;
- Strengthening the support available to family carers;
- Rethinking attitudes to risk;
- Refocusing on local communities as networks of resources;
- Valuing the professional



contribution of the care and support workforce and rewarding them appropriately;
- Ensuring a mixed economy of care and support services includes community-based initiatives alongside formal services which are characterised by relationships of trust and transparency between commissioners and providers;
- Facilitating greater openness to improve diversity and quality of provision;
- Enabling appropriate alignment across adult care and support;
- Revaluing the contribution of adult care and support to society.

However, the very need for a new agreement on what matters to people in relation to adult care and support means that the discussion needs citizens to agree the parameters as well as detail of a reformed system to support people. We are in no doubt that this is a major transformational task which requires many established cultures to change and one which realistically might take 10 years to be fully implemented. **We are mindful also that our remit to develop proposals is considerably easier than the task of turning proposals into actions!**

It had been intended that alongside our review and the development of proposals, separate work would be commissioned to get an expert view on the cost of implementing various proposals. Although we have had the benefit of some systems analysis as a means of exploring the impact of the proposals, no detailed financial modelling has been undertaken.

Notwithstanding the encouraging appetite for change that we have witnessed in our discussions with key stakeholders, we would not wish to underestimate the scale of the reform that is necessary. We have been struck by the high level of interest in the review and the enthusiasm with which people have engaged – and at all levels. The response to the Call for Evidence was positive and in addition we received a significant number of papers, reports and references to follow up. In fact we have continued to receive papers and comments throughout the time we have been meeting. There has been remarkable unanimity in the view expressed that the current system of adult care and support is considered broken and unfit for purpose. **The care and support system is not sustainable ... and everyone with any knowledge of the care and support system seems to know this and acknowledge it.**

A shared vision

It is perhaps not surprising that we met some cynicism that the inadequacies of the system have either been ignored, or periodically tinkered with, to little beneficial effect. In essence there is a growing recognition that the structure of adult care and support does not match the changed demands and expectations of the 21st century. This is hardly surprising given that the origins of the Welfare State are now 70 years old. However, most of the views we have heard are those of the 'professionals' with a knowledge of the adult care and support system. Arguably there is much less understanding amongst most members of the public. Typically, people experience the care and support sector at times of personal crisis when they find the system confusing and difficult to navigate. There is insufficient information, care services are not part of the health service generally, they are difficult to access and some are means-tested. No wonder many people simply don't understand social care.
It is the view of the Expert Advisory Panel that a 'shared vision' for the future of care and support services is required as part of a fundamentally new approach. And a vision that is shared by everyone – not just those that know because they are in contact with services or work in the sector. This touches on attitudes to age and disability, risks and responsibilities.

It is therefore much broader than social care or care and support services. We have considered in the report some of the implications where adult care and support borders other services and sectors, such as health and housing, leisure and employment. Our vision is to place the person receiving care and support at the centre, building on their strengths and, as far as possible, complementing family and community resources. We describe this new settlement as a Concordat. **A co-produced agreement in which citizens are able to be well informed about their entitlements and rights, as well as their responsibilities and duties.** It would be a new settlement between the individual and the State.

The development of a Concordat is fundamental to transforming the experience of care and support to ensure it is truly person-centred and able to challenge the notion of a risk-averse culture which appears to have developed around services. Our proposal for a new settlement between individuals and the State is only the starting point to raising awareness about the purpose of adult care and support and its relationship to aspects of public health, enabling people to maintain their independence and plan for future needs. It is evident that in Northern Ireland (as elsewhere in the UK and beyond) public understanding of care and support systems is severely limited, with public perceptions of the adult care sector often incorrectly assuming it is already a part of the NHS. Although there are pockets of truly integrated provision it is far from the norm. It seems reasonable therefore to suggest that this lack of understanding contributes to a lack of appreciation of the complexity of the current system and in turn a devaluing of its place and purpose.

Developing a new Concordat would provide the opportunity to engage the wider public in a conversation about what adult care and support should be for, how it should be organised and managed, who might deliver services and how they should be costed and funded. This would bring a measure of transparency to the processes that surround adult care and support including procurement and regulation. It would enable people to better understand how care and support services link to health, housing, transport, leisure and other services. The anomalies that exist in the different ways in which adult care and support services are funded compared to the healthcare sector could also be clarified. Accountability, attitudes to risk, choice and control, rights and entitlements could be properly considered alongside responsibilities. The process could include setting parameters for profit by those providing care services and agreeing that the professional task of caring deserves to be rewarded with at least the Living Wage. The infrastructure to facilitate scalability of local initiatives would be necessary alongside new ways of working for existing care and support services. Ideally such community development would also involve multidisciplinary working with professionals from primary health.

> “A facilitated debate should take place to consider the balance of responsibility between the state and the individual.”
>
> **AGE NI**

Despite the fact that very many people's lives are directly touched by the provision of adult care and support services the understanding of social care remains patchy at best. As life expectancy rises, and medical advancements develop, we can assume that many more people will live longer with an increased likelihood of the need for some support at a later stage in life. A better understanding of the service offer and what it seeks to do has to be a good thing. Similarly improving the public awareness of services including availability, quality, regulation, charges and the ways in which services are managed would help to reinforce their contribution to society as a whole. **It is vital that the public understand the difficult choices now implicit in a system widely considered to be broken and unsustainable.**

Principles underpinning the Concordat

The Concordat would be an opportunity to make explicit policy intentions of personalisation, prevention and enablement, support for carers, developing community capacity and intermediate care for example. Through public education the boundaries between social care and other public services can also be clarified. In our view the discussion necessary to refine the Concordat would best be undertaken through a process of genuine involvement in which the elements relating to adult care and support are co-produced by those regarded as 'experts by experience'. Furthermore, it is our view that it is necessary to ensure that the Concordat is informed by the following fundamental principles:

- A human-rights approach;
- Person-centred and self-directed;
- Simple and easy to understand;
- Transparent;
- Fair and equitable;
- Flexible and responsive;
- Clarifying rights and entitlements alongside responsibilities;
- Suitably aligned with healthcare, the NHS and other key partners;
- Affordability and value for money.

However, we want to make explicit our view that the very process of developing and designing the Concordat would, in itself, need to determine the appropriate underpinning principles.

Once agreed the widest promotion of the Concordat will be necessary and, we would suggest, should form a part of the curriculum in schools so that children and young people have the opportunity to discuss the issues of future care and support and have the opportunity to understand the implications from an early age.

The challenges that this review was established to consider are substantial.

And they are being faced by all the countries of the UK and far beyond. The Expert Advisory Panel had a brief to provide proposals on the nature of the reform needed to ensure that the future system of adult care and support in Northern Ireland is "both sustainable and

designed to respond to individual preferences about how needs are met." The evidence we have received and the discussions that have followed reinforce the view that the social care system is probably one of the least understood parts of our welfare system.

'Rebooting' the care and support system

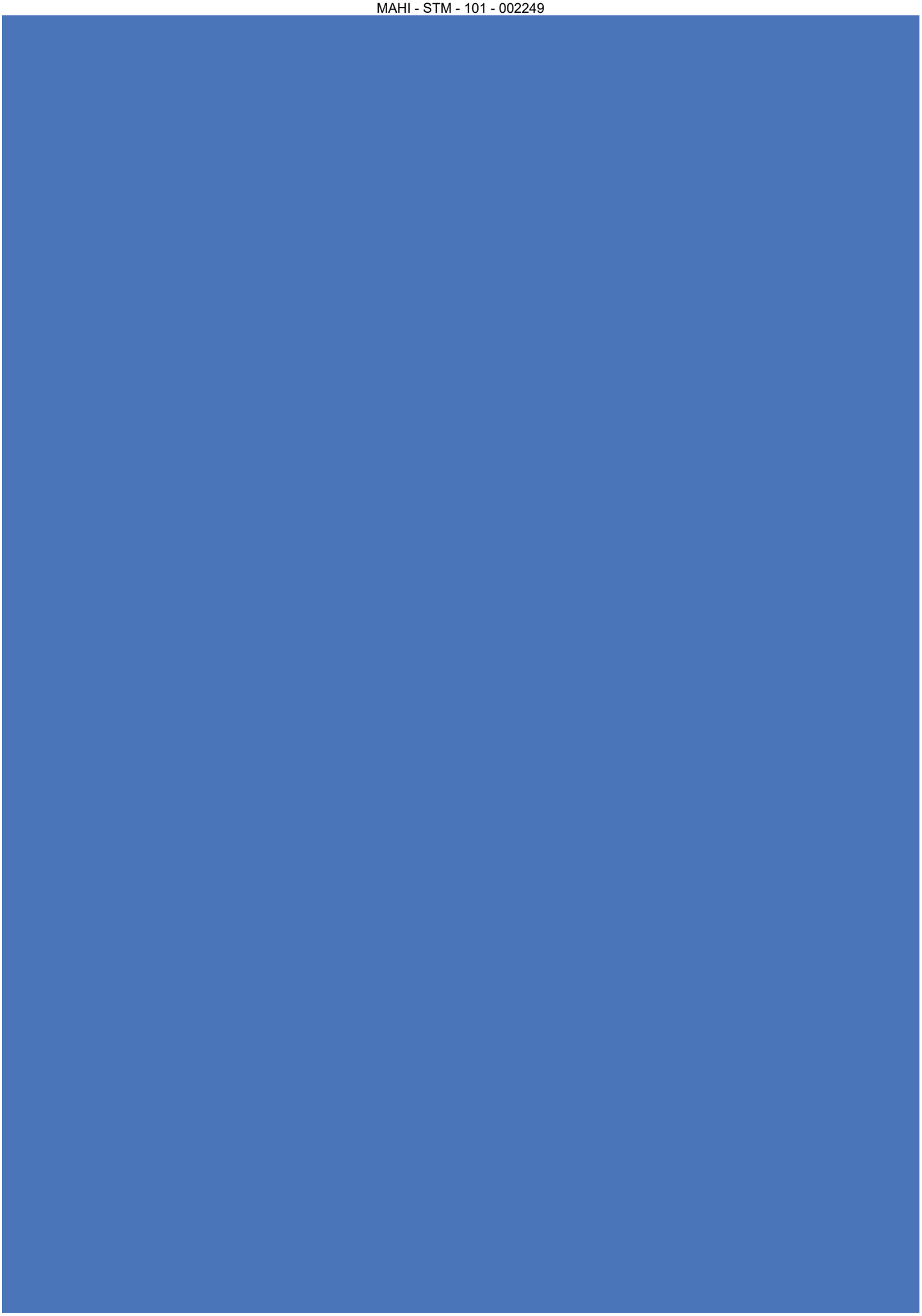
During the discussions we have had with people with different interests in the system it has become ever more apparent that meeting the challenges of individual preferences within a sustainable system of care and support will only be possible with major reform. We have argued strongly that doing a bit here and a bit there just won't do it. Isn't this really what has been done many times before? Incremental adjustments might have worked in the past to hold structures together so that services could continue to operate, but so many things have now changed and new demands and expectations mean that there will be further pressures on the fragile system of care and support.

In producing this Proposals Paper and reflecting on the issues that have been raised with us we have sought to direct our attention at areas we feel have the potential to make a difference to reforming the system of adult care and support. We therefore offer a limited number of proposals as they are the really core elements that need to change. The proposals within this report, and the proposed Concordat that we argue flows from our findings, are intended to be implemented as a package of measures to stimulate and embed the necessary change to reform and 'reboot' the system. Whilst it would obviously be possible to pick out proposals from this report as individual recommendations we do not intend them to stand alone. We want to emphasise this point as strongly as we can. **Only through a co-ordinated approach of taking forward the proposals will a successful implementation be possible and real change achieved.**

Our final proposal is:

Proposal Sixteen

The Expert Advisory Panel proposes that a Concordat is developed as the major means of stimulating a comprehensive debate, and agreement, with the public about the principles underpinning a transformed adult care and support system, including its purpose, how it is organised and funded. The debate should also review attitudes to risk and how citizens can be more enabled to be the determinants of their own risk tolerance and mitigations.



LIST OF PROPOSALS

Proposal 1

The Expert Advisory Panel proposes that consensus on the need for, and direction, of transformational change is achieved and that the leadership responsibilities for the adult care and support system are made more explicit. It is proposed that a cross-government initiative, led by the Department of Health, is undertaken to raise awareness of the purpose and value of adult care and support. The Panel also proposes that the HSC Trusts, together with other key bodies in Northern Ireland, take a specific lead in promoting the positive contribution of adult care and support.

Proposal 2

The Expert Advisory Panel proposes that models of self-directed support become the norm in order to empower citizens with effective demand. Further priority should be given to how Self Directed Support funds could be used as catalysts to create and shape a diverse market of care and support provision and that mechanisms to stimulate such models are facilitated as a matter of priority.

Proposal 3

The Expert Advisory Panel proposes that the rights of family carers are put on a legal footing and that a strategy to bring them into the heart of transformation of adult care and support is adopted.

Proposal 4

The Expert Advisory Panel proposes that neighbourhood based, preventative and citizen-focused community support models are encouraged and enabled. This should include the concept of a social worker-led Community Navigator role with such models available to every locality in Northern Ireland.

Proposal 5

The Expert Advisory Panel proposes that the reform of adult care and support is fully aligned with the Community Planning responsibility of local councils. This should include consideration to the development of a more diverse range of funding vehicles, such as Social Impact Bonds to create incentives and capacity in the development of resilient communities.

Proposal 6

The Expert Advisory Panel proposes that the care and support sector should be, at least, a Living Wage sector as a first step to recognising it as a professional workforce. In the longer term the vision should be to equalise pay and conditions across the social care workforce.

Proposal 7

The Expert Advisory Panel proposes that the Northern Ireland Social Care Council (NISCC) leads efforts to elevate the status of the social care workforce, through registration and the development of a shared induction, training and career development standards. That the NISCC further considers the representation of the social care workforce in the development of a professional body to ensure that the voice of frontline staff is effectively heard in the transformation of care strategy.

Proposal 8

The Expert Advisory Panel proposes that commissioners and care providers work collaboratively and openly together to develop and introduce a framework based on an agreed true cost of care which includes agreement of a 'sustainable return' for providers. This should recognise the workforce considerations set out in Proposals 6 and 7.

Proposal 9

The Expert Advisory Panel proposes that the Department of Health should ensure that charging arrangements should be based on the principle that where a person can afford to contribute to the cost of a service they should do so. This principle should be applied consistently and equitably across all adult social care support models.

Proposal 10

The Expert Advisory Panel proposes that the HSC Trusts make explicit their commitment to a process for planning the supply of care and support services and which involve all stakeholders early in developing the strategic vision for future provision.

Proposal 11

The Expert Advisory Panel proposes that the Department of Health considers whether additional powers should be given to the Regulation and Quality Improvement Authority to regulate the professional care market. In particular assuring adherence by care providers to the principles in Proposal 8 including the oversight of a fair and agreed return.

Proposal 12

The Expert Advisory Panel proposes that HSC Trusts are enabled to more effectively discharge market shaping responsibilities. In this way requirements to facilitate self-directed support and encourage community based models of intervention alongside formal systems of care and support can be monitored.

Proposal 13

The Expert Advisory Panel proposes that the Department of Health oversees the introduction of a whole-systems approach to facilitating joint working between commissioners, health services and care providers, which include a clear mechanism for involving people receiving services and carers within all the HSC Trusts.

Proposal 14

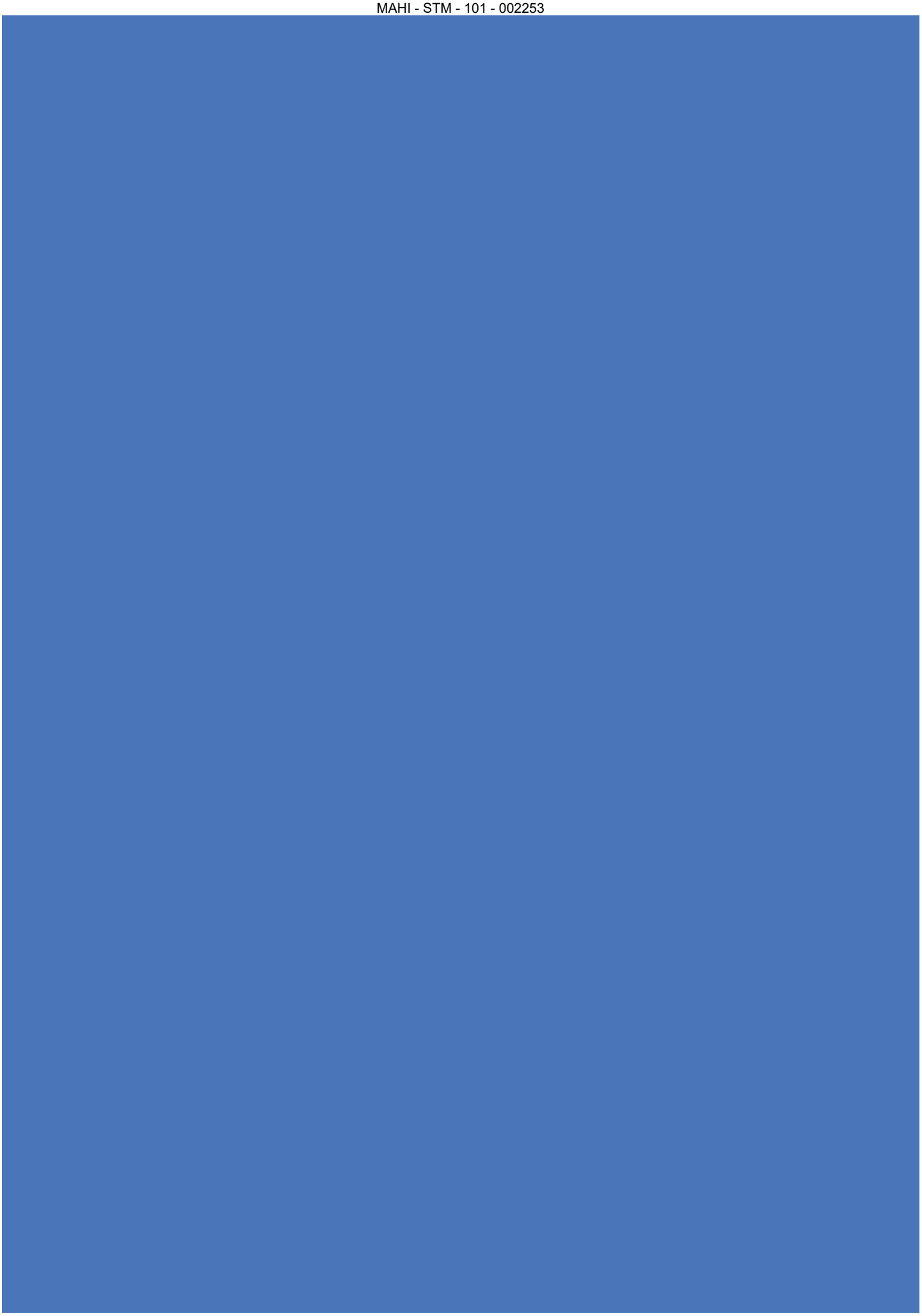
The Expert Advisory Panel proposes that the HSC Trusts promote a collaborative, rather than competitive, ethos which fully involves all key stakeholders in the care and support system.

Proposal 15

The Expert Advisory Panel proposes that the Department of Health and the HSC works more closely with the Department for Communities and NI Housing Executive around future strategies for specialist and supported housing to ensure more effective alignment between housing and social care.

Proposal 16

The Expert Advisory Panel proposes that a Concordat is developed as the major means of stimulating a comprehensive debate, and agreement, with the public about the principles underpinning a transformed adult care and support system, including its purpose, how it is organised and funded. The debate should also review attitudes to risk and how citizens can be more enabled to be the determinants of their own risk tolerance and mitigations.



EXPERT ADVISORY PANEL ON ADULT CARE AND SUPPORT SUPPORTING ANNEX

Background to Establishment of Panel

This paper 'Power to People: Proposals to Reboot Adult Care and Support in Northern Ireland' is the second stage in a three stage process the Department of Health is undertaking to reform adult care and support services. This process began in September 2012 with stage one, an extensive consultation on the discussion document 'Who Cares? The Future of Adult Care and Support in Northern Ireland'. This document sought to build public consensus on the need to reform care and support, given the challenges the system was facing and will continue to face in the years to come. That consultation ran until March 2013, receiving over 180 responses and reaching over 600 people through public meetings and focus group sessions. A paper summarising the findings of the Who Cares? consultation can be accessed at the following link: **https://www.health-ni.gov.uk/publications/who-cares-consultation-analysis-report.**

The second stage of the Reform process was initiated with the establishment of a Project Board and Project Team, which began the process of developing a stage two paper for public consultation that would outline draft proposals for change. Then, in early 2016 the then Minister for Health, Simon Hamilton, announced his intention to appoint an independent panel of experts to consider and review adult care and support.

On 5 December 2016 the former Health Minister, Michelle O'Neill, announced the establishment of the Expert Advisory Panel on Adult Care and Support. Des Kelly OBE and John Kennedy were appointed to the Panel as independent experts with a wealth of experience in adult care and support policy development and delivery. The Panel was tasked with producing robust, evidence-based proposals for change. This was one of the key commitments outlined in 'Health and Wellbeing 2026: Delivering Together', a 10 year vision for health and social care.

The Expert Advisory Panel on Adult Care and Support commenced their work on 5 December 2016. The Panel's Terms of Reference can be found at Appendix A to this paper.

Call for Evidence

To assist the Expert Advisory Panel in undertaking their work, a Call for Evidence was also launched on 5 December 2016, seeking evidence from stakeholders in relation to the challenges facing adult care and support, existing examples of good practice and potential solutions or reforms. The Call for Evidence sought evidence under six Priority Areas:

1. Empowering people to make positive choices and plan for the future
2. Supporting people to regain, retain and maintain their independence
3. Supporting carers
4. Choice and control
5. An effective, innovative and resilient care and support market underpinned by a valued social care workforce
6. Financial sustainability

In total, 46 separate submissions were received from a range of organisations and some individuals. An additional 46 papers were also submitted as supplementary evidence. A list of respondents is provided at Appendix B. We have chosen not to publish the names of those individuals who have responded in a private rather than professional capacity. A number of respondents requested that their responses not be published or quoted; this has been respected and no references to those responses have been included in the Expert Advisory Panel's report.

Each of the responses were individually read and analysed by the Expert Advisory Panel and the Department of Health, and the key points under each of the Priority Areas were collated in a spreadsheet to support the Panel in drafting their report. The table below provides a short synopsis of some of the views, suggestions and examples shared in submissions to the Call for Evidence. This does not reflect every response submitted, but rather gives a flavour of some of the points made.

Priority area	Responses
1: Empowering people to make positive choices and plan for the future • Initiatives which encourage positive lifestyle choices; • Most effective means of providing information.	Good evidence of local projects: • Southern Trust (walking, Cycling for Health, Cook it), MEEAP Ageing Well and Reaching Out Programme (156 Age Champion Volunteers), Western Trust Later Years sub-group Health and Wellbeing Plan, YMCA Lisburn project supporting and educating young adults with a learning disability to choose a healthy lifestyle; Potential of Active Ageing strategy to deliver in this area; UU have developed a training programme and manual to assist professionals to work with families to make a future plan; Information shouldn't be digital by default. One stop shop supplemented by advocacy services. Mencap give example of wraparound one stop shop for children's services and disabledgo.com website; Consider NHS Accessible Information Standard; Needs to be a review of legislation as a first step.
2: Supporting people to regain, retain and maintain independence • Local initiatives; • Improving awareness of community support; • How services can be redesigned to promote independence; • Working more closely with housing, transport and technology.	Good evidence of local projects: • Coalition of Community Groups (Good Neighbour, Home Secured, Schools Volunteering, Good Carer projects), Mencap (Link Me, Lifestyle Support, Golden Lane Housing), Western Trust flexicare, Beyond Words Peer Support, CLARE project – positive outcomes i.e. social connectivity, clients treated with dignity and respect; Local groups an effective means of sharing information, e.g. Age NI's Age Sector Networks. Also suggestion of preventative visit (COPNI); Support for role of a Navigator (e.g. dementia), possibly linked to older person's support hub;

Priority area	Responses
	Should be a regional database of events/activities. Western Trust has a local one and Belfast Trust is developing a community hub; Number of suggestions about how we could better promote independence: • Expansion of Shared Lives around hospital interface, development of Circles of Support to act as a community around service users, Living Well model (Cornwall evidence suggests increased wellbeing and reduced acute and social care costs); • Move towards outcome-based commissioning; • Care homes could become community hubs for local hospitals; • Implement service models such as Living Well. **Technology:** Risk-averse nature of HSC. Easy access video technology can help with social isolation, apps can prompt medicating, eating and drinking. Remote monitoring of vital signs or falls. SOL Glasgow given as an example of low level technology which has enabled service users who required 1:1 supervision to cope on their own for some time. Also Good Morning NI Connected Health Tech pilot showed improved wellbeing and intergenerational connection and there are plans to extend this to the wider population. **Housing:** Different budget cycles make alignment difficult. Federation of Housing Associations suggests that there is huge potential for assistive technology but this is restricted by lack of clarity on funding responsibilities. Supporting People – voids/ responsibility between partners. **Transport:** Ensure Regional Transport strategy is taken forward. Example schemes such as Rural Lift, volunteer/buddy lift.

Priority area	Responses
3: Supporting Carers • Effective support for carers; • Initiatives which can encourage people to become/remain carers.	Good examples of effective services: • Shared Lives (evaluated by Cabinet Office) and Mencap's Caring Breaks (95% of carers felt the service had reduced their stress levels). Key features include early identification, wider public recognition of carers, more training. Consider approach in Netherlands – preventative counselling and support offered. Assessment must be carer-blind. Carer's Assessments – lack of statutory basis an issue and there needs to be resources available to respond to those assessments. Information important - Consider role for Carer Navigators. Also Shared Care Scotland's one stop shop. Impact on employment a big factor. Consider Scotland's 'Carer-Friendly' accredited Employer scheme.
4: Choice and Control • Barriers; • Initiatives which empower; • Balance between risk and choice.	Barriers include lack of professional knowledge of range of options, the availability of services to buy and the low rate of SDS – not high enough to attract skilled personal assistants. Also fear of unknown, rules on top-ups restrict choice, inflexibility of commissioning. Empowering – increasing staff awareness, consider Individual Service Funds as a means of administering Direct Payments, use social and community networking. Positive Futures is the NI-rep on the UK-wide National Brokerage Network. Majority view that right to make a choice should come first but concern among some that choices have to be informed and decisions safe (which unregulated SDS may not be). Consider DH document 'Nothing ventured noting gained' re. risk enablement.

Priority area	Responses
5: Care and Support Market/ Workforce • Challenges specific to NI; • How do we improve the market; • How do we improve the experience of the workforce.	Impact of regional rate and regional contract needs to be considered: regional rate assumes everyone has the same level of need, no promotion of improving outcomes, smothers creativity. Other challenges include staff turnover, low domiciliary care rates, current model of procurement discouraging the sharing of ideas and expertise. NI market isn't resilient as evidenced by home closures. Capital investment has slowed because banks are reluctant to lend. Workforce a challenge – IPPR dashboard suggests up to 10% vacancies in the workforce. Need for review of: • needs assessment; • rates paid for care (including VfM audit comparison of statutory and independent sectors). Suggestion of a price regulator; • skill mix required (Standard 41 highlighted as a major concern. Four Seasons have developed the CHESS model of staffing) Should consider market oversight measures as per England. Quality – Four Seasons introduced a Quality of Life Programme to improve quality; Southern Trust established an Independent Sector Governance Committee. Workforce summary – career progression, terms and conditions, training and development. Also social care pays apprenticeship levy but doesn't benefit from it – should be explored. Consider economic value of the workforce. Focus on people's core values to attract the right workforce. Consider 'I Care' ambassadors developed by Skills for Care in England. Ensure workforce has adequate time to carry out tasks and enable meaningful engagement.

Priority area	Responses
	Consider new carer roles to enable career development. Four Seasons suggests an advanced healthcare assistant role would help.
6: Financial Sustainability • Evidence of efficiencies; • Unique NI factors that should be taken into account re. charging; • Evidence of impact of charging; • Measures to address perceived unfairness of charging for residential care	Alternative ways of supporting people - Shared Lives suggests it costs less than other forms of care for both people with a learning disability and mental health needs. Social Farming suggests for every £1 invested, £3.50 is returned in benefits. UNISON suggests removing the purchaser provider split would release funding. Role of care homes in facilitating timely discharge should be more fully explored. Thinktanks like Respublica have suggested the creation of a Fast Track Discharge Fund with funds redirected from hospitals to residential care. Residential care supported by in-reach nursing could support some clients currently in more expensive nursing homes. Charging – some support for considering all benefits in charging but taking into account factors such as levels of pensioner poverty. Suggested that any charging would have to be coupled with investment. No measures suggested to address the issue of unfairness.

STAKEHOLDER ENGAGEMENT

Meetings and Visits

The Expert Advisory Panel's contract was for 30 days over five months (December 2016 to May 2017). During this time they spent 18 days in Northern Ireland and 12 days working from their home base in England.

On the days the Panel spent in Northern Ireland, they met with a wide range of key stakeholders and visited a number of services. During these visits the Panel were also able to meet and speak with people using services, carers, and professionals in the care and support system.

It was not possible for the Panel to meet face-to-face with Professor Bengoa, but they were able to consult with him via teleconference sharing a late draft of the report. The Panel were greatly encouraged by the feedback and his observations on linkages and coherence in relation to his work on the healthcare system.

Information on all meetings and visits is provided in Appendix C.

Adult Care and Support Reference Group

Throughout the course of their work, the Panel, have sought to engage meaningfully with the wide range of interested parties and stakeholders. To promote and facilitate service users' and carers' involvement, the Patient Client Council established an Adult Care and Support Reference Group on behalf of the Department of Health. This was intended to provide an independent mechanism to facilitate service users' and carers' engagement with the Panel and the Reform process. The Panel met with the Reference Group on two occasions: in early February 2017 to present their early views following the close of the Call for Evidence, and again in late April 2017 to present a summary of their draft report. The Reference Group also provided written evidence to the Panel to assist in their work. A short summary of some of the comments and suggestions made by the Reference Group is outlined below.

- government departments need to work significantly closer together to respond to the needs of the population;
- need to see a greater acknowledgement of the needs of other populations, specifically younger people with disabilities;
- need a genuine commitment and dialogue regarding preventative care;
- need a 'mutual approach' to service delivery based on 3 elements: prevention, performance improvement and partnership working;
- service users and carers should be empowered to determine the level of risk acceptable in their own homes and communities, e.g. the current menu of services is restricted by standards and regulations;
- recommended maximising the use of volunteering and training people in

other walks of life who would like to take on community volunteering;
- need to look at the whole community as a workforce in terms of training and service development;
- family carers are part of the workforce and there is a need to define 'mandatory' training for carers;
- it should not always be seen as the responsibility of parents to continue caring into adulthood;
- carers should be protected and supported in their role;
- there is a legal right to choose not to be a carer;
- families need to be supported in planning for the future;
- it is important to have an open discussion about funding;
- concern about the role of for-profit providers;
- need to start other conversations on topics such as; reinstating prescription charges, increasing National Insurance, charging for domiciliary care; and younger people taking out insurance policies to cover future care costs;
- concern that funding is weighted towards acute services - this must be addressed for care in the community to have a solid foundation.

In addition to the Group's discussion, a number of members also shared papers and submissions with the Panel. The Panel were very grateful for the opportunity to meet with and work with Reference Group members, whose input throughout the process played a crucial role in shaping the their thinking and the Proposals Paper.

Workshops

In early March the Department of Health facilitated three workshops to support the Panel in testing their early ideas with a range of stakeholders. These workshops took place in Craigavon, Derry and Belfast, and each workshop covered a different theme:

Date	Venue	Theme
Monday 6 March 2017	Oxford Island, Craigavon	Choice, Control and Community Engagement
Tuesday 7 March 2017	City Hotel, Derry	Building Capacity and Sustainability
Wednesday 8 March 2017	Malone House, Belfast	Workforce

In total, around 130 people attended the workshops, although this may include an element of double counting as some people attended more than one event. The Panel were very impressed at the high levels of engagement during each of the workshops, and found the feedback received to be of great benefit in further shaping and consolidating their thoughts.

Some of the issues raised are noted below:

- Support greater emphasis on prevention – including role of voluntary and community sector, addressing social isolation, promoting active ageing, housing solutions and supporting carers;
- Funding needed to pump prime new services and build public support;
- Small amount of targeted community support can make an enormous difference;
- Developing the workforce will help reduce risk;
- Service user should control the money – in vast majority of cases it will be used appropriately and with positive outcomes;
- Different budgets within Trusts can act as a constraint;
- Need sufficient and appropriate housing stock to allow more people to remain at home;
- Can't allow technology to become an excuse to isolate people from human contact;
- Need to consider that younger people with disabilities do not have the means to build up capital to pay for social care;
- Challenge of balancing choice (greater choice equals greater complexity) and simplicity;
- Perhaps too much emphasis on older people – consider younger people with progressive conditions;
- Build on potential of community planning through local government;
- Need to consider the impact on care homes of any introduction of charges for domiciliary care;
- Charging discussion needs to take place in the context of improved/higher quality services;
- Need to avoid race to the bottom;
- Can be difficult to include social value clauses like the Living Wage;
- Commissioning could be done at individual service user level;
- Consider the impact of BREXIT on the workforce;
- Need long term commissioning plan and funding arrangements;
- Need to avoid blame culture, give leaders confidence;
- System should be easier to navigate;
- Needs to be a shift from reactive to preventative;
- Money has to be invested in a planned way to build towards outcomes;
- Service users need to understand at outset what outcomes are sought, and what the agreed journey is;
- Needs to be accredited, transferrable training to enable people to build careers;
- Need to look at bad PR around social care – only the mistakes get reported by media;
- More support needed for carers;
- Concern that the voice of carers is not being heard;
- Pressure on domiciliary care workforce due to increasing complexity of need;
- Standard of service delivery more important than whether a provider is private;
- People need to understand cost of care.

Further details on the workshops, including the questions asked at each event and the organisations who attended, can be found in Appendix D.

APPENDIX A

EXPERT ADVISORY PANEL ON ADULT CARE AND SUPPORT

Terms of Reference

The Expert Advisory Panel will supplement the work of the Core Team in developing proposals for change in the following areas:

- Steps which can be taken to empower people to encourage positive lifestyle choices and planning for the future;
- Supporting people to regain, retain and maintain their independence through, for example, a focus on preventative services and technology;
- Supporting carers in their caring role;
- Facilitating choice and control over how care and support needs are met;
- Ensuring an effective, innovative and resilient care and support market underpinned by a respected, quality social care workforce; and
- Measures which can be taken to ensure the financial sustainability of the care and support system.

In this context, the Panel will help shape proposals through:

- A call for evidence inviting stakeholders to share ideas on potential reforms;
- A review of evidence and international best practice in these areas;
- The identification of further areas for potential reform which could contribute to a better system of support; and
- Assessing impact of reforms on balance of responsibility between government, people who use services and carers.

The Panel will report directly to the Minister.

APPENDIX B

List of Respondents to Call for Evidence

Reference Number:	Organisation:
CFE1	Chartered Society of Physiotherapy
CFE2	Individual
CFE3	Royal College of Speech & Language Therapists
CFE4	Prof Assumpta Ryan, Professor of Ageing and Health, Ulster University
CFE5	Acquired Brain Injury Rehabilitation Team, Southern Health and Social Care Trust
CFE6	Bardan Cottage
CFE7	Carers NI
CFE8	Mid & East Antrim Agewell Partnership (MEAAP)
CFE9	CLARE CIC
CFE10	Optimum Care & Domestic Care Group
CFE11	UK Home Care Association (UKHCA)
CFE12	Dalriada Pathfinder Partnership
CFE13	Independent Health and Care Providers (IHCP)
CFE14	Positive Futures (1)
CFE15	MS Society
CFE16	MD Healthcare
CFE17	Southern Health and Social Care Trust
CFE18	Confederation of Community Groups (CCG)
CFE19	Shared Lives Plus
CFE20	Social Farming
CFE21	Dr Laurence Taggart, Lead for the Centre of Intellectual and Developmental Disabilities, Ulster University
CFE22	Four Seasons Health Care
CFE23	Western Health and Social Care Trust

Reference Number:	Organisation:
CFE24	RDB Star Rating
CFE25	Praxis Care
CFE26	Positive Futures (2)
CFE27	Commissioner for Older People in Northern Ireland (COPNI)
CFE28	Northern Ireland Social Care Council (NISCC)
CFE29	Association for Real Change (ARC)
CFE30	The Cedar Foundation
CFE31	Cruse Bereavement Care NI
CFE32	Individual
CFE33	Age NI
CFE34	Dr Lorna Montgomery, Lecturer in Social Work & Dr Bernie Kelly, Senior Lecturer in Social Work, Queen's University Belfast
CFE35	RQIA
CFE36	UNISON
CFE37	Mencap NI
CFE38	Lancashire Care Association Co. Ltd
CFE39	Carer Coalition, incl. Age NI, Cause, MacMillan Cancer Support, MS Society, Positive Futures, Carers NI, Mencap NI, Detail Data, and Northern Ireland Council for Voluntary Action (NICVA)
CFE40	Northern Ireland Association of Social Workers (NIASW)
CFE41	College of Occupational Therapists
CFE42	Individual
CFE43	Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC)
CFE44	Individual - Easy Read
CFE45	Positive Futures (Easy Read response)
CFE46	Health and Social Care Board (HSCB)

APPENDIX C

Meetings and Visits

Date	Meeting/Visit
5 December 2016	Meeting with Reform Team: **Chris Matthews**, Director of Mental Health, Disability and Older People's Policy, Department of Health (DoH), and Reform Project Manager **Dean Looney**, Reform Core Team, DoH **Taryn McKeen**, Reform Core Team, DoH **Ruth Todd**, Reform Core Team, DoH
	Meeting with DoH Adult Social Care Policy Leads: **Jerome Dawson**, Head of Elderly and Community Care Unit **Colin Dunlop**, Acting Head of Physical and Sensory Disability Unit **Alison McCaffrey**, Head of Learning Disability Unit **Andrew Dawson**, Head of Mental Health Policy and Legislation Unit
	Meeting with Reform Project Senior Responsible Owner: **Seán Holland**, Deputy Secretary and Chief Social Work Officer, DOH

Date	Meeting/Visit
9 January 2017	Meeting with DoH Social Work professionals: **Jackie McIlroy**, Acting Deputy Chief Social Work Officer **Jillian Martin**, Lead Social Work Professional for Older People and Community Care **Christine Smyth**, Strategy Director (Social Work)
	Meeting with: **Kathy Fodey**, Director of Regulation and Nursing, Regulation and Quality Improvement Authority (RQIA)
	Meeting with representatives of provider organisations: **Colin Angel,** Policy and Campaigns Director, UK Home Care Association (UKHCA) **Pauline Shepherd**, Chief Executive, Independent Health and Care Providers (ihcp) **Carol Cousins**, Managing Director, Four Seasons Northern Ireland
	Meeting with Department for Communities (DfC): **Stephen Martin**, Housing Lead **Ronan McClean,** Housing Affordability Branch

Date	Meeting/Visit
10 January 2017	Meeting with AgeNI representatives: **Linda Robinson**, Chief Executive **Duane Farrell**, Charity Director **Paschal McKeown**, Head of Policy and Influencing
	Visit to Hemsworth Court (supported living facility for people with dementia). Meeting with Belfast Health and Social Care Trust representatives coordinated by **Marie Heaney**, Co Director, Adult Health and Social Care Services.
	Meeting with: **Colum Conway**, Chief Executive, NI Social Care Council
	Meeting with Housing Association representatives: **Cameron Watt**, Chief Executive, NI Federation of Housing Associations (NIFHA) **Denise Magill**, Director of Support Services, Triangle Housing **Fiona McAnespie**, Director of Care Services, Fold Housing
	Meeting with UNISON representatives: **Patricia McKeown**, NI Regional Secretary **John Patrick Clayton**, Policy Officer **Anne Speed**, Head of Bargaining and Representation

Date	Meeting/Visit
11 January 2017	Visit to Learning Disability services (supported living facility and Acceptable Enterprises (Larne) Ltd), Northern Health and Social Care Trust, coordinated by: **Iolo Eilian**, Lead Commissioner for Learning Disability, Health and Social Care Board **Alyson Dunn**, Assistant Director, Northern Health and Social Care Trust
	Meeting with Office of the Commissioner for Older People in NI (COPNI): **Eddie Lynch**, Commissioner for Older People in Northern Ireland **Evelyn Hoy**, Chief Executive **Emer Boyle**, Head of Legal and Policy Advice
	Meeting with Health and Social Care Board: **Kevin Keenan**, Assistant Director, Adult Social Care
30 January 2017	Meeting with Reform Team staff to discuss Call for Evidence responses
13 February 2017	Meeting with: **Orla Donaghy**, Head of Social Care Procurement Unit, Business Services Organisation (BSO)
	Meeting with: **Reform of Adult Care and Support Project Board** (multi-agency)
	Meeting with: **Professor Roger O'Sullivan**, interim Chief Executive of the Institute of Public Health (IPH)

Date	Meeting/Visit
14 February 2017	Visit to Meadowvale Court, Cedar Foundation Supported Living unit. Meeting with: **Stephen Mathews OBE**, Chief Executive, Cedar Foundation **Eileen Thomson**, Deputy Chief Executive **Professor Suzanne Martin**, Professor of Occupational Therapy, Ulster University **Bria Mongan**, Director of Adult Services, South Eastern Health and Social Care Trust **Nicola McEvoy**, Case Officer, Inclusion Works (Cedar programme) **Former Inclusion Works participant** **Cedar User Forum representative**
	Meeting with: **Adult Care and Support Reference Group** (managed by Patient Client Council)
	Meeting with Carers NI representatives: **Clare-Anne Magee**, General Manager, Carers NI **Simon Hodgson**, Director of Scotland and NI **Lesley Johnston**, Advice and Information Officer
23 February 2017	Meeting with Mencap NI representatives: **Margaret Kelly**, Director **Jamie Greer**, Employment & Personal Development Manager **Neil Calvin**, Area Operations Manager **Fiona Cole,** Campaigns and Policy Officer **Geraldine McGurk**, Lifestyle Support Service Manager
	Meeting with Association for Real Change (ARC) representatives: **Leslie-Anne Newton**, NI Director, ARC **Delores Finnerty**, Caring Breaks **Agnes Lunney**, Positive Futures **Linda Wray,** Presbyterian Board of Social Witness

Date	Meeting/Visit
27 February 2017	Visit to Inspire Wellbeing learning disability service and mental health supported living facility
	Meeting with: **Professor Peter McBride**, Chief Executive **Margaret Cameron**, Director of Learning Disability Services **Billy Murphy**, Director of Mental Health Services
	Meeting with: **Sarah Wylie**, System Dynamics economist (Department of Finance)
7 March 2017	Meeting with CLARE CIC representatives: **Mandy Cowden**, Project Coordinator **Laura Feeney**, Board member
3 April 2017	Meeting with: **Jackie Johnston**, Deputy Secretary, Delivering Together Transformation Programme
	Meeting with: **Richard Pengelly**, Permanent Secretary, DoH
12 April 2017	Meeting with Reform Team to discuss draft report.
24 April 2017	Meeting with: **Reform of Adult Care and Support Project Board** (multi-agency)
25 April 2017	Meeting with: **Adult Care and Support Carer Reference Group** (managed by Patient Client Council)
	Meeting with: **Reform of Adult Care and Support Project Team** (multi-agency working group)

Date	Meeting/Visit
18 May 2017	John Kennedy presentation to NICON conference on Panel's work
22 May 2017	Teleconference with: **Professor Rafael Bengoa**, Chair of Expert Panel who produced "Systems, Not Structures: Changing Health and Social Care"
31 May 2017	Presentation of the final report to the **Transformation Implementation Group** (TIG), who are responsible for overseeing the wider transformation programme outlined under "Delivering Together"

APPENDIX D

Workshop Details

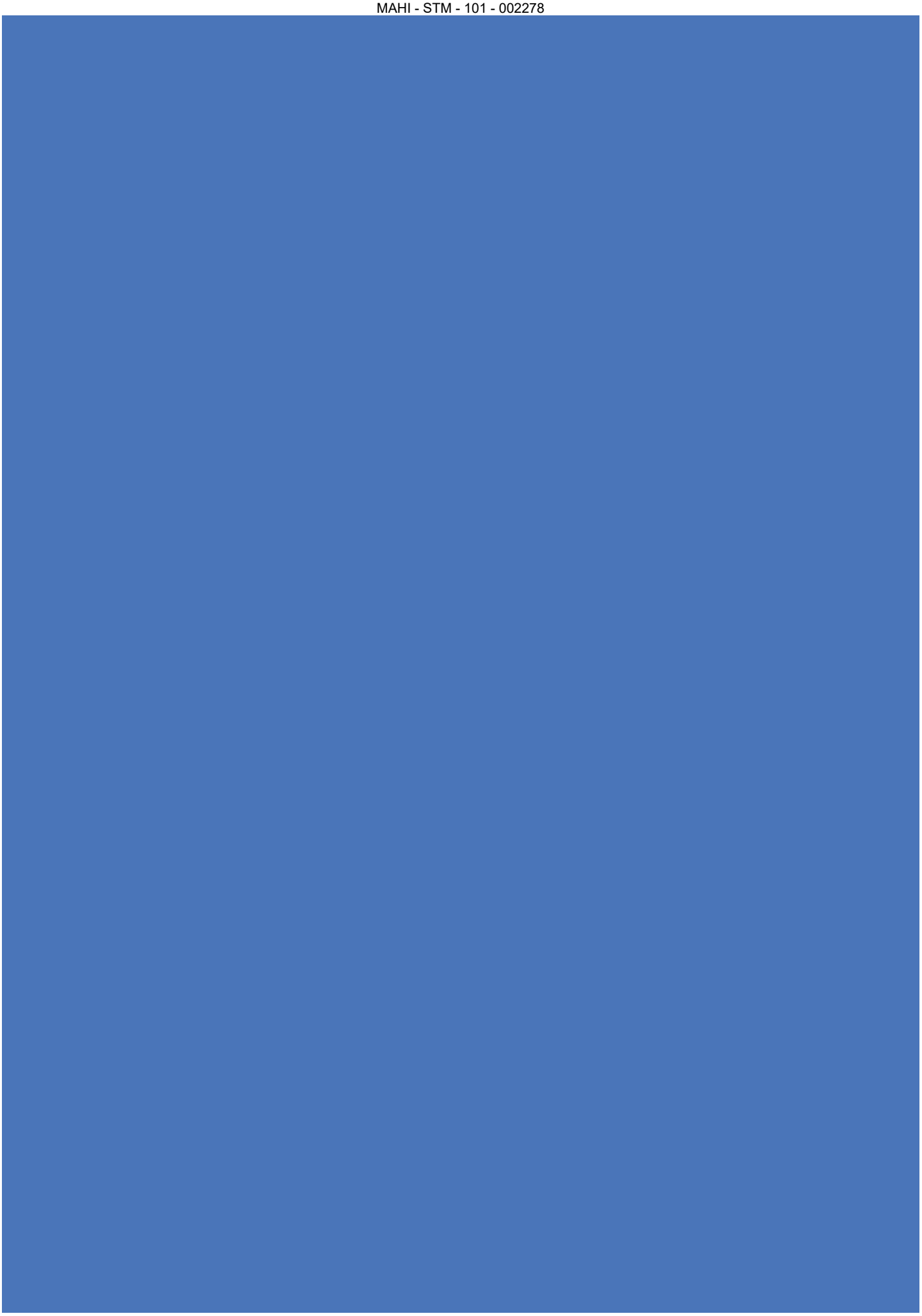
Monday 6 March 2017: Choice, Control and Community Engagement	
Venue:	Lough Neagh Discovery Centre, Oxford Island Nature Reserve, Craigavon
Questions:	1. Does there need to be a new concordat? 2. What should the role of carers be and how should they be supported? 3. What does choice and control really mean? 4. What does the perfect system look like for citizens? 5. What is the role of communities and how should they be supported?
Number of attendees:	45
Organisations attending:	Royal College of Speech and Language Therapists (RCSLT), Volunteer Now, Western HSC Trust, Inspire Wellbeing, UNISON, Positive Futures, Four Seasons Health Care, CLARE, Health and Social Care Board (HSCB), Independent Health and Care Providers (ihcp), Business Services Organisation (BSO), NI Local Government Association (NILGA), Cruse, MS Society, Adult Care and Support Reference Group, Southern HSC Trust, Shared Lives, Department of Health (DoH), College of Occupational Therapists (COT), Alzheimer's Society, Centre for Independent Living (CIL), Patient Client Council (PCC), Regulation and Quality Improvement Authority (RQIA), NI Social Care Council (NISCC), Equality Commission NI, NI Association of Social Workers (NIASW), Institute of Public Health (IPH), Northern HSC Trust, Department for Communities (DfC), Rural Support, Domestic Care, South Eastern HSC Trust, Age NI, Department of Finance (DoF).

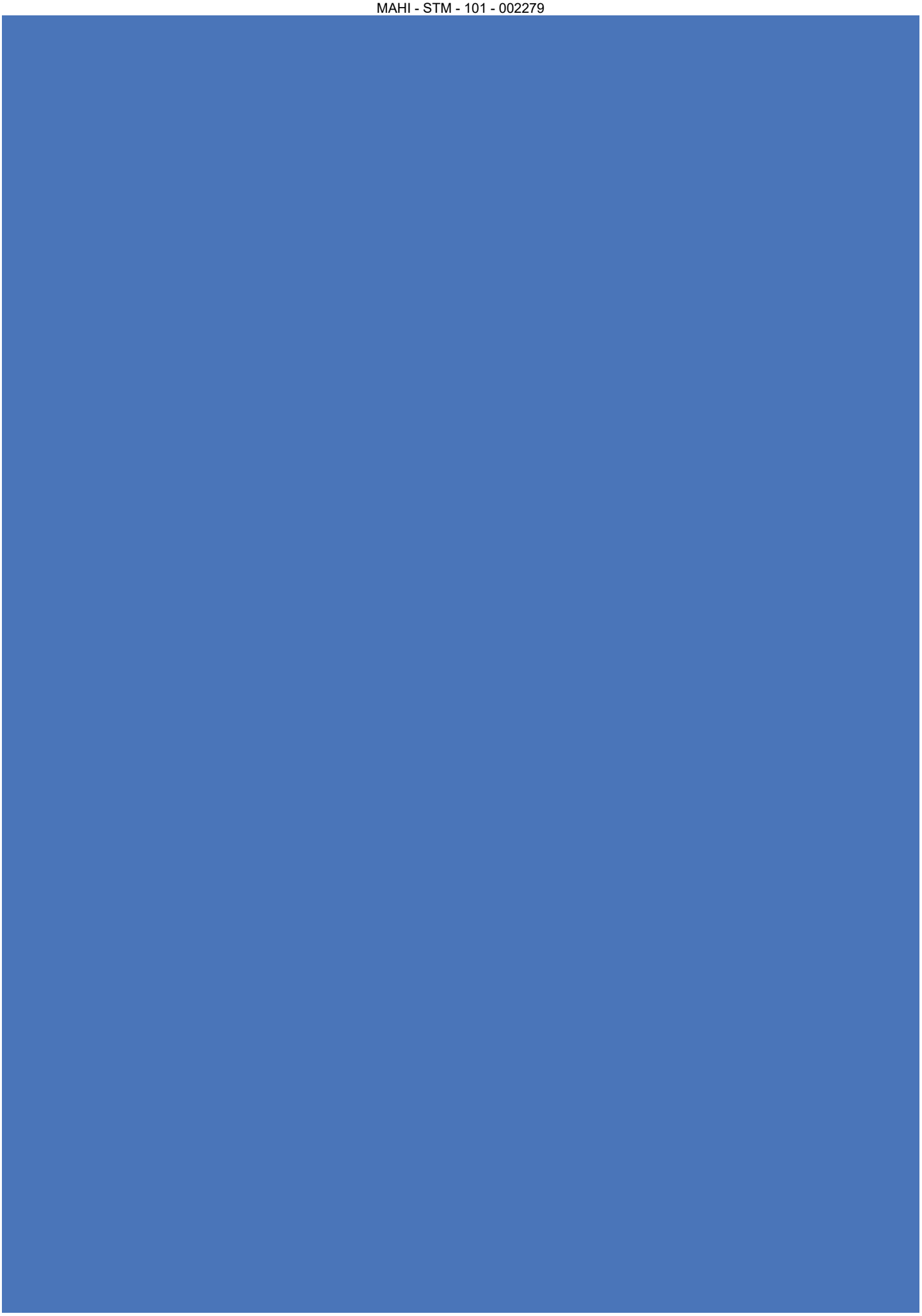
Tuesday 7 March: Building Capacity and Sustainability	
Venue:	City Hotel Derry, Queens Quay, Londonderry
Questions:	1. What is a fair and clear Charging Policy? 2. Do we need commissioning and who should do it? 3. Is a mixed economy of care the best way of providing care and support? 4. What does the perfect system look like for citizens? 5. How do we better promote innovation and creativity?
Number of attendees:	35
Organisations attending:	NI Federation of Housing Associations (NIFHA), UNISON, Western HSC Trust, Public Health Agency (PHA), Southern HSC Trust, UNISON, NISCC, Law Centre NI, Four Seasons Health Care, Alzheimer's Society, HSCB, Age NI, DoH, PCC, Rural Support, Shared Lives, COT, MS Society, Inspire Wellbeing, Association for Real Change (ARC), Northern HSC Trust, Chartered Society of Physiotherapists (CSP), Domestic Care, Cedar Foundation.

Wednesday 8 March: Workforce	
Venue:	Malone House, Barnett Demesne, Belfast
Questions:	1. How do we empower leaders to deliver change? 2. What does the perfect system look like for citizens? 3. What would an ideal career pathway look like? 4. How can the system be reshaped to place greater emphasis on the value of the workforce? 5. Does it matter if the employer is private, voluntary or statutory?
Number of attendees:	51
Organisations attending:	Southern HSC Trust, South Eastern HSC Trust, Domestic Care, DoH, Adult Care and Support Reference Group, RQIA, Northern HSC Trust, Cedar Foundation, Inspire Wellbeing, NISCC, PHA, RCSLT, Age NI, Four Seasons Health Care, Positive Futures, NIASW, Western HSC Trust, Alzheimer's Society, Shared Lives, Praxis Care, COT, UNISON, CIL, PCC, NI Practice and Education Council for Nursing and Midwifery (NIPEC), HSCB.

115

NOTES





NICE National Institute for Health and Care Excellence

NICE guideline

Learning disabilities and behaviour that challenges: service design and delivery

NICE guideline

Published: 28 March 2018
www.nice.org.uk/guidance/ng93

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

Overview 5
Who is it for? 5
Context 6
Background 6
The aim of this guideline 7
What is the status of this guidance? 7
How does it relate to legal duties and other guidance? 8
How has it been developed? 8
Recommendations 10
Aims and principles 10
1.1 Achieving change: strategic planning and infrastructure 11
1.2 Enabling person-centred care and support 15
1.3 Early intervention and support for families and carers 21
1.4 Services in the community – prevention, early intervention and response 23
1.5 Housing and related support 28
1.6 Services for children and young people 30
1.7 Short break services 33
1.8 Making the right use of inpatient services 35
1.9 Staff skills and values 37
Terms used in this guideline 39
Putting this guideline into practice 42
Recommendations for research 45
1 Models of person-centred support 45
2 Supporting family members, carers and staff 45
3 Models of supported living 46
4 Effective components of integrated regional services for people with a learning disability and behaviour that challenges 46

Finding more information and committee details 48

Update information 49

This guideline is the basis of QS101.

This guideline should be read in conjunction with NG11.

Overview

This guideline covers services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. It aims to promote a lifelong approach to supporting people and their families and carers, focusing on prevention and early intervention and minimising inpatient admissions.

This guideline should be read alongside the NICE guideline on challenging behaviour and learning disabilities: prevention and interventions.

NICE has produced an EasyRead version and video for people with a learning disability.

Who is it for?

- Commissioners and providers of health and social care services for children, young people and adults with a learning disability and behaviour that challenges
- Health and social care practitioners working with children, young people and adults with a learning disability and behaviour that challenges
- Providers of related services, including housing, education, employment and criminal justice services
- Practitioners working with children, young people and adults with a learning disability and behaviour that challenges in other services or settings, including education, housing, voluntary and community services, employment and criminal justice services
- Children, young people and adults with a learning disability and behaviour that challenges and their families and carers, including people who pay for their own care

Context

Background

An estimated 1.2 million children, young people and adults in England have a learning disability, and of these it is estimated that 10–17% display behaviour that challenges (see Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. Allen et al. 2007). A more recent report suggested that there are over 40,000 children with learning disabilities who display behaviour that challenges (see Estimating the number of children with learning disabilities in England whose behaviour challenges. Emerson et al. 2014). In addition, approximately 1% of the adult population has an autism spectrum condition and 60–70% of these also have a learning disability (see Estimating the prevalence of autism spectrum conditions in adults Brugha et al. 2012).

The most commonly used definition of behaviour that challenges is: '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 deny access to and use of ordinary community facilities' (Emerson et al. 1987). Later definitions have highlighted the role of cultural context in determining whether behaviour is perceived as challenging (Emerson 1995).

This guideline was developed in a context of changes to policy and practice for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. The support needs of these vulnerable groups were set out in 1992 in the Mansell report, which identified the need to invest in developing local services with appropriate levels of skilled staff to meet people's needs. This was restated in a later review, the so-called 'Mansell 2 report' (see Services for people with learning disabilities and challenging behaviour or mental health needs. Department of Health), which also highlighted the increased use of placements away from people's homes.

The exposure of widespread abuse at Winterbourne View hospital in 2011 led to a review of care provided in this hospital, and across England more widely, for people with a learning disability and behaviour that challenges. The resulting report (see Transforming care: a national response to Winterbourne View hospital. Department of Health) started a programme of work to improve services for people with a learning disability or autism who

also have mental health conditions or behaviours described as challenging. In particular, this aimed to shift emphasis from inpatient care in mental health hospitals towards care based on people's individual needs and wishes and those of their families, provided by general and specialist services in the community. The programme did not meet its original targets, as highlighted in a report by the National Audit Office (see Care services for people with learning disabilities and challenging behaviour), and was reconfigured in 2015.

The 'transforming care programme' is now led jointly by NHS England, the Association of Directors of Adult Social Services, the Care Quality Commission, Local Government Association, Health Education England and the Department of Health. The national plan (see Building the right support. 2015) included plans for 48 'transforming care partnerships' to pilot new arrangements of services. The national plan was followed by NHS England's national service model (October 2015) that set out the range of support that should be in place no later than March 2019. To support implementation of the interim service model, NHS England developed 3 model service specifications (see Transforming Care: service model specification. January 2017) and supplementary guidance on Developing support and services for children and young people with a learning disability, autism or both (September 2017). This guidance also supports the recommendations of Dame Christine Lenehan's review (January 2017) on providing care and support for children and young people with complex needs who display challenging behaviour.

The aim of this guideline

This guideline takes into account the direction of travel in the transforming care programme. It complements this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges to live their lives in the community like everyone else.

It is based on evidence about effectiveness and cost effectiveness of different support and services, and how those services are coordinated. It is also informed by the views of people who use services and their families on what is important to them in their care and support.

What is the status of this guidance?

The application of the recommendations in this guideline is not mandatory. Although there

is no legal obligation to implement our guidance, health and social care practitioners, and practitioners in related services, are actively encouraged to follow our recommendations to help them deliver the highest-quality care.

How does it relate to legal duties and other guidance?

This guideline complements statutory duties and good practice as set out in relevant legislation and guidance. The recommendations cross-refer to legislation and other guidance where appropriate. Relevant legislation and guidance includes:

- Autism Act 2009
- Care Act 2014 and associated guidance
- Children Act 1989 and associated guidance
- Children and Families Act 2014
- Children and Young Peoples Act 2008
- Chronically Sick and Disabled Persons Act 1970
- Human Rights Act 1998
- Mental Health Act 1983, 2007
- Mental Capacity Act 2005 (amended 2007) and associated guidance on Deprivation of liberty safeguards.

How has it been developed?

The guideline has been developed by a committee of people who use services; family members and carers of children, young people and adults with a learning disability who display behaviour that challenges; and professionals. It has used information from an extensive review of research evidence, and from expert witnesses. The development followed the methods outlined in developing NICE guidelines: the manual and the interim methods guide for developing service guidance (2014).

Equality and diversity issues have been considered throughout the development of the

guideline. The committee also gave careful consideration to the potential resource impact of the recommendations.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in 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.

Aims and principles

This guideline is based on the principle that children, young people and adults with a learning disability and behaviour that challenges should have the support they need to live where and how they want. It will help local areas shift their focus towards prevention and early intervention, enabling children, young people and adults to live in their communities, and increasing support for families and carers. This should reduce the need for people to move away from their home or community for care, education or treatment.

The guideline recommends ways of designing and delivering services that aim to:

- help people to have a good quality of life
- support people to have good physical and mental health and emotional wellbeing
- maximise people's choice and control
- promote person-centred care and support
- help children, young people and adults take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do
- respect people's cultural, religious and sexual identity
- identify when children, young people and adults are at risk of developing behaviour that challenges, so that support can be offered as early as possible

- promote continuity of relationships
- take a 'whole life' approach.

1.1 Achieving change: strategic planning and infrastructure

Local leadership

Recommendations for local authorities and clinical commissioning groups

1.1.1 Local authorities and clinical commissioning groups should jointly designate a lead commissioner to oversee strategic commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.

1.1.2 Ensure that the lead commissioner:

- plans and oversees joined-up commissioning arrangements
- has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services
- plans services that take a 'whole life' approach from early childhood onwards and enable smooth transitions.

Joint commissioning and funding

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.1.3 The lead commissioner should ensure that budgets and other resources are pooled to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges. These should be pooled:

- across health, social care and education **and**
- with neighbouring authorities.

1.1.4 Consider jointly commissioning the most specialised behaviour support services across areas for children, young people and adults with particularly complex needs.

1.1.5 Ensure that funding mechanisms for service providers support creative and flexible community-based responses, for example, a contingency fund that service providers can draw on quickly if there is a crisis.

Planning and delivering services according to local need

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.1.6 Ensure that service planning and delivery is based on an assessment of current and future service needs using:

- the local population prevalence of learning disabilities in children, young people and adults and the proportion who are likely to display behaviour that challenges
- an analysis of assessed needs in education, health and social care plans, to provide an early view of likely service needs and enable prevention and early intervention
- other sources of information, such as registers of people at risk of admission and other dynamic risk data; disabled children's registers; and records of referrals from liaison and diversion teams, youth offending teams and police.

1.1.7 Ensure that services are planned and delivered in a way that:

- is co-produced with children, young people and adults using services and their families, carers and independent advocates
- enables person-centred planning and provision

- addresses the needs of different age groups but also takes a 'whole life' approach to planning
- includes planning for a range of future housing and employment support needs
- integrates health, social care and other relevant services.

1.1.8 Develop local and regional plans that have a single care pathway and point of access for children, young people and adults with a learning disability and behaviour that challenges, and their families and carers. Make sure this is reflected in local authorities' commissioning strategies and key documents such as the Market Position Statement.

For further information on how to develop care pathways, see the section on organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

Managing risk

Recommendation for local authorities and clinical commissioning groups

1.1.9 Take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person.

Quality assurance

Recommendations for commissioners and service providers

1.1.10 Ensure services meet set service-level and individual outcomes, and that service providers show evidence of achieving these outcomes. This evidence could include:

- satisfaction and quality-of-life ratings of children, young people and adults who have used the service, and their family members, friends and carers

- outcomes measured by personalised and validated tools such as the 'measure of processes of care' (MPOC) tool, or the 'patient feedback questionnaire' (PFQ)
- a reduction in duration and frequency of behaviour that challenges
- stability of placements
- participation in education by children and young people
- reports on the use of restrictive interventions, including medication
- contact time with specialist professionals
- evidence from quality reviews and spot checking involving experts by experience
- quality checks by user-led organisations.

1.1.11 Inpatient services should provide the evidence in recommendation 1.1.10 in addition to evidence of detailed assessments, treatment outcomes and time to discharge.

1.1.12 Commissioners should establish a multi-agency group, or make use of an existing group, including experts by experience and service providers, to monitor the quality of services and the outcomes achieved.

1.1.13 Service providers should use evidence gathered to continuously improve services. They should record the results and make them available to people who use services, and their families and carers.

Involving people in commissioning and service improvement

Recommendation for commissioners

1.1.14 Commissioners should make use of expertise from experts by experience to inform decision-making and quality assurance of services.

1.2 Enabling person-centred care and support

Involving people with a learning disability and behaviour that challenges

Recommendations for practitioners working with children, young people and adults, and their families and carers

1.2.1 Practitioners working with children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services.

For more information on involving people in their care and support, see the section on working with people with a learning disability and behaviour that challenges, and their families and carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.2 Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005.

1.2.3 Assess whether a child or young person under the age of 16 is Gillick competent and work in partnership with all children and young people. Include them in decisions about their treatment and ask them how they would like their families or carers to be involved.

1.2.4 Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental Capacity Act 2005. This should be done unless there is a compelling reason not to (for example, if there are safeguarding concerns).

1.2.5 Support children, young people and adults with a learning disability and behaviour that challenges to live where and how they want. Give them

support that:

- is person-centred, reflecting their individual needs and choices, and maximising their control
- helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do
- takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history
- respects their cultural, religious and sexual identity
- helps them before problems occur or as soon as they emerge, not just when crisis has been reached
- encourages people to speak out if they have any worries
- promotes continuity of relationships.

1.2.6 Find out children, young people and adults' information and communication needs, record them and share this information with everyone working with them in line with NHS England's Accessible Information Standard.

Recommendation for commissioners and practitioners working with children, young people and adults

1.2.7 Ensure that people with a learning disability and behaviour that challenges have access to speech and language therapy when they need it.

Advocacy

Recommendations for local authorities

1.2.8 Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum, it must be offered by local authorities as

described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007.

1.2.9 Ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services.

See also recommendations 1.8.3 and 1.8.4 on independent advocacy in relation to inpatient admissions.

Coordinating care and support

Recommendations for local authorities, clinical commissioning groups and service providers

1.2.10 Local authorities working in partnership with healthcare professionals should assign a single practitioner, for example, a social worker (in a disabled children's team or community learning disability team) or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to meet their needs over the long term.

1.2.11 The local authority, clinical commissioning group and service providers should liaise regularly with the named worker, keeping them informed and involved in decision-making.

Recommendations for the named worker

1.2.12 Arrange regular meetings to discuss the person's care and support, and invite people in their support network, including family members, carers, independent advocates and practitioners from all services that support them. This could build on existing processes, for example, the education, health and care planning and review process for children (see Gov.uk's children with special educational needs and disabilities).

1.2.13 Recognise and use the expertise brought by all members of the person's support network (not only those who are paid).

Care and support planning

Recommendations for community learning disability teams and service providers

1.2.14 Community learning disability teams (or relevant children's services, for example, disabled children's teams) and service providers should work in partnership with the child, young person or adult, their family members, carers and independent advocates and their named worker to develop, deliver and review their care and support plan. Develop a care plan that:

- meets the person's needs and preferences
- works to support and maximise the person's mental capacity
- takes into account people's fluctuating mental capacity and needs
- adopts a 'whole life' approach that covers what they want to achieve in both the short and long term, and supports smooth transitions
- takes a positive approach to managing risk
- sets out what to do to prevent or respond to a crisis.

1.2.15 Service providers and agencies responsible for commissioning and planning services (including specialist services) should match the specific skills of staff to the characteristics of the person with a learning disability and behaviour that challenges. Do this as soon as care and support planning begins.

1.2.16 Community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers should review children, young people and adults' care and support with their named worker:

- according to timings agreed in their plan **and**
- whenever there is a significant change, for example, if the person is placed out of area.

1.2.17 When reviewing plans:

- involve people as set out in recommendations 1.2.1 to 1.2.4
- take account of people's fluctuating mental capacity
- check that staff are following the behaviour support plan recommendations in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- think about plans for the future, including whether changes might be needed to the person's housing or support.

1.2.18 As soon as a child, young person or adult develops behaviour that challenges, community learning disability teams (or relevant children's services, for example, child and adolescent mental health learning disability teams) and service providers should offer to work with them and their family or carers to develop a behaviour support plan.

For more information on what this should include, see the recommendations on behaviour support plan in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

Supporting people to use personal budgets

Recommendations for local authorities and clinical commissioning groups

1.2.19 Ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences.

1.2.20 Offer people a choice of funding arrangements (see recommendation 1.2.19) and support people to use these budgets, where they wish to, by:

- telling them how each element of their support will be funded
- telling them how much money is available and how much control they have over how the money is spent
- giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer

- supporting them to try out different mechanisms for managing their budget
- offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded
- offering information about benefits entitlement
- ensuring that carers' needs are taken fully into account.

  [This recommendation is adapted from NICE's guideline on older people with social care needs and multiple long-term conditions.]

Delivering care and support

Recommendations for staff in all settings

1.2.21 In all settings, staff working with children, young people and adults with a learning disability, and their families and carers, should aim to reduce the risk of behaviour that challenges developing by:

- identifying health or sensory problems early
- providing strategies and interventions to support communication.

  Follow recommendations on psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.22 For people taking medicines:

- follow recommendations in NICE's guideline on managing medicines for adults receiving social care in the community **and**
- if the reason for the medicine relates to the person's behaviour or mental health, ensure it is reviewed regularly in line with recommendations on medication in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions, and recommendations in mental health problems in people with learning disabilities: prevention, assessment and management.

1.2.23 Ensure that children, young people and adults with a learning disability and behaviour that challenges know about and are able to use services to support their health and wellbeing. These should include:

- services helping people to make and maintain friends, relationships and social networks in their community and take part in community activities
- access to employment and pre-employment opportunities
- day opportunities where activities can be tailored to the person's interests, preferences, strengths and abilities
- universal healthcare services and health checks
- peer support opportunities.

1.3 Early intervention and support for families and carers

See section 1.6 for more recommendations on services for children and young people.

Recommendations for local authorities

1.3.1 Ensure that families and carers of children, young people and adults with a learning disability and behaviour that challenges are given support that helps them to:

- manage their role as carers
- care for the person and meet their needs, in relation to behaviour, care and support, communication, physical health, mental health, educational needs or any offending behaviour
- access support from specialist services when needed.

1.3.2 Provide information, guidance and ongoing support for families and carers of children, young people and adults with a learning disability and behaviour that challenges, which address different aspects of their life. Sources of support could include:

- peer support
- parent and carer groups or forums
- email support
- individual phone and face-to-face support
- family networks
- independent advocacy
- managed email networks (a shared discussion forum)
- social media groups.

1.3.3 Give family members and carers information in line with the section on support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. This could be in the form of a 'welcome pack'. Provide this information:

- at the first point of contact with families
- through the local authority website, local libraries and universal services such as GP surgeries.

Recommendations for the named worker

1.3.4 Help people and their families to understand information about available support (see recommendation 1.3.3) from first contact onwards.

1.3.5 Advise family members and carers how to access:

- short break services
- specialist behaviour support
- training as set out in recommendations 1.7.1 and 1.7.2 in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- support in an emergency

- community resources, including voluntary organisations, networks and support groups
- local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.

1.3.6 Ensure that family members and carers have information such as contact details of staff and key dates and appointments.

1.4 Services in the community – prevention, early intervention and response

Developing services in the community

Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

1.4.1 The lead commissioner should commission services in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system). These services:

- should be able to cater for lower-level needs up to intensive, complex or fluctuating needs
- could be set up either as 1 large team with different subteams or as several separate teams
- should be provided wherever possible as an alternative to, and to reduce the potential need for:
  - inpatient care for children, young people and adults **or**
  - residential placements for children and young people.

1.4.2 Services in the community should fulfil the following core functions:

- specialist prevention and early intervention

- developing capacity in non-specialist community services to prevent unnecessary inpatient admissions
- giving support and training to families and carers (by following the recommendations on support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
- quality assurance and service development
- short-term assessment and intervention
- longer-term complex intervention
- crisis response and intervention.

1.4.3 Ensure that children, young people and adults with a learning disability can get specialist support through their community learning disability team that meets their needs, for example, in relation to:

- behaviour
- communication
- social care and support needs
- physical health
- mental health
- education
- offending behaviour.

  This could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.

Recommendations for community learning disability teams and service providers

1.4.4 Services who provide support through the community learning disability

team should work together and provide consultancy and support to each other. They should work with children, young people and adults, and their family members and carers, in a way that is:

- personalised
- flexible
- responsive
- accessible
- reflective.

1.4.5 If a child, young person or adult develops, or is at risk of developing, offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible (see recommendations 1.4.12 to 1.4.16). These services should:

- provide evidence-based early interventions that are adapted for people with a learning disability and address the specific behaviour
- work in an ongoing partnership with each other and with the community learning disability team whenever needed.

1.4.6 Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that:

- they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable
- people who need support can be diverted from the criminal justice service to community learning disability teams.

Specialist behavioural support

Recommendations for the lead commissioner (acting on behalf of local

authorities and clinical commissioning groups)

1.4.7 Ensure that specialist assessment and behavioural support are available in the community so that children, young people and adults can stay where they currently live and avoid moving.

1.4.8 Ensure that specialist services for behaviour that challenges are available to everyone with a learning disability and behaviour that challenges, based on an assessment of each person's need and risk and taking into account the benefit of early intervention.

1.4.9 The lead commissioner should:

- set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support
- ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards.

Intensive behavioural support during a crisis

Recommendations for local authorities, clinical commissioning groups, community learning disability teams and specialist services

1.4.10 Provide a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should:

- focus on keeping people in their own home
- have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems
- provide face-to-face support within 4 hours if needed, based on initial triage
- involve partnership with other commissioners, service providers and family members and carers

- include giving staff access to the person's information if they are already in contact with services
- provide short-term support to achieve aims that are agreed with the person
- include clear contact details for children's services (as set out in the Local Offer) and adults' services.

1.4.11 Use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. Learn from what happened and use this knowledge to inform future early intervention and prevention services and support crisis plans.

Services for people in contact with, or at risk of contact with, the criminal justice system

Recommendation for local authorities and clinical commissioning groups

1.4.12 Commission local community forensic services for children, young people and adults with a learning disability and behaviour that challenges who are in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement. These could be provided as stand-alone teams, or as a specialism within an existing team, for example, a community learning disability team, or a learning disability specialism within a community forensic team.

Recommendations for service providers, including forensic services

1.4.13 When forensic community learning disability services are supporting children, young people and adults with a learning disability (for example, if they are subject to a forensic community rehabilitation order or a community treatment order), they should enable them to live in the community, as close to home as possible, and in the least restrictive setting.

1.4.14 Forensic community learning disability services should stay in frequent contact with the person they are supporting, including those who are in out-of-area placements or criminal justice settings, and help them build

and maintain social links in their community.

1.4.15 Forensic learning disability services and probation services should work together to agree who is best able to support the person in meeting the requirements of their treatment or rehabilitation order.

1.4.16 Forensic learning disability services, mental health, specialist voluntary sector organisations, learning disability services and social care services should establish care pathways and close links with each other to help them refer people quickly between these services to get the right support and effectively manage risk.

1.5 Housing and related support

Giving people a choice of housing

Recommendations for local authorities, clinical commissioning groups and service providers

1.5.1 Commissioners should work with local housing and social care providers to identify the specific housing needs of adults with a learning disability and behaviour that challenges. They should ensure areas have a range of housing and care options available that meet these needs and cater for different preferences and person-centred support needs (see also section 1.2).

1.5.2 Enable adults to live close to their family, friends and community unless they choose not to or there is a compelling reason not to.

1.5.3 Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test.

1.5.4 When helping adults with a learning disability and behaviour that challenges choose where to live:

- provide information on the range of possible options

- take into account their preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation on environmental factors in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
- give them advice on adapting their current home if needed.

1.5.5 Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them.

1.5.6 If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. Involve people in choosing how many people, and who, they live with.

1.5.7 Offer adults housing outside their local community only:

- if it is what the person wants
- if it is indicated after a full assessment and planning process, which takes into account the person's preferences, needs and risks
- for a specified time that has been agreed with the person, or agreed in their best interests if they lack capacity to decide this – for example, if they are in crisis and there is no local placement available.

1.5.8 If someone is moving outside their local area, local authorities, clinical commissioning groups and commissioners should:

- establish the commissioner who is responsible for paying for the person's care and support
- ensure they will still have the support they need
- make a plan that enables them to return to their local area if they want to, or if it is in their best interests if they lack capacity to decide this.

1.6 Services for children and young people

Recommendations for local authorities, clinical commissioning groups and the lead commissioner

1.6.1 Local authorities should ensure that parents and carers of children and young people with a learning disability and behaviour that challenges have support to care for their child (see section 1.3).

1.6.2 Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with section 17 of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to residential placements away from home and to reduce the potential need for such placements.

1.6.3 The lead commissioner should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges.

Recommendations for local authorities, service providers and practitioners

1.6.4 Health, mental health and behaviour support practitioners should work with other services, for example, education and social care, to:

- deliver the outcomes agreed in a child or young person's education, health and care plan
- provide support and interventions in line with NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- maximise life opportunities for children and young people, including by ensuring they have access to meaningful education

- support smooth transitions between services in line with the section on organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- support children and young people to develop skills for independence
- take a positive approach to managing risk.

  This applies to children and young people in residential placements, as well as those living at home.

1.6.5 If a child or young person's behaviour that challenges is deteriorating or causing concern, the local authority should carry out a multi-agency review of their education, health and care plan (or other relevant plan) and involve the child or young person and their parents or carers. Review whether the plan needs to be updated and additional support provided if the child or young person's needs have changed.

Exploring alternatives to residential placements for children and young people

Recommendations for the lead commissioner, service providers and practitioners

1.6.6 Support parents and carers to understand the full range of options for education, care and support for their child.

1.6.7 When considering a residential placement, arrange a multi-agency review to explore all options and to review the child or young person's education, health and care plan. Include in this discussion:

- the child or young person, and their parents or carers
- the lead commissioner on behalf of the local authority and clinical commissioning group
- at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging

- an independent expert by experience
- special educational needs staff, or staff from their school or college.

1.6.8 Only offer children and young people a residential placement:

- if assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted, **or**
- following a request by the child or young person's family, which has been considered under the Children and Families Act 2014.

Living in residential placements

Recommendations for local authorities, clinical commissioning groups and service providers

1.6.9 Commission residential placements for children and young people as close to home as possible. Take into account in local authority contracts that some families may need financial support to help them see their child and for their child to visit them.

1.6.10 Support children and young people to maintain links with their family, friends and community (for example, members of their religious community) while they are in a residential placement.

1.6.11 Local authorities and service providers must promote maximum contact between children and young people living in residential placements and their family members and carers (in line with schedule 2 of the Children Act 1989). If a placement lasts longer than 3 months, the government's Visiting Regulations 2011 must be followed, for both local and out-of-area placements (see The Visits to Children in Long-Term Residential Care Regulations 2011). Help families stay in touch between visits, for example, using Skype.

Planning and review to support children and young people leaving a residential placement

Recommendations for local authorities, clinical commissioning groups and practitioners

1.6.12 As soon as a child or young person moves into a residential placement, local authorities and clinical commissioning groups should ensure that:

- a plan is developed for how they will progress towards returning to their family home, if appropriate, and towards greater independence
- they continue to be supported to meet the outcomes identified in their education, health and care plan.

1.6.13 Review the plan in recommendation 1.6.12 at least every 6 months to check that progress is being made. This could be done as part of a looked-after child review, an education, health and care plan review, or sooner if needed.

1.6.14 Plans should be reviewed by the practitioner responsible for overseeing the child or young person's education health and care plan and all other practitioners involved in their care and support, including a specialist in behaviour that challenges.

1.6.15 If progress towards the outcomes in the plan has not been made, explore and address the reasons for this. If the child, young person or their family disagrees with the decision made at the review meeting, explain how they can challenge the decision if they want to.

1.7 Short break services

Recommendations for local authorities, commissioners and service providers

1.7.1 Local authorities must, in line with government legislation on Breaks for Carers of Disabled Children Regulations 2011 and the Children and

Families Act 2014:

- provide a range of short breaks for children and young people with a learning disability and behaviour that challenges **and**
- publish as part of their Local Offer a statement of the range of services available and how eligibility will be assessed.

1.7.2 Commissioners in health and social care should provide sufficient, reliable, flexible and varied short break options, including both breaks away and support at home, for adults with a learning disability and behaviour that challenges.

1.7.3 Ensure that short breaks are:

- community-based and close to home
- available based on need, and at short notice both in crisis and to prevent a crisis
- tailored to the needs of the person and their family or carers, taking into account the person's interests and preferences
- able to provide a positive experience for the person being supported
- able to deliver what is agreed in the education, health and care plan or care and support plan; carer's assessment; or behaviour support plan
- planned in advance wherever possible and involve people and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it
- provided by staff who understand and respect people's cultural norms and values and their choices about personal care, private life and lifestyle.

1.8 Making the right use of inpatient services

Exploring alternatives to inpatient admission

Recommendations for commissioners, service providers and practitioners

1.8.1 Admit children, young people and adults with a learning disability and behaviour that challenges to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted.

1.8.2 When thinking about inpatient admission, arrange a discussion to explore all other viable options. Include in this discussion:

- the person and their family members and carers
- at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging
- at least 1 independent expert by experience.

For further guidance, see NHS England's information on community Care and treatment reviews or, for children and young people, community Care, education and treatment reviews.

Providing information

Recommendations for local authorities, clinical commissioning groups and service providers

1.8.3 When there is a possibility that someone will be admitted to hospital, including as an informal admission, local authorities and clinical commissioning groups should give them and their family and carers accessible, independent information and advice about their rights, access to independent advocacy and other possible options for treatment, and care and support.

1.8.4 Service providers must provide information about independent mental health advocacy as required by the Mental Health Act 1983.

When a placement is needed

Recommendation for local authorities and clinical commissioning groups

1.8.5 Provide an inpatient placement that is as close as possible to where the person usually lives.

Recommendations for inpatient services and community learning disability teams, including the named worker

1.8.6 The named worker should support the person to maintain links with their family, friends and community (for example, members of their religious community) while they are in hospital, and give their family and friends information about their progress.

1.8.7 If people are admitted as inpatients outside their local area, social workers in the community learning disability team and the named worker should stay in contact with the person, and help them stay in contact with other key practitioners in their own area.

1.8.8 When someone is admitted as an inpatient, offer them interventions in line with recommended psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. Ensure that these interventions specifically address their needs and the reason for their admission.

Planning and review to support discharge

Recommendations for inpatient services and community learning disability teams

1.8.9 As soon as the person is admitted, the hospital and community learning disability team should work together to develop a discharge plan.

1.8.10 Practitioners involved in the child, young person or adult's care and support should review the person's discharge plan at least every 3 months. Include in these reviews:

- the person and their family members or carers
- the practitioner responsible for agreeing discharge
- a specialist in behaviour that challenges.

1.8.11 Think about using NHS England's Care and treatment review process or the Care programme approach as a framework for reviews to support discharge for adults. For children and young people think about using the Care, education and treatment review or education, health and care planning process.

1.8.12 If the person is not discharged after the meeting with practitioners involved in their care and support, provide sufficient reason for this and develop a new plan towards discharge. Explain to the person and their family or carers how they can challenge the decision if they want to.

1.8.13 Tell people who might apply to, or are referred for, a first-tier mental health tribunal relating to being an inpatient, about their right to request an independent clinician (in line with section 76 of the Mental Health Act 1983) to:

- visit them at any reasonable time and examine them in private
- inspect any records relating to their conditions and treatment.

1.9 Staff skills and values

Recommendations for commissioners, local authorities and service providers

1.9.1 As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support the children, young people and adults they are working with. This includes:

- the skills and knowledge recommended in the section on staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- being resilient and compassionate
- showing that they care
- understanding and respecting the person's human rights, faith, culture, identity and values.

1.9.2 Ensure that staff providing direct support to children, young people and adults with a learning disability and behaviour that challenges have the 'direct contact' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.

1.9.3 Give staff providing direct support access to advice from behaviour support specialists with 'consultant' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.

1.9.4 Local authorities and clinical commissioning groups should plan for and resource training among service providers who provide day-to-day support about how to work with young people and adults with a learning disability who are at risk of offending.

1.9.5 Organisations should ensure that staff have supervision and support, in line with the recommendations on staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.9.6 Involve young people and adults with a learning disability and behaviour that challenges in staff recruitment. Involve their family members and carers too if the person agrees, unless there is a compelling reason not to.

1.9.7 Think about how to involve children with a learning disability in staff recruitment.

Terms used in this guideline

The Think Local, Act Personal care and support jargon buster explains many of the social care terms used in this guideline.

Adult

In this guideline, 'adults' are aged 18 years or older.

Behaviour support specialist

A practitioner who has training in helping people and their family members and carers to understand and change their behaviour if it is causing problems for them.

Behaviour that challenges

Behaviour of such an intensity, frequency or duration that the physical safety of the person, or others around them, is likely to be placed in serious jeopardy. It also includes behaviour that is likely to severely limit or deny access to and use of ordinary community facilities.

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

Children

In this guideline, 'children' are aged 12 years or younger.

Contingency fund

A sum of money set aside to fund any unforeseen expenditure, and to respond quickly in an emergency.

Experts by experience

People with lived experience of using services, including people with a learning disability themselves and their family members and carers.

Forensic services

Specialist services that work with people in contact with, or at risk of contact with, the criminal justice system.

Lead commissioner

A commissioner appointed by the local authority and clinical commissioning group who oversees strategic joint commissioning arrangements for health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.

Learning disability

In line with NICE's guideline on challenging behaviour and learning disabilities, a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

A person's learning disability may be described as mild, moderate, severe or profound. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

Positive behaviour support

Positive behavioural support is a person-centred approach that uses a multi-element format to better understand and so reduce behaviour that challenges. It can include changing the person's environment, developing their skills, providing focused support and developing reactive strategies.

Real Tenancy Test

The Real Tenancy Test is a quick test to check that a person who lives in supported accommodation enjoys the same rights and protections in law as a person who has a full tenancy agreement for their rented home.

Residential placement

Examples of residential placements include residential care homes for adults and, for children and young people, placements that involve living away from their family home, for example, in residential schools and colleges.

Service providers

This can be any organisation in the public, private or voluntary sector that offers a service to people with a learning disability and behaviour that challenges. This can include services such as hospitals, care homes and organisations that provide support for people to live in their own homes or with their family.

Short breaks

Also known as respite care, these involve a person with care and support needs spending regular short periods away from their main carer, to give the carer a break and the person a chance to do something different. These breaks may take place in the person's own home, in the home of an approved carer or in a residential placement.

Young people

In this guideline, 'young people' are aged 13 to 17 years.

Putting this guideline into practice

NICE has produced tools and resources to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Children, young people and adults with a learning disability and behaviour that challenges are likely to use both health and care services throughout their lives. However, a lack of integration across services, including children's and adults' services, can impact on quality of care. Local authorities, working together with clinical commissioning groups, can provide a more joined-up and person-centred approach by designating a lead commissioner who is responsible for commissioning health, social care and education services for both adults and children with a learning disability, including for people whose behaviour is described as challenging. For some services, creating this role may involve a significant change in practice.
- Family members and carers often play a significant role in supporting people with a learning disability and behaviour that challenges, but they can find it difficult to access information, guidance and support. Many families need ongoing training and support for their caring role from specialist services, including positive behaviour support services. Families may also benefit from services such as peer support. Local authorities and health services need to provide this information and support, and tell families how to get it. For areas that do not currently provide comprehensive support for families, this will involve a significant change in practice.
- Developing good general and specialist community services is important for supporting children, young people and adults with a learning disability and behaviour that challenges to live how and where they want, and to avoid the need for hospital admission or residential placements. Developing capacity in services and housing to support people in the community is likely to be a challenge in areas where resources are focused on inpatient care. Clear plans will need to be developed, agreed and put in place to make this change.

- Children, young people and adults with a learning disability and behaviour that challenges should not be admitted to inpatient units unless all other possible options have been considered and exhausted. Similarly, children and young people should only be provided with a residential placement if all other possibilities have been considered. Where inpatient care or residential placements are used, planning should begin immediately for the person to return to their family or community. The plan should be reviewed regularly. Where this is not current practice, significant change will be needed.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the full guideline.

1 Models of person-centred support

What models of delivering person-centred support are effective and cost effective for people with a learning disability and behaviour that challenges, and their families and carers?

What are the views and experiences of people with a learning disability and behaviour that challenges and their family members and carers, of different models of delivering person-centred support?

Why this is important

Person-centred support is the current recommended approach and is at the centre of this service guideline. However, there is little published research about what configurations of services and resources provide the best person-centred support for people with a learning disability and behaviour that challenges, and their families and carers. There is also limited research from the point of view of people with a learning disability and their families and carers on what good person-centred support looks like, how it can be measured or benchmarked or what it means for them.

2 Supporting family members, carers and staff

What types of services or approaches are effective in supporting family members, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?

Why this is important

Enabling family members, carers and staff to provide continuing care and support can help prevent placements from breaking down, which can lead to out-of-area placements.

Investment in carers, support networks, initiatives that support independent living, and community networks are key to helping people develop greater resilience. This is especially important if new approaches to service delivery, such as personalisation, are to succeed. However, there is no direct empirical evidence of the social and economic benefits associated with investment in such approaches and services.

3 Models of supported living

What is the effectiveness and cost effectiveness of models of shared, supported living, such as Shared Lives?

What are the views and experiences of people sharing their home and people who live with them under programmes such as Shared Lives?

Why this is important

It is important that people with a learning disability and behaviour that challenges have more choice and control over where they live. Models of supported living, such as Shared Lives, are promising models for people with a learning disability. However, the support needs of people with a learning disability and behaviour that challenges are more complex and there is very limited evidence about which types of supported living are effective specifically for them. It would be useful to know what kinds of supported living are acceptable and feasible for people with a learning disability and behaviour that challenges and their families and carers, as well as for Shared Lives families.

4 Effective components of integrated regional services for people with a learning disability and behaviour that challenges

What are the effective components of an integrated regional service for people with a learning disability and behaviour that challenges across health and social care (including pooling budgets and other resources)?

What are the barriers and facilitators to pooling budgets and other resources across regions?

Why this is important

The Winterbourne View Review Action Group and the Transforming care programme recommended that health and social care services should pool budgets. However, reports from the National Audit Office highlight that there has been little evidence of this happening in practice. Research is needed to know what mechanisms enable or stop this practice from happening, and whether the practice results in better outcomes for people with a learning disability.

Finding more information and committee details

You can see everything NICE says on this topic learning disabilities and behaviour that challenges.

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on people with learning disabilities.

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 our guidelines into practice, see resources to help you put NICE guidance into practice.

Update information

Minor changes since publication

October 2019: The definition of behaviour that challenges has been amended to say that it can deny access to services. The definition also appears in context.

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Accreditation



NICE National Institute for Health and Care Excellence

NICE guideline

Care and support of people growing older with learning disabilities

NICE guideline

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www.nice.org.uk/guidance/ng96

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

Overview 4
Who is it for? 4
Context 5
Health and social issues of older people with learning disabilities 5
The purpose of this guideline 6
How does it relate to legal duties and other guidance? 7
Recommendations 8
1.1 Overarching principles 8
1.2 Organising and delivering care and support 12
1.3 Identifying and assessing care and support needs 15
1.4 Planning and reviewing care and support 16
1.5 Identifying and managing health needs 19
1.6 End of life care 28
1.7 Staff skills and expertise 29
Terms used in this guideline 31
Putting this guideline into practice 34
Recommendations for research 37
1 Models of care and support at home 37
2 Identifying health conditions 37
3 Education and training programmes: self-management 38
4 Dementia education and training programmes for family members and carers 39
5 Advance planning about end of life care 40
Finding more information and committee details 41
Update information 42

This guideline is the basis of QS187.

Overview

This guideline covers care and support for adults with learning disabilities as they grow older. It covers identifying changing needs, planning for the future, and delivering services including health, social care and housing. It aims to support people to access the services they need as they get older.

We have produced an Easy Read version and video to explain this guideline which are available from information for the public.

Who is it for?

- Providers of social care, health and housing support for people growing older with learning disabilities
- Practitioners in social care, health and housing who work with people growing older with learning disabilities and their families and carers
- Commissioners and people with a strategic role in assessing and planning local services
- Practitioners in other related services, including older people's services, adult learning disability services, employment, education and criminal justice services
- People with learning disabilities, their families, carers and advocates

Context

People with learning disabilities are now living significantly longer. The population of older people with learning disabilities will increase 4 times faster than the overall adult learning disability population (see People with learning disabilities in England. Emerson and Hatton 2008). As they grow older, people with learning disabilities have many of the same age-related health and social care needs as other people but they also face specific challenges associated with their learning disability. Many people with learning disabilities, especially those with milder disability, are not known to health or social services (see People with learning disabilities in England 2013. Public Health England 2014), whereas others may find it difficult to express their needs and be heard. Management of their needs will therefore be more complex than for other populations. This will create substantial pressure on services, which has not yet been fully quantified.

Health and social issues of older people with learning disabilities

People with learning disabilities have a poorer health profile than the general population. For example, there is a high prevalence of dementia in people with Down's syndrome. Practitioners may have difficulty distinguishing the symptoms of a condition such as dementia from those associated with learning disabilities, or with other mental health difficulties. People with learning disabilities may also have poorer health resulting from lifestyle issues such as diet and exercise for which they have not received enough advice and support.

People with learning disabilities also face barriers to accessing healthcare, including health and dental checks. The Michael report on Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities (2008) and the subsequent Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD, Heslop et al. 2013) identified a failure of services to take account of the needs of people with learning disabilities and make reasonable adjustments. This led to misdiagnosis and, in some instances, premature death. People with learning disabilities may have an increased risk of mortality from conditions associated with their learning disability (for example, epilepsy and aspiration pneumonia). Such conditions are often diagnosed late in the course of illness.

Adults with learning disabilities are far more likely to have sensory impairment compared with the general population, but are less likely to access sight or hearing checks, particularly if they are living independently or with family. Sensory impairment is also a barrier to accessing services.

Older people with learning disabilities also have particular housing and social support needs. Two-thirds of adults with learning disabilities live with their families, usually their parents. In some instances, they may be caring for an older frail parent while they too are getting older. Eventually, ageing family carers may reluctantly explore alternative care arrangements when they are no longer able to provide long-term care. More serious is when family care ends through parental illness or death and, due to lack of future planning, the person may be moved inappropriately, or have multiple moves.

For people living in homes designed for adults with learning disabilities, these may be considered unsuitable for them as they age, which can lead to a move. Older people with learning disabilities are thus likely to be placed in older people's residential services at a much younger age than the general population, even though this may not meet their preferences or needs, especially in relation to communication, support and activities.

The purpose of this guideline

The purpose of this guideline is to help commissioners and providers identify, plan and provide for the care and support needs of people growing older with learning disabilities and their families and carers. It covers integrated commissioning and planning; service delivery and organisation; providing accessible information, advice and support; identifying and assessing people's changing needs; care planning; and supporting access to services including health, social care, housing and end of life care. It aims to ensure that people with learning disabilities are given the help they need to access a range of services as they grow older so they can live healthy and fulfilled lives.

The guideline covers care and support in all settings, including people's homes and family homes, temporary accommodation, supported living (see the KeyRing network and Shared Lives schemes) and specialist accommodation. It also covers day services, residential and nursing homes, and primary and secondary healthcare.

A specific age limit is not used in this guideline because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age, than the general population. The guideline does not cover people on the autistic spectrum who

do not have a learning disability.

How does it relate to legal duties and other guidance?

This guideline complements statutory duties and good practice as set out in relevant legislation and guidance. The recommendations cross-refer to legislation and other guidance where appropriate. Relevant legislation and guidance includes:

- Care Act 2014 and associated guidance
- Equality Act 2010
- Mental Capacity Act 2005 (amended 2007) and associated guidance on Deprivation of liberty safeguards
- Mental Health Act 2007.

Safeguarding is the responsibility of all practitioners. Practitioners must be familiar with, and follow, their local safeguarding procedures.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in 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 Overarching principles

Access to services and person-centred care

1.1.1 Ensure that people growing older with learning disabilities have the same access to care and support as everyone else. In line with the Equality Act 2010, this must be based on their needs and irrespective of:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race, religion and belief
- sex and sexual orientation
- socioeconomic status

- other aspects of their identity.

  [This recommendation is adapted from the NICE guideline on service user experience in adult mental health.]

1.1.2 Ensure that care and support for people with learning disabilities is tailored to their needs, strengths and preferences and is not determined solely by their age or learning disability.

1.1.3 Service providers and commissioners must make reasonable adjustments to health, social care and housing services to ensure they are fully accessible to older people with learning disabilities and their family members and carers, in line with the Equality Act 2010.

1.1.4 Recognise that people with learning disabilities may be carers, but may not see themselves as such. Ask the person if they have caring responsibilities and, if so, offer them a carer's assessment to meet their needs (see NICE's guideline on supporting adult carers).

[This recommendation is adapted from the NICE guideline on older people with social care needs and multiple long-term conditions.]

Communicating and making information accessible

1.1.5 Support people's communication and information needs in line with NHS England's Accessible Information Standard. This could also include:

- Seeking advice from, or referring people to, a speech and language therapist whenever needed.
- Providing an independent interpreter (that is, someone who does not have a relationship with the person) so that people can communicate in their first language.
- Finding out before an appointment how the person prefers to communicate and receive information.
- Extending appointment times to give more time for discussion.

- Giving people written information (such as appointment letters and reminders) in different languages or in an accessible format of their choice, for example Easy Read, audio books, films or by using online resources such as specialist learning disability websites.
- Providing information on advocacy services and, if the person needs it and consents to it, providing an independent advocate who will attend appointments.
- Using visual aids and short, clear sentences during consultations and conversations.
- Talking to the person's family members and carers if appropriate, and with the person's consent.

1.1.6 Provide people with learning disabilities and their family members, carers and advocates with accessible, tailored information about:

- the range and role of different health services (such as health checks and screening)
- how to access health, social care and support services
- the community and specialist services that are available, and their purpose
- housing options that they could think about for the future
- planning for end of life care
- financial issues, including wills, trusts and benefits
- how to raise a safeguarding concern if they have one.

1.1.7 Social care and primary care practitioners should regularly review the communication needs of people with learning disabilities as they grow older to find out if they have changed. This should usually be when:

- other needs are being assessed, for example, during general health and dental checks
- there is reason to believe their communication needs may have changed.

Decision-making, mental capacity and consent

1.1.8 Health and social care practitioners must understand and take into account the Mental Capacity Act 2005 when working with people with learning disabilities, including:

- assuming the person has the mental capacity to take part in decision-making unless it is established that they lack capacity
- supporting people to make decisions – finding out their views, encouraging them to take part in the decision-making process and ensuring all steps have been taken to help them express their views and make their own decisions
- assessing their capacity to make decisions – this assessment should take place where and with whom the person wishes
- undertaking best interests decision-making when it is established that a person does not have capacity to make a decision. (NICE's guideline on decision-making and mental capacity covers supporting people to make decisions, assessing mental capacity and best interests decision-making.)

Involving people, family members, carers and advocates

1.1.9 Health and social care practitioners should listen to, actively involve and value key members of the person's support network in the planning and delivery of their current and future care and support, if the person agrees to this. Regularly check people's willingness and ability to be involved in this way.

1.1.10 Ask people who they want to involve in planning and providing their support, regardless of whether they have close family. Be aware that some people do not have close family members, friends or carers.

1.1.11 Offer independent advocacy whenever it is wanted or needed by a person with a learning disability. As a minimum, it must be offered as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007.

1.1.12 Find out and prioritise the needs and preferences of the person. Ensure

these are not overshadowed by the decisions or preferences of others, including when the person lacks capacity.

1.1.13 Be aware that people with learning disabilities may need support to communicate their needs or retain information. With the person's consent, share information with their family members, carers or advocate, for example about:

- any changes that might be needed to their care and support
- symptoms, management and prognosis of the person's health conditions.

1.2 Organising and delivering care and support

Planning and commissioning local services

1.2.1 Health and social care commissioners should have an understanding of the needs of people growing older with learning disabilities in their area and know what mainstream and specialist services are available locally to support people as they grow older.

1.2.2 Commissioners should identify the number of adults in their area with a learning disability (and the number of families and carers), and use this information to identify gaps in provision, organise services and plan future provision. This could be done by encouraging GPs to develop and maintain registers of people with learning disabilities and getting information from other support services, including education and the Department for Work and Pensions.

1.2.3 Commissioners and service providers should ensure family members, carers and advocates of people with learning disabilities have access to age-appropriate community support services and resources such as:

- day opportunities
- short respite breaks (both at home and away from home)
- family placements

- support groups for family carers, including siblings, and for older people with learning disabilities who have caring responsibilities
- a single point of contact for practical information, emotional support and signposting.

1.2.4 Commissioners and service providers should provide housing options that meet the changing needs of people with learning disabilities as they grow older. This includes:

- making reasonable adjustments to support people to stay in their current housing as their physical and emotional needs change, for example providing equipment or housing adaptations
- arranging housing for people with learning disabilities who are in unstable housing situations, for example those who are homeless or in temporary accommodation (including people seeking asylum)
- supported living
- residential and nursing care, which reflect gender, sexual orientation and cultural preferences.

1.2.5 Commissioners should make available locally a wide range of family and community support options to meet the needs of people with learning disabilities as they grow older, including the needs of people in later old age, and their family members and carers. These might include:

- ensuring accessible transport links are available to help people access local facilities
- access to advocacy services.

1.2.6 Consider the use of technologies such as telehealth and telecare to complement but not replace the support provided by people face to face.

1.2.7 Commissioners should identify where there are gaps in community optometry, audiology and dental services for people with learning disabilities and address those gaps.

1.2.8 Mental health commissioners should develop protocols to ensure that

people with learning disabilities, including people in later old age, have access to mainstream mental health services for older people, including dementia support.

1.2.9 Commissioners and service providers should ensure that people with learning disabilities have equal access to a range of community services that reflect the cultural diversity of the local area and people's hopes, preferences, choices and abilities as they grow older.

1.2.10 Commissioners and service providers should establish links between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups.

1.2.11 Commissioners and service providers should provide opportunities for people with learning disabilities to meet up and socialise, for instance through social clubs and support groups.

1.2.12 Commissioners and service providers should ensure there is a wide range of community-based physical activity programmes available and encourage people to take part to promote their health and wellbeing. Examples include dancing, swimming, bowls, using the gym, organised walks and chair-based exercise classes.

1.2.13 Commissioners and service providers should arrange accessible opportunities for people with learning disabilities to engage in education, employment and volunteering.

1.2.14 Local authorities should consider introducing schemes to make transport easier for older people with learning disabilities. For example:

- providing free travel such as London's 'Freedom pass'
- using minibuses as community transport
- starting 'buddy' schemes to enable independent travel
- developing transport especially for people living in rural locations

- schemes such as 'JAM' cards (Just A Minute) – which can be used to alert transport staff that people have a learning disability
- schemes to help people with a personal budget to travel to activities and self-advocacy groups.

1.3 Identifying and assessing care and support needs

Assessing people's need for care and support

1.3.1 Ensure that all assessments of care and support needs are strengths based, person centred and conducted as early as possible. Follow the recommendations on care and support needs assessment in NICE's guideline on people's experience in adult social care services.

1.3.2 Practitioners carrying out assessments of care and support needs should have:

- access to the person's full history (medical, social, psychological and the nature of their learning disability) **and**
- an understanding of their usual behaviour.

1.3.3 Practitioners carrying out assessments of care and support needs should be alert to any changes in the person's usual behaviour. This could include how they are communicating or their activity levels, and symptoms (such as weight loss, changes in sleeping patterns or low mood) that could show something is wrong or they are unwell.

1.3.4 Be aware that people growing older with learning disabilities might have difficulty communicating their health needs. When their needs change, think about whether these changes could be age-related and do not assume they are due to the person's learning disability or pre-existing condition (diagnostic overshadowing).

1.3.5 Practitioners carrying out assessments of care and support needs should help people to think about what they want from life as they age. This

should include:

- asking people how they would like to spend their time and with whom, and enabling them to explore personal and sexual relationships
- encouraging them to develop support networks and to build and maintain links with friends and family and with community groups – these might include social, cultural and faith-based groups.

Assessing the needs of family members and carers

1.3.6 Practitioners carrying out assessments of care and support needs should take into account the needs, capabilities and wishes of families and carers. Also take into account that there may be mutual caring between people with learning disabilities, and their family members and carers, who are likely to be older themselves and have their own support needs.

1.3.7 Practitioners must offer people who are caring for a person with a learning disability their own carer's assessment, in line with the Care Act 2014.

1.3.8 Based on assessment, provide families and carers with support that meets their needs as carers (see NICE's guideline on supporting adult carers).

1.3.9 Review the needs and circumstances of carers at least once a year and if something significant changes (see NICE's guideline on supporting adult carers).

1.3.10 Actively encourage carers to register themselves as a carer, for example, with their GP.

1.4 Planning and reviewing care and support

Person-centred planning and review

1.4.1 Practitioners should carry out regular person-centred planning with

people growing older with learning disabilities to address their changing needs, wishes and capabilities and promote their independence. This should include planning for the future (see recommendations 1.4.5 to 1.4.13). Involve their family members, carers and advocates as appropriate.

1.4.2 Include transport needs in people's care and support plans, to help them get to services, appointments and activities.

1.4.3 Local authorities should plan people's care and support in a way that meets the needs of all family members, as well as the person themselves. This might include combining the personal budgets of different family members.

1.4.4 Give help and information to families and carers, including siblings, as part of planning and providing support for people growing older with learning disabilities. For example, tell them about sources of support for people after a family bereavement.

Planning for the future

1.4.5 Health and social care practitioners should work with the person and those most involved in their support to agree a plan for the future. Help them to make decisions before a crisis point or life-changing event is reached (for example, the death of a parent or a move to new housing).

1.4.6 Planning for the future should:

- be proactive
- be led by the person themselves with input from family members, carers or advocates as appropriate (regardless of whether they provide care and support themselves)
- involve a practitioner who has a good relationship with the person and communicates well with them
- involve practitioners who have good knowledge of local resources

- take into account the whole of the person's life, including their hopes and dreams as well as the things they do not want to happen
- include considering the needs of family members and carers
- seek to maintain the person's current support and housing arrangements, if this is their preference
- be reviewed every year and whenever the person's needs or circumstances change.

1.4.7 Include as key components of a future plan:

- Housing needs and potential solutions.
- Any home adaptations or technology that may address people's changing needs as they grow older.
- Members of the person's support network (both paid and unpaid).
- Any help the person gives to family members, whether this will continue as they age, and the impact this may have on their health and wellbeing.
- Planning for what will happen if someone who the person relies on dies, or is no longer able to provide care and support.
- Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person.
- The provision of information on wills, trusts and benefits.
- Planning for unexpected changes or emergencies.
- Planning for a time when the person may lack capacity to make decisions themselves, in line with the Mental Capacity Act 2005.
- Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment are likely to increase restrictions on the person.
- End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.

Future housing

1.4.8 When helping the person plan where they will live in the future and who they will live with, take into account whether other family members rely on them for support.

1.4.9 Encourage and support people to be active and independent at home regardless of their age or learning disability. This might include doing household tasks, making their own decisions and plans or leading group activities.

1.4.10 Make reasonable adjustments to people's homes as they grow older to make it possible for them to stay in their current home if they want to. For example, consider a support phone line, daily living equipment, telehealth monitoring and home adaptations, such as shower room conversion, wider doorways or a lift between floors.

1.4.11 Review at least once a year the housing needs of people who are being supported by social care staff at home.

1.4.12 Ensure that the person is centrally involved in any decisions about moving from where they currently live. Also include an advocate or, if appropriate, a family member or carer.

1.4.13 If a move is agreed with the person, practitioners should work with them and their support network to start planning for this straightaway. Planning could include:

- arranging for the person to visit the new setting
- discussing how they will maintain their existing support networks and develop new ones.

1.5 Identifying and managing health needs

1.5.1 Healthcare practitioners should encourage people growing older with learning disabilities to choose a family member, carer or advocate to bring with them to medical examinations and appointments if they would

like this support.

1.5.2 Explain clearly to people with learning disabilities what will happen during any medical appointments as well as their likely follow-up care. In line with the Mental Capacity Act 2005, healthcare practitioners must take all reasonable steps to help the person understand this explanation.

1.5.3 As well as explaining to people beforehand what will happen, continue to explain what is happening throughout the appointment and ensure there is enough time set aside to do this. If the person agrees, also explain to their family member, carer or advocate what will happen.

1.5.4 If the person needs a medical examination, give them a choice, wherever possible, about where it takes place. Aim to do it in a place that is familiar to them, which is welcoming and appropriate to their needs.

1.5.5 Support family members and carers, for example by providing information, so that they can help people with learning disabilities to access health services.

1.5.6 Consider commissioning training for people and their family members and carers in recognising changes and managing age-related conditions such as:

- blood pressure and cholesterol
- cancer
- changes to skin condition such as itchy or fragile skin
- dementia
- diabetes
- dysphagia (difficulty swallowing)
- epilepsy
- hearing loss and sight problems
- incontinence

- osteoporosis
- malnutrition
- menopausal symptoms
- mental health, including depression
- thyroid problems.

Coordinating care and sharing information

1.5.7 Managers in healthcare settings should identify a single lead practitioner to be the point of contact for people with learning disabilities and their family members, carers and advocates. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities.

1.5.8 Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by holding regular multidisciplinary meetings. Involve the person in all discussions.

1.5.9 Primary and secondary healthcare teams should identify at least 1 member of staff who develops specific knowledge and skills in working with people with learning disabilities and acts as a champion, modelling and sharing good practice. Use the expertise of people with learning disabilities to ensure the champion understands their needs.

1.5.10 Record a person's learning disability and any reasonable adjustments in their health records and share this information when making referrals. With the person's consent, make sure all relevant practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.

Health checks and screening

1.5.11 Recognise that people with learning disabilities may need additional

health surveillance to help them identify and communicate symptoms of age-related conditions.

1.5.12 Offer annual health checks to older people with learning disabilities as long as these are followed by prompt referral to specialist services wherever needed. Explain what annual health checks involve and how to arrange them. Record any actions identified by the annual health check in the person's health action plan.

1.5.13 Offer older people with learning disabilities the same routine screening and health checks as other older people.

1.5.14 Discuss with people the changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions or changes in any existing conditions, including:

- blood pressure and cholesterol
- cancer
- dementia (also see recommendations 1.5.36 and 1.5.37).
- diabetes
- dysphagia (difficulty swallowing)
- epilepsy
- hearing loss and sight problems
- incontinence
- osteoporosis
- malnutrition
- menopausal symptoms
- mental health, including depression
- thyroid problems.

1.5.15 During a person's annual health check, give them information about other

available services, including a care and support assessment under the Care Act 2014 if they have not already had one.

1.5.16 During a person's annual health check, ask if they are registered with a dentist, how often they see the dentist and check that they understand the importance of looking after their teeth and mouth.

1.5.17 Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them access, services such as breast screening, smear tests, testicular and prostate checks, dental checks, hearing and sight tests, and podiatry.

1.5.18 When designing and delivering breast screening services, address specific barriers to accessing breast screening among older women with learning disabilities, including support to:

- understand breast cancer
- understand the screening procedure
- be breast aware and check their breasts regularly
- understand any information provided
- attend appointments.

Primary care

1.5.19 Primary care and community services should aim to ensure that older people with learning disabilities can see the same GP and other healthcare practitioners, wherever possible, to help practitioners:

- become familiar with the person's medical history, which the person may have difficulty remembering themselves
- build good relationships and understand the person's usual behaviour and communication needs.

1.5.20 General practices should allocate a named member of staff to remind people with learning disabilities about appointments for screening and

health examinations. This staff member should help the person attend the appointment by:

- using each person's preferred method of communication
- giving them information in a way they can understand
- ensuring the person understands the reason for the appointment and why it is important
- finding out their transport needs
- making reasonable adjustments to help the person and their carer or supporter to attend.

1.5.21 If the person is diagnosed with a health condition, give them and their family members, carers or advocate accessible information on the following (taking time to explain it to them as well):

- symptoms and management
- benefits, and potential side effects, of treatment
- how to take their prescribed medicines.

1.5.22 Support people to manage their own health conditions by getting to know them and adapting health advice to suit their personal choices and the activities they already enjoy (for example, playing football).

Dental care

1.5.23 Commissioners and managers should ensure that support staff have knowledge of oral health so they can support people with learning disabilities to maintain good oral health and access dental services.

1.5.24 Dental practices should ensure their services are accessible to people with learning disabilities, for example by:

- reminding people about their appointments by phone
- sending letters in an accessible format, for example Easy Read

- suggesting that the person brings a carer or supporter with them
- ensuring staff have the skills to communicate with people with learning disabilities and put them at ease.

For further guidance on managing oral health, see the NICE guidelines on:

- oral health promotion: general dental practice
- oral health for adults in care homes.

Outpatient appointments

1.5.25 Hospitals should offer an opportunity for the person and a family member, carer or advocate to visit the hospital before their outpatient appointment to meet the staff who will conduct any tests or examinations, see the equipment that will be used and identify what adjustments will be needed.

Before and during a hospital stay

1.5.26 When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members, carers or advocate. At this meeting:

- complete the pre-admission documentation, which should include information from the person's hospital passport
- discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.

1.5.27 Hospitals should actively encourage staff to use pre-admission documents and flagging systems so that all relevant hospital staff know about the person's learning disability. At discharge, review how well this is working.

1.5.28 Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay,

including overnight.

1.5.29 Hospital staff should continue to offer health and personal care (toileting, washing, nutrition and hydration) to people with learning disabilities even if they have a family member, carer or advocate there to support them.

1.5.30 For further guidance on planning admission and admitting adults with identified social care needs to hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Transfer of care from hospital

1.5.31 If the person agrees, invite family members, carers or advocates to pre-discharge meetings, as well as the person themselves.

1.5.32 If the discharge plan involves support from family members or carers, take into account their:

- willingness and ability to provide support
- circumstances, needs and aspirations
- relationship with the person
- need for respite (short breaks).

[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]

1.5.33 Give the person (and their family members and carers) an accessible copy of their discharge plan when they are discharged, and make sure their GP has a copy within 24 hours. Make sure everyone knows what will happen next in the person's care and support.

[This recommendation is adapted from the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.]

1.5.34 After the person is discharged, the hospital learning disability liaison nurse, community learning disability team and primary care practitioners should work together to provide ongoing support to help the person manage their health condition.

1.5.35 For further guidance on discharging adults with identified social care needs from hospital, see NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Dementia

1.5.36 Explain at an early stage to people with learning disabilities (particularly people with Down's syndrome) and their family members, carers and advocates about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people:

- printed information on dementia
- opportunities for one-to-one discussion with a professional
- advice on communication strategies for people with dementia.

1.5.37 Commissioners should ensure information is provided to family members, carers and advocates of people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover:

- types of dementia
- how dementia might present in people with different learning disabilities
- care pathways for different dementias
- practical steps to manage daily life
- communication skills
- how to find further advice and ongoing support, including support groups and respite services (short breaks).

1.6 End of life care

Access to end of life care services

1.6.1 Give people growing older with learning disabilities and their family members, carers and advocates accessible, timely and person-centred information about all the potential care options available for end of life care, including hospice services.

Making sure end of life care is person centred

1.6.2 Practitioners providing end of life care should spend time getting to know the person to understand their needs. Get to know how they communicate, their cultural background, what they like and dislike, how they express pain, their health conditions and the medication they are taking. Be aware that this understanding will make it easier to identify when the person's health is deteriorating.

1.6.3 Identify who the person would like to involve in creating their end of life plan. Include the person themselves and everyone who supports them in discussions and planning.

1.6.4 Ask the person regularly who they would like to involve in discussions about their end of life plan, in case they change their mind. Do this every 6 months, or more often if the person is close to the end of life.

1.6.5 Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).

Involving families and support networks

1.6.6 During end of life care planning, talk to the person and their family members, carers or advocate to understand the person's wishes and any cultural needs at the end of their life.

1.6.7 When providing end of life care, learn from family members, carers or advocates about the person's needs and wishes, including those associated with faith and culture, nutrition, hydration and pain management. This is particularly important if the person has difficulty communicating.

1.6.8 Learning disability providers delivering care at the end of life should work collaboratively and share information with other practitioners and services involved in the person's daily life.

1.6.9 Social care providers should work in partnership with healthcare providers to share knowledge about the person and to develop expertise for end of life care.

1.6.10 Provide training, information and support for family members and carers, for example, in medication, pain, nutrition and hydration, to enable the person to die where they wish.

1.6.11 Make sure that key members of the person's support network have the knowledge, confidence and understanding to communicate with the person about their illness and death. This includes being able to talk to the person about symptoms, pain management and their preferences about resuscitation.

1.6.12 Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with, throughout palliative and end of life care and bereavement.

1.6.13 For further guidance on end of life care, see NICE's guideline on care of dying adults in the last days of life.

1.7 Staff skills and expertise

1.7.1 Managers in health and social care services should ensure that staff in older people's services have the expertise to support people growing older with learning disabilities from a wide range of backgrounds.

1.7.2 Managers in health and social care services should ensure that learning disability staff have the skills and understanding to support people's changing needs as they grow older. Provide this skilled support in all settings, including people's own homes.

1.7.3 Managers in health and social care services should ensure that all staff working with people with learning disabilities have skills and knowledge in:

- communication methods, including non-verbal communication
- building good relationships with people with learning disabilities and making them feel at ease
- the physical, mental health and sensory needs of older people with learning disabilities, related to both their age and disability
- the application of the Mental Capacity Act 2005
- safeguarding issues, including how to report concerns and keep people safe
- common health conditions to which people with learning disabilities are predisposed, for example, the earlier onset of dementia
- assessing people's changing needs as they grow older, and not assuming that any new problems are due to their learning disability when they could be symptoms of other conditions or difficulties (diagnostic overshadowing)
- the main causes of early death in people with learning disabilities.

1.7.4 Managers in health and social care services should provide opportunities for learning disability staff and practitioners working with older people to share expertise with each other as part of their knowledge and skills development.

1.7.5 Staff should know what local services are available (including housing options) so they can support people with learning disabilities and their family members, carers and advocates to make informed choices about their care and support.

Staff skills and expertise for supporting end of life care

1.7.6 Commissioners and providers of end of life care should recognise the complex needs of people with learning disabilities. They should provide ongoing training for staff to ensure they have the expertise to provide good-quality coordinated care, enabling people to die in their own home or another place of their choice. Training should include:

- having discussions about resuscitation intentions
- finding out and responding to cultural preferences
- recognising pain and discomfort
- managing symptoms, pain and medication
- nutrition and hydration
- understanding communication preferences and being able to communicate – this might include using augmentative and alternative communication methods.

1.7.7 Provide in-service training for learning disability and palliative care practitioners so they have the skills to support people at the end of life. This might include joint study days and training of professionals by people with learning disabilities and their family members and carers.

Terms used in this guideline

Annual health check

An NHS initiative for adults and young people aged 14 and over with learning disabilities to provide additional health support and help to identify health conditions that could otherwise go undetected.

Augmentative and alternative communication

An umbrella term that includes methods of communication to supplement or replace speech or writing for people who need support to understand or express language.

Diagnostic overshadowing

In this guideline, this is used to mean the tendency to attribute all behavioural, emotional, physical and social issues to a person's learning disability or a pre-existing condition, while overlooking the possibility that they could be symptoms of other conditions or difficulties. An example would be attributing challenging behaviour to a learning disability when it could be a reaction to abdominal pain, which in turn might be symptomatic of a physical health problem.

Family members and carers

This includes people who are related to the person with a learning disability and anyone else who helps to provide informal support, for example friends. It does not cover staff who are paid to provide care or support.

Health action plan

A personal plan for people with learning disabilities about how to stay healthy. It should detail what help and support they need to look after their health. This might include support to manage physical or mental health conditions, or actions in relation to lifestyle issues such as diet and exercise.

Hospital passport

A hospital passport is designed to give hospital staff useful information that is not limited to illness and health. For example, it could include details about what the person likes and dislikes in terms of physical contact or food and drink. The idea is to help hospital staff understand how to make the person feel comfortable.

Lasting power of attorney

Lasting power of attorney is a legal document that lets someone appoint one or more people to make decisions on their behalf, should they be unable to. Lasting power of attorney can be made in relation to health and welfare, and property and financial affairs.

People growing older with learning disabilities

For the purpose of this guideline, a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

A person's learning disability may be mild, moderate, severe or profound in severity. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

A specific age limit is not used to define older people because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population. This is reflected in the guideline title 'people growing older with learning disabilities'. Within the recommendations, this long form is used at the beginning of each section but in subsequent recommendations 'people' or 'people with learning disabilities' is used as a short hand. In all cases, the intended population is 'people growing older with learning disabilities'.

Practitioner

In this guideline, 'practitioner' is used to mean a health or social care practitioner who provides care and support for older people with learning disabilities.

Support network

All the people who provide emotional and practical help to a person with a learning disability. A person's support network could include their family (including siblings), friends, carers, advocates, non-family members living with the person in supported housing, and members of the person's religious community.

For other social care terms, see the Think Local, Act Personal care and support jargon buster.

Putting this guideline into practice

NICE has produced tools and resources to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Ensuring integrated, person-centred care and support for people growing older with learning disabilities, and their families and carers. This will mean health and social care practitioners and providers involving and listening to the person and their family and carers, and agreeing a care plan that reflects their needs and aspirations. Offering an annual health check, including explaining what it will involve and how to arrange it, is an important part of this. It will also mean challenging assumptions and looking beyond the person's learning disability to provide the support needed to help them live an active, community-involved life.
- Ensuring a well-trained and supported workforce, with the knowledge needed to support people growing older with learning disabilities. Health and social care services are structured in a way that tends to mean practitioners work in either learning disability or older people's services, and their training and support reflects this. Moving to a workforce with expertise from across both disciplines may be challenging to achieve.
- Planning and commissioning local health, social care and housing services to meet the needs of the local population. Commissioners need to know the size of their local population of adults with learning disabilities, and any likely future growth in this population. Learning disability services are often seen as separate from other services, but all pathways of care and support need to consider the needs of people with learning disabilities in order to improve access and funding.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant

boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Recommendations for research

The guideline committee has made the following recommendations for research. The full list of research recommendations is in the full guideline.

1 Models of care and support at home

What is the effectiveness and cost effectiveness of care and support models (for example, assistive technology) for people growing older with learning disabilities to enable them to live in the family home?

Why this is important

There is no evidence from studies published later than 2005 about the effectiveness and cost effectiveness of care and support models for people growing older with learning disabilities living in the family home, or about their experiences of that support. For example, we did not identify any evidence on the effectiveness and cost effectiveness of assistive technology for supporting older people with learning disabilities and their ageing family carers.

Comparative studies are needed to evaluate the costs and impact of different approaches, like assistive technology, on care and support for older people with learning disabilities in the family home. Resource use information, demonstrating the impact on paid and unpaid care (whether it increases or decreases as a result of the different support models) is needed as well as outcome data relating to families and carers. These should be supplemented by qualitative studies to explore the views and experiences of older people with learning disabilities, including those from minority backgrounds, and their families and carers, in relation to different models of support.

2 Identifying health conditions

What is the effectiveness and cost effectiveness of different ways of identifying age-related and other physical and mental health conditions, in people growing older with learning disabilities?

What can mainstream and specialist health services do to facilitate:

- early identification of health conditions in people with learning disabilities?
- equal access to health services in people with learning disabilities?

Why this is important

Apart from studies on annual health checks, we did not find any evidence about different methods and pathways for identifying health conditions among people growing older with learning disabilities. There is a need for effectiveness and cost-effectiveness studies using longitudinal, comparative designs to evaluate the costs and outcomes, in particular the final health outcomes, of different approaches to identifying health conditions in people with learning disabilities. These should be complemented by qualitative studies to explore the views and experiences of people with learning disabilities, including those from minority backgrounds, and their families, carers and practitioners, on the facilitators and barriers of these approaches. This includes their views on how, where and by whom these services should be provided.

3 Education and training programmes: self-management

What is the effectiveness and cost effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example, obesity, diabetes and cardiovascular disease) for people growing older with learning disabilities, and their family members and carers?

Why this is important

Evidence suggests that people growing older with learning disabilities value the medical knowledge and authority of health professionals. There is a small amount of evidence that practitioners could play a greater role in providing education and advice to support self-management of health conditions in people with learning disabilities. There is also evidence that families and carers play a central role in supporting and advising people with learning disabilities about their health conditions and promoting healthier lifestyle choices.

There is currently a lack of information about the cost effectiveness of such education

programmes. However, there is evidence that people with learning disabilities are more likely to have missed appointments with health professionals, do not have optimal medication management and have problems to access to healthcare more broadly, all of which can have costly consequences; some of those might be avoided or reduced through self-management.

Comparative effectiveness and cost-effectiveness studies are needed to evaluate the impact of education programmes to support self-management for people with learning disabilities. These need to be supplemented with studies exploring the views and experiences of people with learning disabilities, including those from minority backgrounds, and their families, carers and practitioners, on the accessibility and acceptability of different approaches to supporting self-management and communicating health messages.

4 Dementia education and training programmes for family members and carers

What is the effectiveness, cost effectiveness and acceptability of training programmes (for example, in the use of life story work) for families of people growing older with learning disabilities who have dementia or are at risk of developing it?

Why this is important

No evidence was found from studies published later than 2005 about the effectiveness and cost effectiveness of interventions or training programmes for family members and carers of people growing older with learning disabilities who have, or are at risk of developing dementia. There is some evidence that some family members and carers of people with learning disabilities and dementia need specialist training in dementia care.

Comparative effectiveness and cost-effectiveness studies are needed to evaluate the impact of specific interventions or training programmes for families and carers of people with learning disabilities, including for people living with conditions such as dementia. Qualitative studies are needed to explore the views and experiences of family, friends and carers of people with learning disabilities, including those from minority backgrounds, about these training programmes.

5 Advance planning about end of life care

What is the effectiveness and cost effectiveness of advance care planning for end of life care for people growing older with learning disabilities, and their family members and carers?

What processes are in place to document and follow the wishes of people growing older with learning disabilities about their decisions on end of life care?

Why this is important

We identified no studies evaluating the effectiveness or cost effectiveness of advance care planning for end of life care in people growing older with learning disabilities, and their family members and carers. Such studies would help to determine how and what reasonable adjustments should be made to ensure that people with learning disabilities receive appropriate care at the end of life, and the costs and cost consequences associated with those. Longitudinal studies should have a naturalistic design with a control group to follow up families and carers who have used advance care planning for end of life care in people with learning disabilities.

Finding more information and committee details

You can see everything NICE says on this topic in the NICE Pathway on care and support of older people with learning disabilities.

To find out what NICE guidance on related topics, including guidance in development, see the NICE webpage on older people and people with learning disabilities.

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 our guidelines into practice, see resources to help you put NICE guidance into practice.

Update information

Minor changes since publication

March 2020: Cross reference to NICE's guideline on supporting adult carers added to recommendations 1.1.4, 1.3.8 and 1.3.9.

May 2018: Minor edits to the advice on communication needs.

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Accreditation



The Regulation and Quality Improvement Authority



Guidelines on Caring for People with a Learning Disability in General Hospital Settings

Revised June 2018

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Assurance, Challenge and Improvement in Health and Social Care

FOREWORD

In accepting that progress has been made in some services, the equity of access to, the implementation of reasonable adjustments within, and the equity of outcome from general healthcare services for people with a learning disability still requires further development. In 2010, the Guidelines & Audit Implementation Network (GAIN) published its orginal set of Guidelines on Caring for People with a Learning Disability in General Hospital Settings.

The number of people with a learning disability has increased since 2010 and services continue to become more community based. It is projected that the number of people with a learning disability will to continue to grow over the next 10 years, in particular among young adults and older people. This will result in a growing number of people with a learning disability, with a range of abilities and complex health needs, coming into contact with departments within general hospitals, including Outpatients, Day Surgery, Emergency Departments and Inpatient wards.

In 2014, an RQIA review provided an assessment of current practice, identifying both examples of good practice and challenges to the implementation of the guidelines since their introduction in June 2010. The review team noted that, while all five Health and Social Care Trusts reviewed are taking account of and implementing certain aspects of the guidelines, there was inconsistency across services and there is more that needs to be done. Consequently, 19 recommendations were made and where appropriate, the actions relating to these recommendations have been incorporated into the 2018 Guidelines on Caring for People with a Learning Disability in General Hospital Settings.

These revisions of the original GAIN (now RQIA) guidelines and the development of these guidelines were jointly undertaken by Professor Owen Barr, Ulster University; Maurice Devine, Clinical Education Centre; Nicola Porter, RQIA with contributions from a range of health and social care professionals; people with a learning disability; and family members and carers (See Appendix 1).

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CONTENTS **Page**

Foreword	2
Contents	3
Introduction	4
Literature Review	5
Attitudes and Values	13
Communication	17
Training & Education	21
Legal Issues	25
Outpatients	29
Admission Process and Support	32
Discharge Planning	37
Emergency Care	40
Support for Carers	43
Nutrition and Hydration	47
Pain	50
Improving the Experience of Children with a Learning Disability	54
Implementation and Audit	57
References	58
Appendix 1- Review Members	60

Introduction

Being in contact with a general hospital can be 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 many 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 being understood and making their needs and wishes known, difficulties in expressing feelings of discomfort or pain, and difficulties with self-management. In addition, a limited understanding of the abilities and needs of people with a learning disability 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, and compromised nutrition, and may be at increased risk of choking, all of which are more common in people with a learning disability.

Current health and social care policy within Northern Ireland is underpinned by the recognition of people with a learning disability 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 with, at times, grave consequences for people with a learning disability.

It is therefore intended that this guideline for care delivery will enhance safe and effective care throughout their 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 disability' and an overview of the published literature on the difficulties people with a learning disability 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" (p.18).

The individual may also have difficulties with social and/or communication skills, and with carrying out activities of daily living independently, and may have associated physical and sensory disabilities.

Accurate estimation of prevalence rates of learning disability is difficult and cannot be definitive (Murphy 2014).

However, it is estimated that 2% of the population will have a learning disability (BILD 2011). The most recent prevalence rates from Mencap state that there are approximately 30,814 adults with a learning disability in Northern Ireland. (Mencap 2018). Based on estimated prevalence needs of children with learning disabilities, when compared with the adult prevalence rates (FPLD 2018), this would mean that there are approximately a further 7,400 children with a learning disability in Northern Ireland. All of this means that there is a potential total population of 38,214 people with a learning disability in Northern Ireland.

For a range of reasons, people with a learning disability are twice as likely to experience contact with general hospitals as 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. The number of people with a learning disability is continuing to increase through a combination of increased survival of premature babies, increased numbers of children with complex disabilities living into adulthood, and the overall increased longevity of adults with a learning disability as a result of increasing access to health promotion, as well as primary and secondary care (DHSSPS 2005). With the wider developments in inclusive community based services and the reduction in general healthcare services within learning disability hospitals, it is clear that people with a learning disability will increasingly have contact with and will require services within general hospitals. Services required can range from outpatient appointments and day procedures through to the need for emergency care provision, medical or surgical intervention and repeated lengthy admissions due to complex health needs.

People with a Learning Disability 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 development. The Service Framework for Learning Disability (DHSSPS 2015) requires that ‘All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.’ (Standard 19, p13) and ‘hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan.’ (p13)

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 a learning disability and that they include the provision of accessible information.

Contact by people with a learning disability with the general hospital service is broadly similar to the general population. Very often, attendance is 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 a learning disability 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 (Hatton et al. 2016, 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 a learning disability has been a growing concern over the past 20 years. 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 a learning disability 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 (Parliamentary and Health Services Ombudsman 2009) instigated as a result of “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 a learning disability 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 a learning disability.

In 2013, a major enquiry into the premature deaths of people with a learning disability reported that there were ongoing challenges in the care of people with a learning disability related to delays in diagnosis and further investigation, and the identification of people with a learning disability in hospitals. They specifically felt that staff failing to make reasonable adjustments, compounded by a lack of coordination within and between hospital services, 'were contributing factors in a number of deaths' (Heslop et al, 2013, p4). This enquiry also reported difficulties with the way 'best interests' decisions were made and the availability of advocates. It also reported that 'Many instances were identified of inappropriate or poorly documented DNACPR' and 'Record-keeping was commonly deficient – particularly in relation to fluid intake, nutrition, weight and seizures, and little attention was given to predicting potential problems e.g. when a person was fearful of contact with medical professionals' (p5).

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 a learning disability, their families and staff within general hospital services, has been documented. This includes:

People with a learning disability:

- experience difficulty in understanding what was happening.
- are provided with limited information, and the rights of the people with a learning disability to be actively involved in decision making are not fully considered.
- do not feel involved in the discussions and decisions which have taken place.
- have a lack of appropriate accessible information.
- 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 a learning disability:

- 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 a learning disability.
- identify that there are limited opportunities for meaningful activities, and the environment results in the person with a learning disability 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 a learning disability. This can result in diagnostic overshadowing where doctors and others make mistaken assumptions about people with a learning disability, resulting in failure to diagnose accurately or the misinterpretation of symptoms.
- may be over relied on by professional staff to provide care to the person with a learning disability, and their needs as relatives may not be fully responded to.

Staff in general hospitals:

- at times have limited relevant information available about the person with a learning disability on admission.
- report having limited confidence and experience in supporting people with a learning disability, and are not familiar with what help they should provide or from whom to get expert advice to update their knowledge and skills.
- may experience difficulties in achieving informed consent and the required level of cooperation.

- may have undertaken limited continuing professional development on the abilities and needs of people with a learning disability.
- may view 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 a learning disability.

(Barr 2004; Sowney & Barr 2006; Sowney & Barr 2007; DH 2008; SHSSC 2008; Backer et al 2009; Parliamentary and Health Services Ombudsman 2009: Heslop et al 2013)

Consequences of Ineffective Hospital Services for People with a Learning Disability

The consequences of ineffective general hospital services for people with a learning disability 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 a learning disability, and for some people these limitations have been reported as causing or contributing to their avoidable death, leaving family members with many unanswered questions (Heslop et al 2013). 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.

These findings have been further reinforced by the findings of the Confidential Inquiry into the Premature Death of People with Learning Disabilities (Heslop et al., 2013) which highlighted that the level of avoidable death is twice as high among people with learning disabilities, and that three times more deaths among people with learning disabilities could

be prevented by ‘good quality care’ compared to the general population. This Inquiry also concluded that the ‘most frequent reasons given for a death to be premature were because of delays or problems with treatment, or because of problems with assessing or investigating the cause of illness’ (Heslop et al. 2013, p32). The Annual Report of the Learning Disability Mortality Review Programme (LeDeR, 2017) again reported that people with learning disabilities continue to die younger than people who do not have learning disabilities. This report identified that ‘the difference in age at death between people with learning disabilities (aged four years and over) whose deaths were notified to LeDeR, and the general population of England and Wales (all ages, 2010 data) is 22.8 years for males and 29.3 years for females.’ (LeDeR 2017, p18).

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) and that ‘All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.’ (DHSSPS 2015, p13).

We recognise that a number of excellent initiatives have been developed in some Trusts to enhance the person’s contact with general hospitals, and many developments have taken place in seeking to implement the 2010 guidelines. However, more work still needs to be done to fully implement the 2010 Guidelines. 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

Based on a review of current published literature on this topic there are 12 areas of improvement identified. These have been prioritised as the most pressing areas of need and 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:

1. Attitudes and Values
2. Communication
3. Training & Education
4. Legal Issues
5. Outpatients
6. Admission Process and Support During the Hospital Stay
7. Discharge Planning
8. Emergency Care
9. Support for Carers
10. Nutrition and Hydration
11. Pain
12. Improving the Experience of Children with a Learning Disability.

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, progress can continue to be made within existing resources, through the actions of services and individual staff members, particularly in how they relate to people with a learning disability and their families.

Attitudes and Values

Best Practice Statement

Every individual with a learning disability using hospital services should have equal access to the full range of services. Staff in a general hospital setting should demonstrate behaviours that are respectful, which include:

- seeing the person as an individual with abilities and needs and not focusing on their disability.
- ensuring that communication is timely and sensitive to the needs and preferences of the person.
- person centred care resulting in safe, dignified, respectful and compassionate care.

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 people 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 five overarching standards that will be central to the achievement of the best practice indicators 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 person with a learning disability does not necessarily mean treating them in the same way. This will often mean the need for reasonable adjustments that provide additional and alternative methods of support established with the person 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 people who have a learning disability. People must be actively involved in decisions regarding their care and steps should be taken to maximise their contribution to decision making (using appropriate, accessible information such as pictures, information leaflets). This will require hospital staff to have a clear understanding of the legal position around capacity and consent (See Best Practice Statement 4).

3. **Contribution of Carers**: When accessing general hospital services, families/carers have an important and unique contribution to make in discussions of the person's care and treatment, with the agreement of the person with a learning disability. With the permission of the person with a learning disabilitiy, 'you should be fully involved as an equal partner at all stages of their treatment including decisions about what needs to happen for a timely and positive discharge. Family members and carers should have a choice about caring for the person when they are in hospital. No assumptions should be made about your willingness to provide care.

4. The importance of listening to the family/carers, recognising their particular knowledge of the person with a learning disability and their ability to communicate with and understand responses can be crucial to effective interventions. Often they are the only people who have a continuous relationship in the person's life and this contribution should be sought, acknowledged, valued, listened to and acted upon.

5. **Advocacy**: Advocacy is the process whereby people who are vulnerable 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 nurse within the hospital. It is important that the person with a learning disability has a choice of someone they want and feel comfortable with. Identifying advocacy arrangements for the person should be a core component of the assessment process in hospital, thereby promoting a person centred approach to care and treatment.

6. **See the person not the disability**: It is vital that health and social care professionals focus on the abilities and needs of the person as an individual and are not distracted by the learning disability, which can sometimes overshadow the presenting condition and may delay the investigation, diagnosis and treatment of their medical condition.

7. **Communication**: ***Everyone can communicate but some people do not use words.*** Health care professionals should establish, where possible, the person's method of communication and support needs required. Staff should recognise the need to communicate directly with the person 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, p12)

8. **Education**: All staff within general hospital services should receive education that increases their awareness of the abilities and needs of people with a 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, education on learning disability issues should also include people with a learning disability and their family/carer.

9. **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 people with a learning disability. When major decisions around best interests need to be taken, there should be a clear understanding of the legal position and due regard must be given to the opinions and wishes of those closest to the person. Everyday practice should place value on the quality of life of a people with a learning disability.

Helpful Resources

- DHSSPS (2008) Improving the Patient & Client Experience. http://www.nipec.hscni.net/download/projects/previous_work/highstandards_practice/patientexperience/PatientEx-standards.pdf

- DHSSPS (2003) Seeking Consent: Working with people with learning disabilities. Seeking Consent: Working with people with learning disabilities.

- Mencap Easy Read Health Statement https://www.mencap.org.uk/about-us/what-we-think/health-what-we-think

- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse. https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities

COMMUNICATION

Best Practice Statement

Everyone can communicate but some people do not use words.

People with a learning disability and their families/carers should experience effective and meaningful communication to support safe and person centred care.

Background

Safe, effective and person centred care is underpinned by timely, effective and sensitive communication. It is well established that the risk of harm increases if there is difficulty in communicating with the person with a learning disability. Effective communication is multi-faceted and should be focused on direct communication with the person with a learning disability, communication with family/carers (with the agreement of the person with a learning disability when personal information is being shared) and communication between professional staff. Effective communication is supported by a number of key principles which include the understanding that:

- all people can communicate and may use a variety of different means; many people with a learning disability have communication support needs, with half having significant difficulties. There is a wide range of communication difficulties but the barriers to successful communication are often due to the environment and other people.
- many people with profound and multiple learning disabilities are able to communicate but may have extremely limited communication which may be restricted to behaviours such as eye gaze and changes to facial expression.
- all people with a learning disability communicate in a number of ways, both verbal and non-verbal.
- behaviour, including behaviours that challenge is often 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 for communicating with people with a learning disability.

Best Practice Indicators

1. Staff should check if the person has a document that highlights how they communicate (e.g. HSC Hospital Passport). Further information regarding the person's method of communication and their communication support needs should be sought from the person, families/carers, and if necessary the community learning disability team (See helpful resources below).
2. The subsequent care plan should highlight the way(s) in which the person communicates specific wishes/needs/problems, for example: activities to do, hunger, thirst, toileting needs, pain or distress.
3. Communication should always take place with the person with a learning disability in the first instance.
4. Staff should adjust their verbal and non-verbal communication to meet the needs of the person. Consider the following when communicating with people who have a learning disability:

    a. Address the person by their preferred name.
    b. Speak slowly and don't shout.
    c. Use very straightforward language and don't use medical jargon.
    d. The use of inclusive communication supports e.g. gestures, pictures, photos, symbols, objects, body language, facial expression and Makaton, can help (see Hospital Communication Book helpful resources section below).
    e. 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.
    f. Be aware that the person may have additional hearing or visual impairments.
    g. Pay attention to eye contact, body language, facial expression and contact via touch.

Staff should make use of and, where necessary, develop relevant resources to assist in the provision of information.

1. A range of easy read information sheets is available in a variety of formats to help people with a learning disability understand what is going to happen during their stay in hospital. Staff may seek advice from a Speech and Language Therapist and other staff who may be experienced in developing accessible information (e.g. Registered Nurses for people with learning disabilities) when producing easy read/accessible information (See helpful resources section).
2. Staff should have regular education and skills development on communication skills, particularly centred on the challenges encountered when a person has cognitive or other sensory impairments.
3. Trusts should develop a resource pack to support effective communication during the hospital journey. The Easy Health website (see below) provides a range of helpful resources for this purpose.
4. Staff should discuss (following consent/best interest decision) with family/carers their role in facilitating communication with the person with a learning disability. Staff should listen to and respect the advice/information given by the main carer, as they will have detailed knowledge of how to communicate best with the person with a learning disability.
5. Expressions of concern by people with a learning disability, family members or carers must be acknowledged and addressed immediately, using the proper and usual procedures. Complaints processes must be made accessible to people who have a learning disability and/or the family/carers. When concerns are addressed and openly discussed at an early stage, this is often reduces the need to progress to formal complaint processes.
6. 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 administrative and 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 that provides very useful resources in terms of easy read information related to health issues.

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

- www.rcslt.org/news/docs/good_comm_standards
- www.makaton.org

- A guide to communicating with people with profound and multiple learning disabilities https://www.mencap.org.uk/sites/default/files/2016-06/2012.340%20Raising%20our%20sights_Guide%20to%20communication_FINAL.pdf

Training & Education

Best Practice Statement

Every person 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 education 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 a learning disability are complex and their health care needs are often misunderstood by health care professionals. Evidence indicates that there is limited confidence, experience, understanding and knowledge of the health problems they experience and the risk of harm to people with a learning disability whilst in hospital (Heslop et al 2013, Parliamentary and Health Services Ombudsman 2009).

A range of reports and inquiries has identified that education 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 a learning disability 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 regulators ‘Codes’ of professional behaviour 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 (DH 2008, Heslop et al 2013).

Best Practice Indicators

1. Academic, professional institutions and third sector organisations that provide both pre and post registration clinical education should incorporate Learning Disability Awareness training within their curricula.
2. Learning Disability Awareness education should be mandatory for hospital staff who will or may have direct contact with people using the hospital services in order to enhance their knowledge and skills in providing safe and effective care to people with a learning disability.
3. All new staff within Health and Social Care (HSC) services should receive appropriate education in learning disabilities, to include disability equality training as part of their Corporate Induction Programme.
4. HSC Trusts and other organisations should have access to the regional e-learning programme that has been developed by GAIN to support the implementation and application of this guideline. The link to this e-learning programme is provided in the helpful resources section below.
5. The education of staff should be designed and delivered in partnership with people with a learning disability and/or their carers. Learning Disability Awareness education, should provide participants with increased knowledge and understanding of the abilities and needs of people who have a learning disability, to enhance safe and effective care throughout their contact with general hospital settings. This education should include the following minimum content areas:

    - Define the meaning of learning disability and the range of ways it impacts on an individual.
    - Describe the changing patterns of mortality and morbidity among people with a learning disability.
    - Use of examples from people with a learning disability to provide an overview of the challenges they may encounter when in contact with general hospital settings.
    - Identify and explore how to implement the best practice guidelines as indicated in reviewed Guidelines, “On Caring For People With A Learning Disability In General Hospital Settings” 2018.
    - Discuss approaches to establish effective communication with a person with a learning disability in a general hospital setting.

- Define and explore the requirement to make “reasonable adjustments” to ensure people with a learning disability have equal access to all services in the general health setting.
- Discuss the requirements in relation to the process of obtaining consent from a person with a learning disability.
- Understand how to access support from local learning disability services.

Helpful Resources

- DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals

- RCN (2013) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing. https://www.rcn.org.uk/professional-development/publications/pub-003024

- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse. https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities

- The e- learning programme - Caring For People With a Learning Disability In General Hospital Settings: This programme has been developed in Northern Ireland to support and complement these guidelines. This programme has input from people with a learning disability, parents of people with a learning disability and from a range of professional staff. They provide an excellent educational resource and can be accessed by anyone who has an interest in this topic.

  The e-learning programme can be accessed **by anyone.** You can apply by visiting the e-learning section of the HSC Clinical Education Centre website http://cec.hscni.net/Courses/Category/23

Legal Issues

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 a learning disability within general hospital settings, three areas of concern have been frequently highlighted:

a) Human Rights: People with a learning disability frequently, are not 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 person'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 legal position in relation to consent and capacity as it applies to people with a learning disability. Consequently, treatment may be delayed or denied and affect the effectiveness of outcomes (The Parliamentary and Health Service Ombudsman 2009).

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 requirement to make reasonable adjustments (at a practice, policy and organisational level). Education about human rights and consent is also vital, with emphasis on its application to people with a learning disability. This education needs to be provided for health and social care staff working in both children and adult settings.

2. Reasonable adjustments should be considered in terms of physical barriers such as ramps and wheelchair access, and other practice, policy and procedural adjustments that may require to be made such as:

    a. providing information in a format that is most likely to aid understanding.
    b. the provision of longer appointments.
    c. effective communication with the person and/or carers.
    d. appropriate mechanisms in place to identify pain and/or distress.
    e. appropriate complaint handling.
    f. the level and extent of involvement of others such as family/carers/advocate.
    g. identifying and implementing the reasonable adjustments that are required within the individual care/treatment plans.

Examples of reasonable adjustments that have made a difference to people with learning disabilities can be accessed at: https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities

3. For planned admissions, a pre-admission meeting involving the person with a learning disability and those close to them (family/carers/advocates) 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 seek the advice and expertise of those who work in learning disability services and of advocates in situations where there is confusion/uncertainty.

5. People 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 for a particular decision, this must be assessed by the professional responsible for the intervention. Family/carers should be involved in this process.

6. Where a person is deemed not to have capacity to make a specific decision at a specific time, 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, and staff should have a clear understsnding of, 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 be based on objective information and should 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

- DHSSPS (2003) Reference guide to consent for examination, treatment or care https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals

  DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals

- DHSSPS (2003) Seeking Consent: Working with Children https://www.health-ni.gov.uk/publications/consent-guides-healthcare-professionals

  Royal College of Nursing (2017) Principles of consent: Guidance for Nursing staff. https://www.rcn.org.uk/professional-development/publications/pub-006047

- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse. https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities

Outpatients

Best Practice Statement

Many people with a learning disability have frequent contact with general hospital via the Outpatients department. 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 people with a learning disability have with hospitals is known about in advance and often relates to outpatient appointments for initial assessment, investigation or treatment. However, it has been regularly noted within the literature referred to in the introduction to this document that people with a learning disability 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 person 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 Outpatients 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. HSC Regional Hospital passport) should be used to gather the information necessary to support the appointment. This should include key information about the person'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 appointment of a session or early clinic appointments. If clinic appointments are running behind time, people with a learning disability should be informed and if the delay is causing the person problems, further reasonable adjustments may need to be made to ensure the person is seen on time and any distress limited.

5. All information about what to expect should be provided to people with a learning disability and their family/carers in appropriate accessible formats, providing contact details for key staff that may be able to provide or organise support if required. Staff working in learning disability services may have a role to play in the provision of this support.

6. Directions sent to the person with a learning disability and signage within the hospital site should provide clear accessible information that will allow the person 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 the opportunity to 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 person in plain language, outlining the sequence of events.

9. Throughout the appointment staff should monitor the person's level of comfort, understanding of what is happening, anxiety and distress.

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

- www.easyhealth.org.uk is a web site run by Generate, a charity working with people who have a learning disability, provides very useful resources in terms of easy read information related to health issues.

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

- https://www.keele.ac.uk/nursingandmidwifery/mnphald/toolkitcontents/ynphald.pdf "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.

Admission Process and Support

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 a learning disability largely reflect the changes in the general population. Many people with a learning disability 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 a learning disability and staff in the hospital to facilitate a safe journey.

Albeit that there are opportunities for planning admissions, there are some reported persistent failings in the care of people with learning disabilities which have resulted in unnecessary distress/suffering, discomfort and avoidable death (The Parliamentary and Health Service Ombudsman 2009, Heslop et al 2013).

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 (e.g. HSC Hospital Passport, 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 abilities and needs that the person 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 to the handover of information to ward staff on admission and throughout the hospital stay. This may be provided by staff within local learning disability services, and should highlight the person'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/department should gather resources that can help when a person with a learning disability is admitted and ensure that this is accessible to all staff. These resources may be in hard copy or electronic and should include: The HSC Hospital Passport; The Hospital Communication Book; Easy read complaints/comments leaflet; The reviewed guidelines: On Caring For People With A Learning Disability In General Hospital Settings 2018 (previously 2010 GAIN guidelines); and visual menus. In addition, each ward/department should have access to a range of accessible information for the common procedures that may be undertaken within that care environment (many examples are available at http://www.easyhealth.org.uk)for example information regarding the contact points of local learning disability services, and 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 Health and Social Care Trust 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 person with a learning disability should have an identified nurse who is responsible for nursing care for the duration of their hospital stay. Where appropriate, the person with a learning disability may be given a picture of the nurse responsible for their care on each shift.

8. Hospital staff should introduce themselves to the person 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 Easyhealth website http://www.easyhealth.org.uk (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 person'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. All 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 provide an ongoing explanation of procedures, changes in circumstances and interventions. This information should be provided in a format that the person with a leanring disability understands. Health and social care staff should ensure that the person with a learning disability and carers understand the information that they have been given and have the opportunity to ask questions.

14. When the person is required to undergo planned surgery, opportunities should be provided for a pre-operative visit by theatre/recovery nursing staff to the person with a learning disability 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, person with a learning disability and main carer. If the person is admitted on the

day of the operation, the following information would need to be collected in another way:

a. The person's previous experiences of anaesthesia and surgery;
b. How to manage the process of 'nil by mouth'/'fasting';
c. Any known behavioural patterns which may become evident when the person recovers from the anaesthetic;
d. The person's communication abilities and needs;
e. Whether the main carer wishes to accompany the person with a learning disability to the anaesthetic room and/or to be present in the recovery room shortly after the person recovers from the anaesthetic;
f. Whether a ward nurse/carer needs to stay with the person in the anaesthetic room until they are anaesthetised, to provide continuity of care and support.

15. Hospital staff should consider the need for increased clinical observation to discuss changes in the health condition of a person with a learning disability, 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

- www.easyhealth.org.uk a web site run by Generate, a charity working with people who have a learning disability, provides very useful resources in terms of easy read information related to health issues.

- RCN (2013) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing.
  https://www.rcn.org.uk/professional-development/publications/pub-003024

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes
  This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

- People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse.
  https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities

Discharge Planning

Best Practice Statement

People 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 person's plan of care.

Background

People with a learning disability 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 people with learning disabilities and their family often falls short of what would be regarded as good practice (The Parliamentary and Health Service Ombudsman 2009). 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 (Michael, 2008, Parliamentary and Health Service Ombudsman 2009).

Personalised discharge planning is known to reduce the length of hospital stay, reduce the likelihood of unplanned readmissions and achieve good outcomes and experiences for the person (Gonçalves-Bradley et al 2016).

Best Practice Indicators

1. For planned admissions, the discharge process should be a partnership approach involving ward staff, the person with a learning disability, 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, people should be placed on the recognised care pathway related to their condition and a potential date of discharge should be communicated to them and their family.

4. Staff also need to be aware of the potential distress that a person 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 person with a clear explanation of the discharge process, respecting and supporting the right of the person 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 person and should include the family/carers and the relevant hospital and community/primary care staff to identify:

    a. the potential date and time of discharge in order to plan the recommencing of normal daily activities, or recommended new care package;
    b. any potential difficulties the person may experience on the day of discharge, such as waiting for lengthy periods in a discharge lounge;
    c. the location and suitability of the environment to which the person is being discharged;
    d. any other community/primary care staff who need to be informed of the person's discharge;
    e. the support that the person and the family/carers may require to help the person remain within their own home environment (wherever home is);
    f. where certain procedures need to be carried out in the home environment, with identified need for training related to care delivery at home, this should be initiated and coordinated by the hospital staff prior to discharge.

    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 person 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, exercise activities or any other requirements.

8. The above information must be communicated in a format that is understood by the person with a learning disability, carers and family members (when appropriate). The Easyhealth website provides a wide range of information and booklets regarding health information and procedures that could be used.

9. Hospital staff should provide the person with a learning disability with a contact number should they require further advice or information regarding their care following discharge.

10. Hospital staff should invite the person with a learning disability, family/carers to provide evaluation or feedback of their experiences during their stay in hospital.

Helpful Resources

- www.easyhealth.org.uk a web site that provides very useful resources in terms of easy read information related to health issues.

Emergency Care

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 is likely to increase 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 vulnerability of the person with a learning disability. 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 person with a learning disability.

Best Practice Indicators

1. Staff within emergency care departments should check with the person or family/carer if they have brought along a HSC Hospital Passport or system documentation that identifies the individual's method of communication and other relevant information that will be useful to support their assessment, investigation and provision of safe care. The HSC Hospital Passport should be read before any assessment, treatment or care is undertaken. If they have not brought a HSC Hospital Passport along, one should be provided for them to complete. These should be available in hard copy with the department and can be downloaded from http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes.

2. Staff within emergency care departments should develop a specific care pathway/protocol for identifying and caring for people with a learning disability. This should clearly consider the need for reasonable adjustments for the person with learning disabilities in order to ensure they receive timely, safe and person centred care.

3. It is important for staff to assess the person's abilities, needs and safety requirements.

4. During triage, staff need to allow extra time to assess the person's abilities and 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.

5. Where possible, the same nurse should care for the person throughout their journey within the emergency department.

6. Staff should be aware that all behaviour is a means of communicating and that people with a learning disability may express feelings of fear, anxiety and/or pain through odd or unusual behaviours. This may be documented in the HSC Hospital Passport.

7. All information on the diagnosis, investigations and care must be provided in a format that is understandable to the person with a learning disability in the first instance. Health and social care 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 Easyhealth website (see helpful resources section below).

8. When people taken to emergency departments as a 'place of safety' during mental health related crises, a person who has suitable training or experience in completing a mental health assessment or mental state examination should be available so that the person's needs can be identified in a timely manner.

9. 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 health and social care professionals. Specific care needs to be taken to ensure that the person with a learning disability and/or their family/carers are familiar with and understand the discharge advice, including any medication, treatments or follow-up arrangements.

10. Staff within emergency departments should familiarise themselves with the contact information of their local Learning Disabilities Services. A referral can be made to the Community Nursing Learning Disabilities Services where the named nurse has any of the following concerns:

    a. the safety of the person with learning disability when in hospital;
    b. mental health and/or challenging behaviour;
    c. the person's ability to comprehend instructions or follow medication regimens.

11. If the person is a frequent user of emergency departments, planned preparatory work (including sharing information on any physical and/or mental health conditions, crisis management plans and protective/coping strategies) can be carried out by local Learning Disability Services to help emergency care staff understand specific needs when such circumstances arise.

12. Where people with a learning disability attend emergency departments and specific additional needs such as alcohol misuse, homelessness, or a breakdown in care are identified, a hospital social worker should liaise with community learning disability team members to share information in relation to any identified needs.

Helpful Resources

- http://www.easyhealth.org.uk/listing/communication-(leaflets) This site provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

Support for Carers

Best Practice Statement

When a person with a learning disability needs to use any general hospital setting, carers, both family and paid carers, should, where appropriate, be engaged as healthcare partners throughout the pathway of care.

Background

People with a learning disability may be vulnerable at times when they use hospital services and therefore, the involvement of those who are closest to the person with a learning disability in their care may 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 gain the cooperation of the person receiving 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 advice of carers and not to consult with them (Michael Report 2008).

Alternatively, it is also too often expected or assumed by health care professionals that family/carers will continue their support and care delivery to the person with a learning disability when they go into hospital. Family/carers and hospital staff should be working together, within the parameters of the person with a learning disability's expressed wishes, his or her capacity and within the parameters of the legal position around consent and confidentiality, to achieve the best outcomes for the person with a learning disability.

If they decide to, the family/carers with the necessary confidence and skills can also be involved in a range of helpful activities during the hospital stay such as, helping with meals, interpreting what the person is trying to say and keeping the person with a learning disability meaningfully occupied.

Best Practice Indicators

1. The crucial role that family/carers play is highlighted throughout all of the 12 areas 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 expressed wishes of the person with a learning disability, his or her capacity and within the parameters of the legal position around consent and confidentiality. Doing so, will help achieve the best outcomes for the person with a learning disability.

2. Family/carers should be made aware of their rights as carers to have their needs assessed and planned for.

3. It is important that there is no expectation that family/carers 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 person with a learning disability is the responsibility of the general hospital staff. There will of course be circumstances when this additional support is provided (e.g. when the person is a child, when the family/carer chooses to do so, or in circumstances where the person may have very specific needs related to their learning disabilities). It is therefore important that hospital staff establish at an early stage the degree to which the person with a learning disability wishes and the extent of the role family/carers are able and willing to play in the provision of care and support during the person's hospital stay.

4. All staff in the clinical area must be made aware of any agreed additional support provided by family/carers and should facilitate the presence of family/carers including agreed arrangements for visiting, breaks and refreshments. Staff should also remain alert to the fact that family/carers may also be concerned or worried about the person with a learning disability and provide the necessary support to them.

5. The poor management of complaints has been highlighted in many of the reports and inquiries that have examined the care of people with a learning disability in hospitals. When concerns are raised or complaints are made, steps should be

taken immediately to make the person and/or their family/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.

6. Family/carers could compile useful information in the form of a HSC Hospital Passport prior to admission. A copy of this should be updated for subsequent contact with hospital.

7. Family/carers may have a key role to play in the process of effective communication and, in particular, in identifying or interpreting indicators of distress. Hospital staff should engage with family/carers to recognise these communication signals.

8. Hospital staff should also ask if independent advocacy is available for the person 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 person and their family/ carers with additional support.

9. Family/carers and individuals with a learning disability themselves, should be involved in the provision of education to health care professionals.

10. Staff should consider whether family/carers would benefit from a carer's assessment.

Helpful Resources

- 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.

- https://northernireland.mencap.org.uk/ 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.

  http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes
  This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

- https://www.health-ni.gov.uk/publications/carers-guidance This webpage provides useful information for carer to understand their rights, the information they should provided with and conversations that they should be involved in prior to a person being discharged from hospital.

Nutrition and Hydration

Best Practice Statement

People with a learning disability will receive high quality nutritional care based on individually assessed abilities and 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 people 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 wellbeing and recovery as the medicines and other treatments that people may receive.

The nutritional needs of people with a learning disability vary depending on the severity of their disabilities and associated conditions. The difficulties in meeting nutritional needs can be exacerbated by challenges in communication in which hospital staff are unable to understand what the person with a learning disability is communicating about 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 not be given the opportunity or means to exercise real choice. Due to hospital staff perception of a person's learning disability and the limitations of the ability of hospital staff to understand the person, , there is a risk that reasonable adjustments will not be put in place to enable the menu options and the opinion of the person with learning disabilities on food choices to be appropriately sought.

The incidence of eating, drinking and swallowing problems is higher in people with learning disabilities than in other population groups. People with dysphagia are at risk of food or drink 'going down the wrong way' and entering the lungs which can cause chest infections, pneumonia, choking and death. A person with dysphagia may also be at risk of not eating or drinking enough to maintain weight or hydration This can be a major patient safety issue in the care provision to people with a learning disability. Therefore, if nutritional needs are not assessed and managed effectively, this can have detrimental health consequences,

especially when the person'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 HSC Hospital Passport (which includes information about communication, eating and drinking). There may also be useful information from the Speech and Language therapist within the local Learning Disability Service.
2. Family/carers (both formal and informal) should be recognised as having important knowledge of the person. This knowledge should be incorporated in the person's care plan and used to implement care while the person is in a general hospital.
3. Children and adults admitted to general hospital should be screened as per standard and routine policy related to MUST nutrition screening, to determine their nutritional status.
4. Following screening, people 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. People who require support with eating and drinking should be clearly identified and receive safe assistance as required.
6. Staff should strive to promote the independence of a person with a learning disability to eat and drink, providing the required reasonable adjustments in discussion with Occupational Therapists, such as accessible menus, plate guards and non-slip mats.
7. Specialist assessment, support and monitoring by a dietician, will be required for those people who have swallowing difficulties and/or require to be fed via enteral/parenteral routes. Specialist assessment and support by a Speech and Language Therapist will be required for people who have swallowing difficulties.
8. People who have a learning disability should have their food and/or fluid intake accurately monitored and reviewed.
9. Additional support may be necessary to assist people with menu choice. Pictorial menu cards for people with a learning disability who are unable to understand written menus should be available so that the person can be helped to choose. Use

of personal place mats (highlighting likes or dislikes, risks, nutritional and nursing support) will be beneficial in assisting 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.

- Choking awareness website – http://helpstopchoking.hscni.net

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes
  This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

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 other people. 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 manifestations of pain 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 read the person's HSC Hospital Passport which will raise awareness of possible indicators and expressions of pain that may be different than those usually seen and are specific to the individual receiving care. These include nonverbal 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 staff from local 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. Pain assessment tools, using self-report or observational methods and proxy reports have been designed for adults and children with a learning disability (e.g. Disability Distress Assessment Tool (DISDAT) for adults and the NCCPC – R (Non-communicating Children's Pain Checklist – Revised) for children. Staff should give consideration to their benefit and utilisation in each individual circumstance (See helpful resources below).

5. Staff should consider using pictorial formats to help them identify the presence, location and severity of the pain being experienced (See helpful resources below).

6. 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.

7. 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.

8. Staff should directly communicate with the person with a learning disability and use straightforward questions about the presence of pain. They should be aware that the person may need more time to respond.

9. Staff must communicate with family/carers well known to the person, paying particular attention to baseline indicators of comfort and contentment, descriptions of changes in behaviour or previous/similar episodes.

10. Investigate indicators of pain and distress fully. Staff should not assume that the person is refusing to co-operate. Take time to explain any plans for investigations, familiarise the person with the environment and consider the assistance of family/carers during investigations where appropriate.

11. 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.

12. Consider the need for regular analgesia rather than ‘as necessary’ prescriptions. Be watchful for a response to analgesia, looking for indicators of wellbeing, a reduction in pain indicators and undesired effects of the medication.

13. Be aware of possible undesired effects of medication and observe for these. Some people with a learning disability 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.

Helpful Resources

- http://www.easyhealth.org.uk/listing/communication-(leaflets) This site provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.

- http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat/disdat-tools.aspx A distress assessment tool and monitoring sheets designed by St. Oswald's Hospice designed to help health professionals assess and identify distress indicators in people who have limited communication.

- http://www.wales.nhs.uk/sitesplus/documents/862/FOI-286f-13.pdf The Abbey Pain Scale is a potential resource for the measurement of pain in people who cannot verbalise.

- https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities People with learning disabilities – Making reasonable adjustments: The website provides a range of documents with examples of reasonable adjustments, including information relation to cancer screening, constipation, obesity and weight management, health checks, dysphagia, and substance misuse.

- http://www.community-networks.ca/wp-content/uploads/2015/07/PainChklst_BreauNCCPC-R2004.pdf The NCCPC is an observational tool for assessing pain in children with cognitive impairment who are unable to communicate verbally. It is intended to be usable by any person involved in a child's care, whether they are familiar with the individual child or not.

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes
  This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

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. It is recognised within policy and legislation that children with a disability should always be regarded as children first, but 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), 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 (2009a).

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. HSC Hospital Passport– see helpful resources) as this will help hospital staff to understand and effectively meet the child’s needs.

2. 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.

3. 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 nurse should provide an appropriate level of community in-reach to the hospital.

4. 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.

5. 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.

6. 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 activities. Where appropriate, any existing therapeutic development programmes, which were in place prior to admission, should be continued when the child is in hospital.

7. 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.

8. Where certain procedures need to be carried out in the home environment after discharge, any identified need for training related to care delivery at home, should be initiated and coordinated by the hospital staff prior to discharge.

9. Particular attention needs to be given at transition points, such as the transition from general hospital to community services and transitions from 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 (2009b).

10. All staff working within Children's wards should have access to relevant education 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.

11. The contact numbers of local Community Learning Disability Services should be provided to all children's' wards within general hospitals.

Helpful Resources

- DHSSPS (2009) Developing Services to Children and Young People with Complex Physical Healthcare Needs. https://www.health-ni.gov.uk/publications/developing-services-children-and-young-people-complex-physical-healthcare-needs

- DHSSPS (2009) Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs https://www.health-ni.gov.uk/publications/integrated-care-pathway-children-and-young-people-complex-physical-healthcare-needs

- http://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes
  This is the Regional HSC Hospital Passport for use throughout Northern Ireland. It replaces all previous Hospital Passports for people with a learning disability. The document can be completed electronically and printed or printed and completed by hand. Guidance notes on completing the Hospital Passport are also available here.

Implementation and Audit

We recommend all staff involved in supporting people with a learning disability to access and make use of general health services, including staff within Health and Social Care Trusts and Independent Sector providers should read and implement these Best Practice Statements. Staff should seek to ensure the people with a learning disability have equity of access to and equity of outcome throughout their contact with general hospital services.

We recommend that relevant departments within HSC Trusts and Independent sector organisations that support people with a learning disability should audit the implementation of these Best Practice Statements. Staff within these departments may wish to use a rolling programme to audit specific Best Practice Statements, thereby ensuring these all audited in a timely manner.

Finally, we recommend that staff across HSC Trusts and relevant Independent Sector providers should share good practice and successful innovations with each other in order to support the embedding of these Best Practice Guidelines across Northern Ireland.

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Appendix 1

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Mental health services for adults with mild intellectual disability

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COLLEGE REPORT

Contents

Working group 4
Executive summary 5
1. Background 7
1.1 Terminology used in intellectual disability (ID) 7
1.2 Mental disorder in people with ID 7
1.3 Barriers to access to services 8
1.4 Attitudes to people with ID and mental health problems 8
1.5 Current mental health service provision for people with ID in the UK 8
2. Evidence for mental health services for people with mild ID 12
2.1 Mental healthcare 12
2.2 Interventions 12
2.3 NICE guidance 13
2.4 Conclusion 13
3. Policy context: caring for people with mild intellectual disabilities and mental illness 14
3.1 England 14
3.2 Scotland 15
3.2.1 Integration 16
3.2.2 Decision making 16
3.2.3 *The Keys to Life* 16
3.2.4 Mental health strategy 17
3.2.5 In-patient services 17
3.2.6 Mental Health Care of people with ID 17
3.3 Wales 17
3.3.1 Services for people with ID 18
3.4 Northern Ireland 18
3.5 Autistic spectrum disorder 19
3.6 Children with intellectual disabilities: transitions 20
3.7 Offenders with intellectual disabilities 20
4. A model of mental health care for people with intellectual disabilities 21
4.1 Practitioner level 21
4.2 General adult psychiatrists supporting people with ID 22
4.3 Psychiatrists in ID who support people with ID and mental illness 23
4.4 Service level 24
4.5 The Green Light Toolkit 24
4.6 Benefits of integrated care 24
4.7 Plans for the future: The NHS Long-Term Plan 25
4.8 Training issues 25

References 27

Appendix 1 – The prevalence of mental illness in people with ID 32

Appendix 2 – Suggested desirable elements of a service for people with ID and mental health problems 33

Models of care 33

Quality in ID service checklist 34

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Executive summary

Meeting the mental health needs of people with mild intellectual disability (ID) can be a challenge to all mental health services. Not everyone with ID will be eligible to receive specialist ID services and therefore they rely on general mental health services to support them. Our purpose with this College Report is to inform readers on the complexities of providing care for this group of people, and on how general and specialist services can co-operate to meet their needs.

The report has been produced by the Faculty of Psychiatry of Intellectual Disability (ID) with assistance from the Faculty of General Adult Psychiatry of the Royal College of Psychiatrists. It revises and replaces CR175 *Enabling people with mild ID and mental health problems to access health care services* (Royal College of Psychiatrists 2012). We have aimed it at psychiatrists and clinical staff working at the frontline of psychiatric services, and general practitioners providing services for people with ID. We include a review of service provision for people with mild ID across the four countries of the UK.

We provide an oversight of the current evidenced-based thinking on what constitutes mild ID from an operational diagnostic perspective, and the role, challenges and ambiguities of cognitive testing in this population. Our systematic review of current evidence on how care for this population is delivered, and review of all relevant NICE guidance on mental health applicable to people with ID, underpin our findings.

People with ID are more likely to have mental health problems; we discuss the complexities of diagnostic overshadowing, communication and vulnerability concerns, presentation with complex psychopathology, and the difficulties in diagnosis and treatment.

We consider the barriers to access to services, at a primary and secondary care level, for either specialist ID input or mental health input, or both. Since the last report there have been significant changes and challenges influencing how mental health services for people with ID are being provided across the country, catalysed by the Winterbourne View scandal, and the resulting responses including *Transforming care: a national response to Winterbourne View* (Department of Health, 2012) and 'Winterbourne View – A time for Change' (Bubb 2014).

We describe the current practice frameworks in the different countries of the UK, identifying the key policy documents, political ambitions and direction of travel for each country for mental health issues, and how this has impacted on people with ID.

We discuss interface issues with other psychiatric subspecialties such as CAMHS and forensic services, to emphasise the need for continuing close working relationships. We recognise the challenges posed by the larger neurodevelopmental spectrum, such as autism, to those not working in non-ID services, and the potential for a vulnerable non-ID individual to fall between services.

Drawing on the evidence, we have designed a broad good-practice framework to enable psychiatrists, other practitioners, and services to self-measure and provide high quality care for people with mild ID and mental health problems. To this end we present various tools; in particular we advocate a wider use of the Green Light toolkit (2013) as this gives a voice to all key stakeholders, particularly patients and their representatives, wanting a service to meet specific local demands.

We highlight the virtues of integrated care from ID and mental health services, and end by focusing on the specifics of what constitutes good training, particularly for psychiatrists.

We present this report as an up-to-date evidence-based practical guide for all stakeholders in the care of people with ID and mental health issues: to help them navigate, deliver and measure within a complex system which can inadvertently become a 'glass ceiling' for a vulnerable population, particularly during times of major reorganisation at a national level, as is currently the case.

1. Background

1.1 Terminology used in intellectual disability (ID)

The classification systems guide our understanding of ID in clinical practice. The DSM-5 (American Psychiatric Association 2013) uses the term *intellectual developmental disorder* emphasising the importance of adaptive functioning in having skills in cognitive (language, reading, writing), social (social judgment, interpersonal communication) and practical (personal care, money management) domains. The DSM-5 emphasises the need to use both clinical assessment and standardised testing of intelligence, but maintains the recommendation of a standardised IQ assessment, with ID considered to be approximately two standard deviations or more below the population IQ mean: an IQ score of about 70 or below.

The ICD-11 (2018) lists ID as neurodevelopmental disorder highlighting the importance of adaptive functioning. The reduction in intellectual functioning on standardised IQ assessment is two or more standard deviations below the mean (World Health Organization 2015). ID is a disorder with onset in the developmental period (childhood, before the age of 18). An IQ of 69-50 achieved on a standardised test, acquired before adulthood, with impaired adaptive behaviour functioning, suggests the presence of mild ID. The global IQ score cannot be used as a concrete measure to define ID; a global IQ score is a summation of various sub-domains of verbal and performance scores, each with its own confidence intervals.

The term 'significant impairment' is defined as a person's measured abilities being two standard deviations below the average; that equates to the lowest 2% of the general population, and is commonly referred to as a standardised score of below 70 for both IQ and Adaptive Social Functioning. The measures are most accurate when, at the time of assessment, the person is not experiencing mental health, social, or other upheaval in their life that could affect their performance in tests.

1.2 Mental disorder in people with ID

The evidence indicates that mental health disorders are more prevalent among people with an ID than in the general population (Cooper and Collacott 1996; Deb et al. 2001). Prevalence rates vary according to patient population examined, diagnostic process, and criteria used. Recent epidemiological research suggests that the prevalence of mental illness within the adult ID population is between 20.1% - 23.4% (excluding challenging behaviour and autism) (Taylor et al. 2004; Cooper et al. 2007; Hughes-McCormack et al. 2017) compared to 16% of the adult general population (Cooper et al. 2007). Sheehan et al. (2015) identified that 21% of people with ID on GP records had a diagnosis of mental illness.

Mental health problems in people with ID are often not recognised; the complexity of multi-morbidity, communication needs, assessment, and diagnosis can lead to failure

to recognize mental disorder, and this is compounded by diagnostic overshadowing (Reiss et al. 1982), where presenting symptoms are attributed to the ID rather than a possible emerging and treatable mental or physical illness.

1.3 Barriers to access to services

Most mental health problems are managed in primary care with a focus on prevention and early identification (Joint Commissioning Panel for Mental Health 2012). Perera & Courtenay (2018) describe the organization and variation of mental health services for people with ID across the UK. There are some barriers to care, that people with ID share with the general population with mental health problems, in accessing specialist secondary care mental health services. These include (British Medical Association 2017):

- Inadequate funding at time of increasing demand
- Access problems and lack of integration and prevention
- Inadequate provision and quality of services
- An understaffed workforce and insufficient training

People with ID and mental health problems, due to their added vulnerability, are at higher risk than the general population of facing barriers to access to specialist care.

1.4 Attitudes to people with ID and mental health problems

People with ID experience discrimination in almost all areas of their lives. Ali et al (2013) reported on the barriers to care for people with physical health problems and ID that included problems with communication, problems in the relationship between health professionals and carers, and sub-standard care. While no similar research has been conducted into access to mental health services, it could be hypothesised that services often are set up in complicated teams and systems, and it can be daunting for anyone to access and navigate those at times of great distress and vulnerability.

1.5 Current mental health service provision for people with ID in the UK

Specialist care for people with ID in the UK is commonly provided by multi-discipline teams of health and social work professionals. Teams work in partnership with general practitioners, other specialties, social care, and private agencies. There is a particularly strong interface with social services, with health and social care integration aiming to further strengthen this link.

The assessment and treatment of mental disorder in people with ID is just one aspect of the care and support provided. Others include sub-specialist teams or pathways focusing

on issues such as challenging behaviour, offenders with ID, autism spectrum disorders, dementia assessment and management particularly in the Down population, complex physical health needs or epilepsy. Specialist ID teams provide highly specialized care delivered by health professionals who have developed the necessary communication skills and experience. The configuration of services varies across the UK.

The guidance for commissioners of mental health services for people with ID (Joint Commissioning Panel for Mental Health 2012) sets out a well-defined service organisation model to meet the mental health needs of people with ID in England (Figure 1).

Good practice example: Transitions



An agreed protocol relating to transitions between ID and general adult psychiatric (GAP) services to remove barriers to access to services. The service receiving the referral completes the initial assessment, arranging a cognitive assessment, while holding case management responsibility. This avoids patients falling between gaps in service provision.

If an ID has been diagnosed and additional needs have been identified, depending on presentation and the wishes of the individual, family, or carers, a joint working approach might be appropriate in order to achieve a more holistic treatment and aim to achieve the best possible outcome for that individual.

Good practice example: Joint working



Miss A has a diagnosis of PTSD for which the GP referred her to primary care mental health services. In the assessment Miss A required additional support to attend to activities of daily living provided by her family. A formal cognitive assessment was undertaken revealing that Miss A was functioning in the mild ID range, with a full scale IQ of 67.

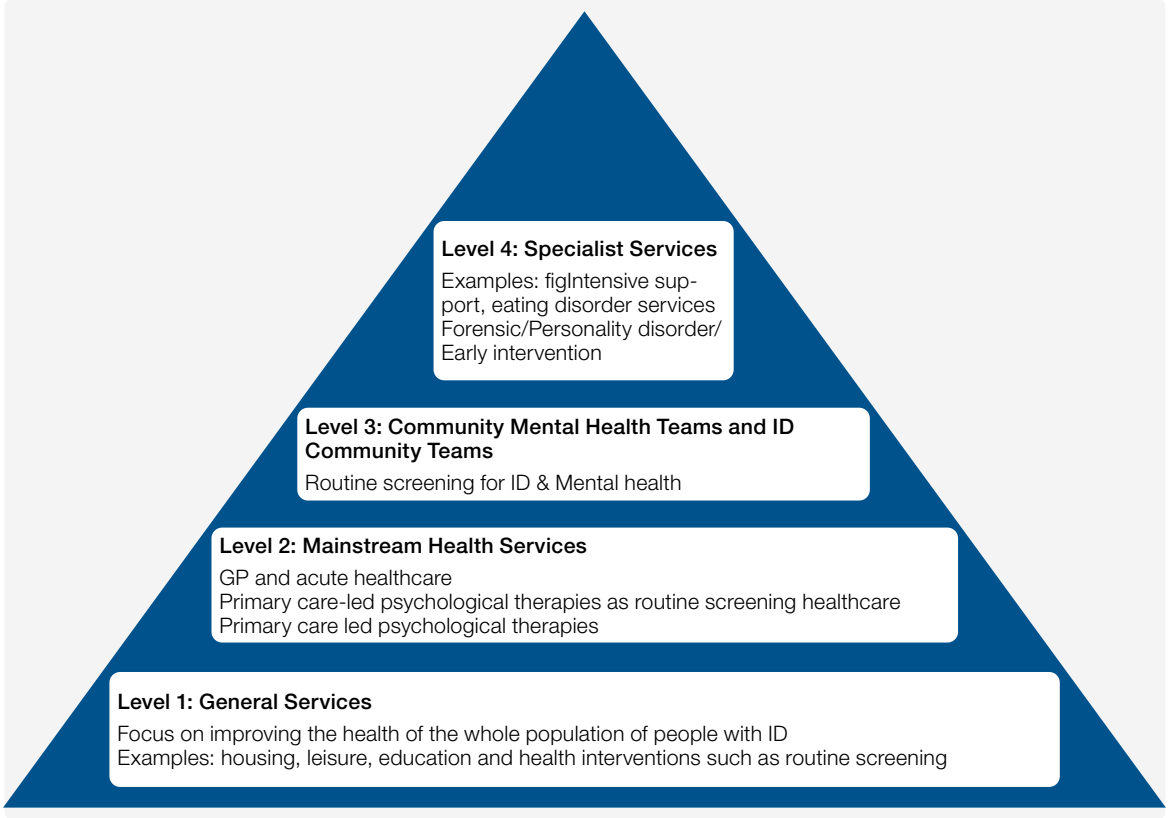
Miss A received psychological therapy from the primary care mental health services, and her additional support needs were met from the local community ID service. The Psychiatrist in ID agreed to act as her RMO if admission to in-patient services was required.

It might be appropriate for individuals treated by the ID specialist service to be shared with colleagues from general adult psychiatric services. These services are at level 4 and examples might include community-based intensive support or specialist services, such as eating disorder services. It is good practice to access the service best situated to meet an individual's needs, irrespective of intellectual functioning, and joint working can be used to support those specialist services on ID related matters such as capacity, consent or communication.

Where there is disagreement on which service is most appropriate for the person, it is good practice to consult the patient for their view. Good communication, and supportive,

reciprocal and fair working relationships between services, can make the experience for service users, their families, and carers good while providing evidence-based, outcome-focused assessments and treatments.

Figure 1: Service organisation model to meet the mental health needs of people with intellectual disabilities in England



2. Evidence for mental health services for people with mild ID

A systematic review on this topic is provided in the supplementary section of this report. The outcomes for people with ID using mental health services indicate that general psychiatric care could be improved by staff training, and in-reach from community ID teams (Chaplin 2009) that enhances outcomes in symptoms and function (Chaplin 2011). The evidence is consistent with the view that lack of skilled staff and non-integration of services are barriers to accessing MH services (Whittle et al. 2017). Enablers were a multidisciplinary approach, collaborative working and clear referral pathways.

2.1 Mental healthcare

Despite an increased rate of mental health problems, people with mild ID do not receive a comparative increase in care (Bouras et al. 2004). Those with borderline ID may benefit from assertive outreach (Hassiotis et al. 2001). The evidence of improvement in the person's level of functioning in specialist in-patient care is limited to Lunsky et al (2010). Chaplin (2011) highlighted the lack of evidence comparing outcomes of general and specialist ID in-patient units.

Access to specialist ID units may preclude people from using other specialised services (Slevin et al. 2008), restricting opportunities for patient therapy and education (Venville et al. 2015). People with dual diagnosis, such as ADHD or autism with mild ID, may experience difficulties or delays in gaining access to appropriate services because they do not fit specific social or health service criteria.

2.2 Interventions

There is limited evidence on the efficacy of group CBT in treating depressive symptoms in people with ID. The evidence is sparse and no randomised controlled trial data is available (Osugo and Cooper, 2016). A meta-analysis of therapeutic interventions in mild ID for mental health problems found no conclusive evidence.

2.3 NICE guidance

In England and Wales, specific NICE guidelines exist on the management of autism and mental illness with ID. The National Service Frameworks (NSF) set quality frameworks to help achieve these. The NICE guidelines, as a group, document some broad approaches which, on the surface, would address these factors for some of the disorders. Specific guidance exists for people with mild ID and mental illness: Clinical Guidelines (CG113 and CG123)(NICE 2011a,b) suggest offering the same interventions to those with mild ID as to those without. There is paucity of data to demonstrate the current provision for those with a mild ID, and therefore it is difficult to ascertain if this approach is in fact taking place, and indeed if it is the most appropriate in terms of patient care. A review of all relevant NICE guidance for people with ID is provided in the supplementary information section of this report.

2.4 Conclusion

The lack of high-quality evidence on people with mental health problems and mild ID is echoed throughout the literature. There is a need for targeted and well-coordinated services to prevent people with mild ID and mental health problems from falling between service gaps (Balogh et al. 2016). Venville et al. (2015) consider that not meeting the needs of people with mental health problems and ID suggests a failure of services to fulfil human rights obligations.

There is a clear need for further evidence. There is no support for divergence from evidence-based guidelines and normal good practice for mental health problems in the general population. Increased awareness and training among all clinicians would benefit people with ID by gaining them access to appropriate services.

3. Policy context: caring for people with mild intellectual disabilities and mental illness

3.1 England

Key policies inform the treatment of those with both ID and mental illness:

- The Equality Act (Legislation.gov.uk 2010) states that public sector agencies such as the NHS must make reasonable adjustments to their practice to make them accessible and effective for people in the protected groups, which includes people with ID. This legal duty is anticipatory and means that mental health agencies are required to consider in advance what adjustments people with ID or autism will require, rather than waiting until such individuals attempt to access services.
- *No Health without Mental Health* (Department of Health Feb 2011) reaffirms the need for '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)'.
- The National Development Team for Inclusion (NDTI) report *Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities* (National Development Team for Inclusion 2012) found that whilst there were significant examples of good practice this was limited. They identified the following issues that require resolution:
  - Thorny issues about differences in eligibility thresholds
  - Access to sophisticated treatment
  - The availability of evidence regarding efficacy of particular interventions

- *Achieving Better Access* (Department of Health 2014) states that services need to become more sensitive to the needs of local populations and the diversity within them, seek to eliminate discrimination, and advance equality of access.
- *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition* (NHS England 2015) recommends 'simplifying the system wherever possible. This will involve reducing boundaries and stand-offs between organisations and services'.
- *Old Problems, New Solutions* (The Commission on Acute Adult Psychiatric Care 2016) identifies the need for mental health services to be fully aware of the implications following the recommendations of *Building the Right Support* highlighting

that it is 'likely to lead to more people with learning disability who may also have mental illness being treated in mainstream mental health services'.

- *Guidance for commissioners of mental health services for people with learning disabilities* (Joint Commissioning Panel for Mental Health 2012) outlines the key values and principles for effective mental health commissioning based on current policy, law and best practice.

National Institute for Health and Care Excellence (NICE) guidance has recently been developed in Mental health problems in people with learning disabilities (NICE 2016). It considers the effectiveness of psychological therapies and medical interventions. It does not recommend one specific model of service delivery to meet the needs of people with IDs and mental health problems but recommends that:

- Services should include intensive support at home and in community settings for those with severe mental health problems, those services to work closely together to facilitate joined up provision.
- Mental health ID specialists should be employed in generic in-patient mental health settings, and dedicated beds should be available to those who require admissions.
- ID services should be able to offer a broad range of psychological interventions.
- People with ID should not fall between the gaps between services, and general mental health services should be able to deliver services tailored to meet the needs of people with ID.
- There should be a leadership team that is responsible for establishing and developing care pathways for people with ID and mental health problems.

People with mild to moderate mental illness should have access to the IAPT (Improving Access to Psychological Therapies) pathway, which provides talking therapies in primary care.

The Green Light Toolkit (Department of Health 2013, rev 2017) seeks to improve mental health services for people who have ID. It is used well in some areas, but the changes to mental health services have affected how well it is used. It has gradually moved expectations away from people with mild ID being open to ID services only and needing to be treated in mainstream services, and being referred to ID services only if they have specific additional health needs needing specialist ID input.

3.2 Scotland

The policy context in Scotland is to provide integrated care delivery in peoples' communities, emphasizing preventative measures. The main policy drivers are:

- Health and social care integration
- The United Nations Convention on the Rights of Persons with Disabilities
- *The Keys to Life* – Scotland's learning disability strategy

3.2.1 Integration

Health and social care integration is a response to the demands of an ageing population with chronic health needs. The principal idea in integration is care built around the needs of the individual, not around the needs of the service.

3.2.2 Decision making

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN General Assembly 2007) was ratified by the UK in 2009. The UNCRPD has potentially major implications for how psychiatric services are delivered, including ID services. Scottish legislation relating to the care of people with ID, including the Adults with Incapacity Act (AwIA)(Scottish Government 2000), the Scottish Mental Health Act (MHA) (Scottish Government 2003) and the Adult Support and Protection legislation (Scottish Government 2007) typically encompasses substituted decision making as an appropriate way of supporting interventions for people with ID. In order to implement the wider provisions of the UNCRPD the Scottish Government have a delivery plan *A Fairer Scotland for Disabled People*, which over the period 2016–2021 aims to make equality of opportunity, access to services and independent living a reality for all disabled people in Scotland (Law Society of Scotland 2017).

3.2.3 *The Keys to Life*

The Keys to Life is a ten-year strategy (Scottish Government 2013b), with an emphasis on health issues acknowledging the worse outcomes for people with ID. It has four strategic outcomes related to the United Nations Convention on the Rights of Persons with Disabilities:

- *A Healthy Life:* People with learning disabilities enjoy the highest attainable standard of living health and family life.
- *Choice and Control:* People with learning disabilities are treated with dignity and respect, and are protected from neglect, exploitation and abuse.
- *Independence:* People with learning disabilities are able to live independently in the community with equal access to all aspects of society.
- *Active Citizenship:* People with learning disabilities are able to participate in all aspects of community and society.

The Keys to Life made 52 recommendations with an emphasis on increasing participation of people with ID in local developments, and on local delivery plans taking account of the needs of people with ID.

3.2.4 Mental health strategy

The 2017–2027 Scottish Government Mental Health Strategy (Scottish Government 2017) echoed previous government publications in noting the inequalities experienced by people with disabilities, and specifically the higher rates of mental illness among people with ID, advising that services be more joined up.

3.2.5 In-patient services

The most recent Scottish bed census showed that there were 179 ID and 82 forensic ID beds in 2017, with occupancy of 90 and 91% respectively, which is significantly higher than the King's Fund recommendation of 85%, indicating that there is an imbalance between in-patient care and community provision (Scottish Government 2013a, 2017). Across Scotland 300–400 in-patient beds are required and health boards need to provide four assessment and treatment beds for every 100,000 population.

3.2.6 Mental Health Care of people with ID

The issues affecting the care of people with ID in Scotland are health inequalities, a shortage of trained staff, and difficulty accessing in-patient care, appropriate high-quality community care, and meaningful day-time activities.

3.3 Wales

Government policy on mental health care for people with ID has evolved over the recent decade.

- *Statement on policy and practice for adults with a learning disability* (Welsh Government 2010) recommends that people with ID must have equal right of access to primary, secondary, and specialist healthcare services to that of any other citizen. It recognises that individuals with ID may have more specific healthcare needs, such as mental health.

- *Together for Mental Health* (Welsh Government 2012) is the ten-year strategy to improve mental health and well-being, stipulating that vulnerable groups should experience equitable access to and provision of services that are responsive to their diverse needs. A national e-learning training program *Treat me Fairly* has been introduced to all health boards and trusts.

- The Mental Health (Wales) Measure (Welsh Government 2010) passed by the National Assembly for Wales provides a legal framework for the support people living in Wales should receive. It places a legal duty on health boards and local authorities to improve support for people with mental ill-health and requires that mental health services focus upon people's individual needs, including the needs of people with ID.

- The Act places a duty upon mental health service providers to improve the effectiveness of secondary mental health services that includes the right of 'relevant patients' to have a care coordinator appointed, and the right to an individual Care and Treatment Plan in order to assist recovery.

- The Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014) provides a framework for determining need, and a threshold promoting early intervention and prevention. Local authorities and health boards are required to work together to assess care and support needs, prioritizing the integration of specific services, including for people with ID.

3.3.1 Services for people with ID

Current practice in Wales for the provision of mental health services for individuals with a mild ID vary widely. In some localities, ID services sit within or are combined with mental health services, and in other areas they are completely separate. The interface between ID and general adult psychiatry services varies dependent upon local settings, pathways and relationships. There is a notable absence of services for offenders with ID in Wales.

The Welsh Government supports an all-Wales Integrated Autism Service to provide consistent and accessible support to those with autism and / or intellectual disabilities.

3.4 Northern Ireland

The Department of Health in Northern Ireland has produced policy on the care of people with ID.

- The Bamford action plan (Department of Health 2003) is the key driver for implementing the much needed positive change in services and legislation for people with ID in Northern Ireland. It recommends that trusts ensure people with ID should have equal access to the full range of primary health care services. As a result, all adults with ID will have annual physical and mental health checks. (*Delivering the Bamford Vision: The Action Plan 2012-15* (Department of Health Social Services and Public Safety 2014)).

- The *Transforming Your Care* report (TYC) (2011) proposed reshaping the integrated health and social care model, with care to be provided closer to home, shifting resources from hospital to community health and social care services (Health and Social Care Board 2011). There are variations in type of service provided between trusts and this could be partly attributed to local demands. TYC acknowledged the concerns raised by the Royal College of Psychiatrists where more work was needed in the area of access to mental health services for people with ID.

- The learning disability service framework (LDSF) in Northern Ireland sets 34 targets in relation to ID and is reviewed annually. Standard 22 of LDSF states that

people with ID who experience mental ill health should have access to appropriate support. A key performance indicator for trusts is that people with ID can access mainstream mental health services.

- The Mental Capacity Act (Northern Ireland) 2016 (Northern Ireland Assembly 2016) is an example of 'fusion' legislation and is widely recognised as the first in the world where mental health law and mental capacity law have been fused in one piece of legislation. The Act defines key elements such as 'decision-making capacity' and 'best interest decision making' to be used when making decisions about care and treatment of a person across health and social care.

- *Service Framework for Mental Health and Well-being* (Department of Health 2018) redesigned the framework of 2010 to focus on 'the required service elements of access to mental health services, assessment, diagnosis, treatment, self-management and the recovery of all adults who have a mental health problem or condition'.

3.5 Autistic spectrum disorder

Autistic spectrum disorder (ASD) is a complex neurodevelopmental disorder, increasingly important as more autistic people are being recognised in childhood and adult life. There is considerable overlap between ID and autistic spectrum disorder, with estimated prevalence rates of 20-30% for ASD comorbidity in people with ID (Emerson and Baines 2011) and estimated prevalence rates of 40% of ID occurring in ASD populations (Autistica 2017). The majority of autistic people do not have ID, although many may have had specific learning difficulties in school years, but comorbid ID does increase health and other problems.

People with autism may present with any type of mental health disorder, but rates of anxiety disorders, ADHD, and mood disorders are especially high (Belardinelli et al. 2016). People with autism have a higher rate of suicide than the general population (7.55 times OR 6.04-9.44) and higher rates of preventable treatable illnesses and premature mortality, similar to premature mortality rates in serious mental illness, or worse if there is comorbid ID (Hirvikoski et al. 2016).

Adults with mild ID and autism usually present to adult or older people's mental health services for any significant co-morbid mental health problems. People with autistic spectrum disorder can present with a pronounced inconsistency between functional and cognitive ability (in either direction) that may result in disputes between services on which should work with the person. The Green Light Toolkit is helpful in enabling services to resolve the question.

Services are expected to make reasonable adjustments to facilitate interventions which take the person's level of ID and/or autistic spectrum disorder into account. There is however still a realistic possibility for individuals to 'fall between stools', or struggle to access appropriate services – with regard to diagnostic assessment, post diagnosis support, and treatment of comorbid mental health disorders. Diagnostic overshadowing also continues to be an issue, in that acute mental health services can attribute presentation and psychopathology to the underlying autistic spectrum disorder, rather than to a treatable mental illness. Likewise an undiagnosed ASD can be attributed to the presence of an ID.

3.6 Children with intellectual disabilities: transitions

Young people entering adult ID services may be referred from a variety of services which may include primary care, social care, child and adolescent mental health, pediatric, neurology, etc. There is a wide variation across the country in how services are provided for children with ID, and up to what age. It is not uncommon to find that although developmental difficulties have been identified by child and adolescent services, no definite diagnosis of ID has been made, and that in turn can delay access to the appropriate adult service. Clarity on ownership in services around transition from CAMHS to adult services is essential. College Report 200 *Psychiatric services for young people with intellectual disabilities* (Royal College of Psychiatrists 2016) discusses and details services for young people with ID and mental health problems, recommending what services should be available, with suggestions of the elements of good service provision.

3.7 Offenders with intellectual disabilities

There are well-recognised issues and risks in the support that offenders with ID receive. They include:

- Failure to report or prosecute behaviours, leading to the person then believing that those behaviours are acceptable
- The risk that specific needs will not be recognised or met
- Difficulty in devising effective systems for joint working
- Recognition of the need for appropriate adults to support people with ID through the criminal justice system.
- Achieving balance between diverting people with ID from prosecution and proceeding with prosecution
- Maximising the use of community disposal
- Access to dedicated community forensic ID teams
- Geographical distribution of forensic ID beds leading to people being placed a long way from home
- Lack of evidence of outcome and cost effectiveness
- Need for commissioning which promotes the least restrictive setting

In *Transforming Care* (NHSE, 2017) model service specifications describe how services for offenders with ID should be provided more in the community, with a shift away from in-patient care. Policy encourages more co-operation between community forensic ID services and generic community mental health services or specialist community adult ID services.

4. A model of mental health care for people with intellectual disabilities

It is an important principle of any integration that care is delivered around what is a good fit for local circumstances and need, and best suited to the local demographic. Therefore the different areas of practice across the UK should not be seen as a problem as long as the eventual goal is delivered, i.e. delivering and evidencing high quality mental health services to people with mild ID. Certain areas have developed safe and efficient structures of care delivery for this vulnerable group. There is recognition that different regions have diverse strengths and weaknesses and it is important that solutions look to build on strengths already present. Equally, when resources are limited thought needs to be given to utilising existing systems and frameworks. The challenge lies in recognising and addressing gaps. Service models of delivery will vary throughout the UK depending on geography and what services are currently in place. The report recommends identifying current expertise and pathways and modelling care along suggested standards involving ID, adult mental health services, therapy streams, and tertiary service availability.

We suggest a two-pronged approach supporting the above working model, aimed to provide a consistent and holistic framework of care at practitioner and at service levels. The model could either be directly utilised in an area with a mainstreaming approach, or help to conceptualise service coverage in areas that retain a specialised ID model for the treatment of mental illness.

4.1 Practitioner level

We propose criteria setting out what are essential and desirable elements for psychiatrists and their services. Service components that are essential include:

- Specialist consultant psychiatrist in intellectual disability
- An intellectual disability multi-disciplinary team
- Community mental health teams
- An intellectual disability liaison nurse

Services should have clear guidelines on the management of emergencies, with appropriate shared access to information such as a HEALTH (Helping Everyone Achieve Long Term Health) Passport. The tables below set out the skills required of a general adult psychiatrist managing people with an ID, and likewise psychiatrists in ID, with regard to mental illness.

4.2 General adult psychiatrists supporting people with ID

Skill set for general adult psychiatrists
Essential skills
Awareness of recent relevant legislation such as Mental Capacity Act 2005, Equality Act 2010, Social care Act 2012, Accessible Information Standard, or appropriate correspondent legislation in other jurisdictions
Provision of a professional development plan with identified CPD in ID
Basic knowledge of major comorbidities such as pervasive developmental disorders, physical health disorders such as epilepsy, and social issues, which can influence mental state
Knowledge of interactions between commonly prescribed psychotropic and other relevant medication more relevant to people with ID, such as epilepsy medication or anti-dementia medication
Knowledge and awareness of local pathways to refer for ID specific issues
Links with ID experts e.g. ID liaison nurse
Ability to make reasonable adjustments to meet the needs of the person with ID; adjustments may b3e required for effective communication by providing easy read material, in particular when planning for appointments
Desirable skills
Completion of a recognised training ID post as part of core training, or special interest in higher training as part of the General Adult Psychiatry CCT or equivalent
Provision of regular clinics/reviews for people with ID
Provision of a personal development plan focused appropriately on ID, and access to a peer group with specialism in ID
Existence of a job plan that clearly recognises activity in ID
Ability to use/interpret specific tools such as Mini PAS-ADD, HoNOS-LD, GDS etc.
Awareness of national developments and good practice in ID

4.3 Psychiatrists in ID who support people with ID and mental illness

Skill set for psychiatrists
Essential skills
Awareness of recent relevant legislation in general adult psychiatry
Professional Developmental Plan includes identified CPD in general adult psychiatry appropriate to the work in mental illness being undertaken
Knowledge of major psychiatric comorbidities such as depression, psychosis, anxiety, and interactions between commonly prescribed medication
Knowledge and awareness of local pathways to refer for mental illness specific issues
Links with mental health experts, e.g. psychiatric liaison nurse
Provision of regular clinics/reviews for people with ID and mental illness
Ability to use/interpret specific tools such as Mini PAS-ADD, HoNOS-LD, GDS etc.
Ability to make reasonable adjustments as required to meet the needs of a person with ID and mental illness; adjustments may be required for effective communication by providing easy read material in particular when planning for appointments
Desirable skills
Completion of a recognised training in general adult psychiatry in core training, or higher training special interest in general adult psychiatry as part of the CCT in Psychiatry of Learning Disability or equivalent
Provision of a clear identified personal development plan in mental illness, and access to a peer group with specialism in mental illness
Existence of a job plan that clearly recognises activity in mental illness
Facilitation of use/interpreting of specific tools such as Mini PAS-ADD, HoNOS-LD, GDS etc.
Awareness of national developments and good practice in general psychiatry

4.4 Service level

Identified clinical groups need to have ownership of delivering evidence-based practice, and adhere to NICE or other approved guidelines for ID and mental illness. High-quality services could be provided with the following minimum key components:

- A psychiatrist in ID with expertise in general psychiatric disorders and/or
- A general adult psychiatrist with an ID interest
- Specialist nursing support
- Appropriate psychology and therapy services
- Transition services
- Access to second opinions and tertiary services, with clear pathways and lines of responsibility.

There are various models of practice across the UK for the treatment of people with ID and mental ill health that include whether people with ID receive psychiatric care primarily from a psychiatrist in ID or a general adult psychiatrist. We recognise the importance of people having access to the service that best meets their need, and that should include access to mainstream mental health services if that is the best fit for the patient.

Appendix 2 includes example schemas for measuring service quality, which are presented as suggested frameworks that could allow commissioners and clinicians to continue to improve services in a way sensitive to local needs and practices.

4.5 The Green Light Toolkit

The Green Light Toolkit (Department of Health 2013, rev 2017) provides information on services that are in place and working well for people with ID and mental health issues. It can help to improve and develop local services. Using the self-assessment checklist at regular intervals allows the provider to track developments, celebrate achievements, and move towards developing better services for people with ID, benchmarked against national guidance and expectation.

With the closure of specialist in-patient beds for people with ID, more are likely to be admitted to local mental health units. Use of the Green Light Toolkit can enhance the services people receive. The current framework of care and treatment reviews could be strengthened to ensure joint participation from psychiatrists in ID in working with general adult psychiatrists to identify rapid and sustainable discharge outcomes, and to ensure specialist placements lead to targeted activities around assessment and management.

4.6 Benefits of integrated care

For a person with mild ID and mental health problems it is essential that there is adequate social care support and on-going assessment and evaluation of changes in social needs, especially to help sustain well-being and prevent future relapse. This requires

commissioners or providers of social care to consider the following requirements as part of their contracting arrangements.

- Ensure that staff supporting the person are trained in mental health problem awareness, with a good understanding of how mental disorder affects the person they support.
- Ensure access to relevant advocacy services, e.g. independent medical capacity advocates or independent mental health advocates in England.
- Providers of social care should ensure that support staff have good links with specialist health staff and are able to provide information about the person that helps with assessment and review of treatment.
- Ensure that staff supporting the person facilitate their attendance at clinical appointments in hospitals or GP practices, including their annual health check.
- Ensure that staff are able to follow the health action plan, and know how to respond in an emergency.
- Providers should be aware of the medication prescribed for people and support the principles of STOMP 'Stopping over-medication of people with ID and or autism' (NHS England 2016).

Social care providers can help the person by understanding how best to manage the environment the person lives in, to reduce mental illness relapse triggers, e.g. sleep disturbance, infections, alcohol etc.

4.7 Plans for the future: The NHS Long-Term Plan

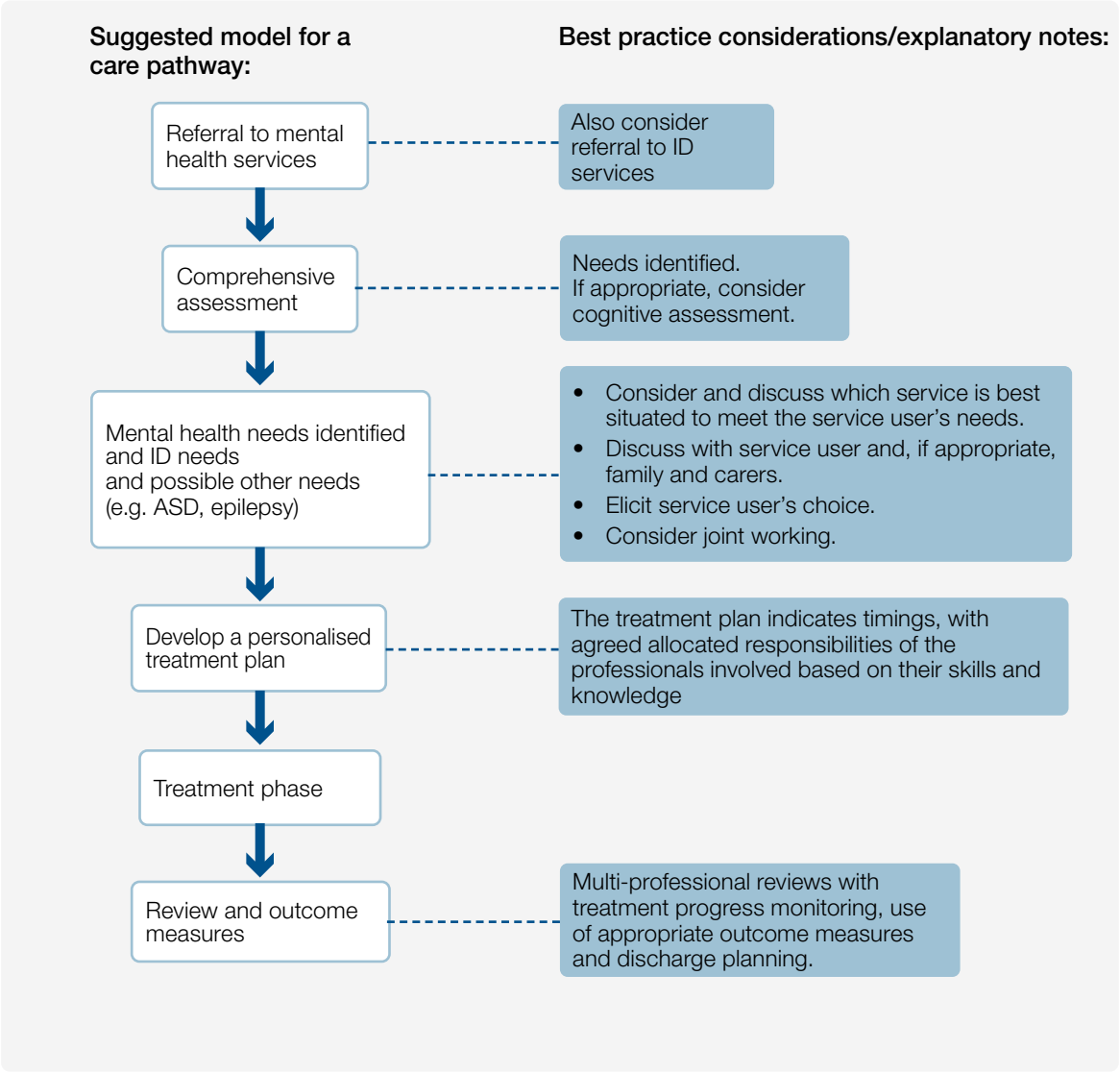
ID and autism are two clinical priorities of the NHS Long-term Plan to be implemented in local services with a focus on integrating services (2019).

4.8 Training issues

The *Shape of Training* review (Greenaway 2013) recommends broadening training in order to provide general care for a wide range of specialties across a range of different settings to deliver care more appropriate to the population. It calls for doctors with a broader general training, who should have the skills to meet the care needs of these individuals.

At present, core trainees in psychiatry are not required to undertake six months of a developmental psychiatric specialty in either psychiatry of ID or child and adolescent mental health, and therefore not every psychiatric trainee will have the opportunity to gain an insight into working with people with ID. In higher training, doctors can avail of dual training programmes of child and adolescent psychiatry and the psychiatry of intellectual disability. Trainees in all sub-specialties of psychiatry can undertake special interest sessions that would allow them to gain experience in working with people with ID. There is potential for these sessions to be actively promoted to general adult psychiatry (GAP) trainees in order to improve confidence and skills in this area. This is an area with great potential for future development, reflecting the needs set out by the *Shape of Training* review.

Figure 2: Suggested model for a care pathway for people with mild intellectual disability and mental health needs



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Appendix 1 – The prevalence of mental illness in people with ID

Disorder	Rate
Schizophrenia	3%
Bipolar affective disorder	1.5%
Depression	4%
Generalised anxiety disorder	6%
Specific phobia	6%
Agoraphobia	1.5%
Obsessive compulsive disorder	2.5%

Appendix 2 – Suggested desirable elements of a service for people with ID and mental health problems

Desirable Service Components
Clinical care • Dedicated joint mental health and psychiatry of ID clinics* • Dedicated clinics for people with ID in general psychiatry, or general adult psychiatry clinic in ID setting • Adequate time to inquire into psychiatric issues in ID clinics
Nursing service • ID nurse with mental health interest* • Mental health nurse with ID interest*
Multidisciplinary team (MDT) Consisting of psychologist, occupational therapist, physiotherapist, speech and language therapist, dietitian and social worker • Dedicated team for mental health* • ID-based with mental health access
Specialist services • On-site* • Link to tertiary centre
Young person to adult transition • Joint clinic* • ID or mental health clinic • Agreed pathway
*Ideal service components

There needs to be recognition that delivery of services to people with major mental health issues and ID is complex, and usually cannot be made by local ID services, mental health services, and nursing in community mental health team (CMHT) services, meeting their own individual essential criteria. There has to be one or more of these services extending themselves to take the lead in ensuring all current good practice requirements are met. This would require one or more of these services/professions taking on a more skilled role. To help provide guidance a table providing different permutations and combinations between the three professions has been created, and the overall picture rated with a star rating. We would suggest that an acceptable model of care should be two stars or above.

The grid would help showcase how changes to roles in different service providers could impact on service delivery. It could help make adjustments in available resources to optimise service delivery.

The table below provides star ratings for care models combining general psychiatry, ID psychiatry and nursing. It is expected that the psychiatrist in ID will have access to a full multidisciplinary teams (MDT), including ID nurses, psychologists, occupational therapists, speech and language therapists, dietitian, physiotherapists, etc. Similarly the mental health psychiatrist is the access point to a CMHT MDT.

Models of care

To be used in conjunction with the qualities of each service as identified:

Star rating	CMHT psychiatrist requirements	ID service psychiatrist requirements	Nurses' competence
1*	E	E	1N/2N
2*	E	E	1C/2C
2*	E	D	1N/2N
2*	D	E	1N/2N
3*	D	E	1C/2C
3*	D	D	1N/2N
4*	E	D	1C/2C
4*+	D	D	1C/2C
5*	D	D	1C and 2C

Key:

CMHT or ID service psychiatrist skill set requirement
E = Essential requirements
D = Desirable requirements

ID nurses' competence in mental health
1N = None
1C = Competent

Mental health nurses' competence in ID
2N = None
2C = Competent

Quality in ID service checklist

Service components	Reviewing	Providing	Implementing	Developing
Psychiatrist in ID with up to date skills and training in the diagnosis and treatment of mental illness OR GAP psychiatrist with essential and desirable skills in ID				
ID nurses with competence in mental health				
Psychology input to multidisciplinary team (MDT) with expertise in ID				
Well-established MDT including OT, SALT, pharmacy support				
Access to named medical link and interface protocols with GAP				
Data systems exist to support the routine monitoring and review of individual and case-load outcomes				

Reviewing – Clear and mature implementation, and regular audit of processes

Providing – Clear existence of component

Implementing – Some aspects of component in place, and plans working towards full achievement

Developing – Implementation at planning stage only



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Standards for Inpatient Learning Disability Services
Fourth Edition

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Contents

Contents 2
Foreword 3
Introduction 4
Section 1: Admission & Assessment 7
Section 2: Care Planning and Treatment 10
Section 3: Referral, Transfer and Discharge 12
Section 4: Patient and Carer Experience 14
Section 5: Environment and Facilities 18
Section 6: Staffing and Training 21
Section 7: Governance 25
References 28

Artwork provided by Louise Lane on Byron Court, Essex.

Foreword

Since publication of the 3rd edition of the Quality Network for Learning Disability (QNLD) standards for Accreditation of Inpatient Assessment and Treatment units for adults with Intellectual Disability, there have been significant national policy initiatives, including STOMP, and guidance from various statutory bodies in the UK. The CCQI has worked hard to ensure that this, the 4th edition reflects the changes in legislation, practice and the evolving ethos in inpatient services since the publication of the last edition.

This revision has involved extensive consultation and collaboration with a wide range of stakeholders ranging from representatives of carer groups, members of various professional Colleges, NHS England, the Intellectual Disability Senate, the third sector and the inpatient units themselves. During the course of this exercise, many new standards have been introduced and some old ones modified or removed following guidance from our stakeholders. There has been a consensus among them towards moving to more Type 1 standards in keeping with the prevailing drive towards improving quality of care of people with intellectual disability. Other changes are as a result of a desire to make the standards as user friendly as possible.

On behalf of the Advisory Committee, I would like to thank our consultees for generously giving their time and advice; and to the team from CCQI for their tremendous work. We sincerely hope these standards ultimately help the people with intellectual disability receive evidence-based treatments, in environments meeting international standards, provided by appropriately trained staff.

It is my pleasure to commend to you, on behalf of the CCQI, the 4th Edition of the QNLD standards for inpatient units for people with an intellectual disability.

Dr Kiran Purandare

Chair of QNLD Accreditation Committee & Advisory Group

February 2021

Introduction

The standards have been drawn from key documents and expert consensus and have been subject to extensive consultation by the Quality Network for Learning Disability Services (QNLD) standards development group, which includes carers and professional groups involved in the provision of inpatient learning disability services. They incorporate the College Centre for Quality Improvement (CCQI) Core Inpatient Standards, as well as specialist standards relating specifically to inpatient learning disability services.

The standards cover the follow topics:

- Admission and assessment
- Care Planning & Treatment
- Referral, Transfer & Discharge
- Patient & Carer Experience
- Environment & Facilities
- Staffing & Training
- Governance

Who are these standards for?

These standards are designed to be applicable to inpatient learning disability services for working age adults and can be used by professionals to assess the quality of the team. The standards will also be of interest to commissioners, patients, carers, researchers and policy makers.

Since inpatient learning disability units differ widely in their configuration and the models used, these standards focus on the function of a team in order to make them as widely accessible as possible.

Categorisation of standards

To support in their use during the process, each standard has been categorised as follows:

· **Type 1:** Criteria relating to patient safety, rights, dignity, the law and fundamentals of care, including the provision of evidence-based care and treatment;

· **Type 2:** Criteria that a service would be expected to meet;

Notation

College Centre for Quality Improvement (CCQI) Core Inpatient Standards are marked with [1] in the reference column throughout the document. Several College Core Standards have been modified to become more in line with the speciality of inpatient learning disability services; those College Core Standards that have been modified have [1] and [2] within the reference column. The remaining standards are not included in the College Core set and relate specifically to inpatient learning disability services.

Terms used in this document

In this document, the inpatient learning disability service is referred to as *'the team'* or *'the unit'*. People who are cared for by the inpatient learning disability services are referred to as '*patients*' and their loved ones are referred to as '*carers*'.

Key principles of the standards

A new edition to this set of standards is the introduction of four key principles that run throughout the standards, which are crucial to providing high quality care. One or more of the principles applies to several standards within the document and below icons are used throughout the document when the principle is key to meeting the standard.

	All information provided to patients and carers must be in an **accessible format**, in line with Royal College of Speech & Language Therapists '5 Good Communication Standards' & NHS Accessible Information Standard.
	If patients lack capacity, decisions are made in their **best interests** as per the Mental Capacity Act 2005.
	When information is given to patients on the unit, staff **check their understanding** of the information and this is recorded.
	**Reasonable adjustments** are made in line with the Equality Act 2010.

References

Please see the list at the end of this document for full references.
The standards are also available to download on our website: www.rcpsych.ac.uk/QNLD

Standards for Inpatient Learning Disability Services

Section 1: Admission & Assessment

No.	Type	Standard	Principle	Ref
1	1	Accessible information is made available, in paper and/or electronic format, to patients, carers and healthcare practitioners on: • How to make a referral; • A description of the unit and its purpose; • Admission criteria; • Clinical pathways describing access, discharge, timescales and treatment pathways; • Main interventions and treatments available; • Contact details for the unit.		[1] [2]
2	1	Assessments of patients' capacity to consent to care and treatment in the unit are performed in accordance with current legislation and repeated at regular intervals.		[1] [2]
3	1	Consent-to-treatment procedures (or best interest decision-making processes) should be followed and documented, as per Mental Capacity Act 2005.		[3]
4	1	When patients lack capacity to consent to interventions, decisions are made in their best interests.		[3]
5	1	There are systems in place to ensure that the unit takes account of any advance decisions and statements that the patient has made.		[1] [2]
6	1	The unit/staff members engage with the patient's carer and people who know them best (with the patient's consent) to gather information and support with the admission process.		[2] [16]
7	1	On admission the following is given consideration: • The security of the patient's home; • Arrangements for dependants (children, people they are caring for); • Arrangements for pets; • Essential maintenance of home and garden.		[1]

8	1	Patients are given accessible information on their rights, which staff members talk through with them and explain how it relates to their care, as soon as practically possible. The information includes: • Their rights regarding admission and consent to treatment; • Rights under the Mental Health Act, Mental Capacity Act, Human Rights Act & Deprivation of Liberty Safeguards (DoLS); • How to access advocacy services; • How to access a second opinion; • Interpreting services; • How to view their records; • How to raise concerns, complaints and give compliments; • Information on restrictive practice. *Guidance: Patients' rights are continuously discussed throughout their time on the unit.*	 	[1] [2]
9	1	Confidentiality and its limits are explained to the patient and carer on admission, both verbally and in writing. Patient preferences for sharing information with third parties are respected and reviewed regularly.	  	[1]
10	1	Patients begin a screening assessment to identify their communication needs, outlining how to effectively communicate with them, within 4 hours of admission or as soon as practically possible. *Guidance: The team utilise the patients' current communication passport/profile during this assessment, where available.*		[2] [8]
11	1	Patients begin a comprehensive mental health assessment within 4 hours of admission, or as soon as practically possible. This involves the multi-disciplinary team and includes consideration of the patient's: • Mental health and medication; • Psychosocial and psychological needs; • Strengths and areas for development; which includes an adaptive functioning assessment and an assessment of sensory needs.		[1] [2]
12	1	Patients have a comprehensive physical health review. This is started within 4 hours of admission, or as soon as is practically possible. The assessment is completed within 1 week, or prior to discharge.		[1]
13	1	Patients have follow-up investigations and treatment when concerns about their physical health are identified during their admission. *Guidance: This is undertaken promptly and a named individual is responsible for follow-up. Patients have a health action plan and advice may be sought from primary or secondary physical healthcare services.*		[1] [9]

14	1	Patients and carers are given an accessible information pack on admission, which staff talk through with them, that contains the following: • A description of the service; • The therapeutic programme; • Information about the staff team; • The unit code of conduct; • Information on safeguarding; • Key service policies (e.g. permitted items, complaints policy, restrictive practice policy); • Resources to meet spiritual, cultural or gender needs.		[1] [2]
15	2	The community team (including the social worker) and the GP are informed about the patient's admission within one working day.		[2]
16	1	When patients are admitted to the unit as an emergency without a Community Care and Treatment Review (CTR), staff at the unit will identify and notify the relevant Clinical Commissioning Group, Local Authority, GP, and Community Team for People with Learning Disabilities.		[2] [16]
17	1	There is a documented Care Programme Approach (or equivalent) or ward round admission meeting within one week of the patient's admission. Patients are supported to attend this and express their views with advanced preparation and feedback.		[1] [2]
18	1	When a young person under the age of 18 is admitted: • There is a named CAMHS clinician who is available for consultation and advice; • The local authority or local equivalent is informed of the admission; • The CQC or local equivalent is informed if the patient is detained; • A single room is used; • A risk assessment is completed.		[1] [2]

Section 2: Care Planning and Treatment

No.	Type	Standard	Principle	Ref
19	1	Every patient has a written care plan, reflecting their individual needs. Staff members collaborate with patients and their carers (with the patient's consent) when developing the care plan and they are offered a copy: *Guidance: The care plan clearly outlines:* • *Agreed intervention strategies for physical and mental health;* • *How to build on skills, strengths and experiences to achieve goals and aspirations;* • *Plans to keep well;* • *Any advance decisions or statements that the patient has made;* • *Reducing restrictive practice plan;* • *Crisis and contingency plans;* • *Review dates and discharge plans.* *Care plans are adapted to the patients' communication needs.*		[1] [2]
20	1	The multi-disciplinary team reviews and updates care plans at least weekly.		[19]
21	1	Patients are supported to prepare for any formal review of their care. During their review they, along with their carer (where consent has been given), are supported to express their views.		[19]
22	1	Patients have a risk assessment and management plan which is co-produced, updated regularly and shared where necessary with relevant agencies (with consideration of confidentiality). The assessment considers risk to self, risk to others, risk from others and safeguarding risk.		[1] [2]
23	1	The team knows how to respond to carers when the patient does not consent to their involvement.		[1]
24	1	Patients begin evidence-based interventions, which are appropriate, for their bio-psychosocial needs, as per individual clinical need. Any exceptions and delays are documented in the case notes.		[1] [2]

25	2	Staff members review patients' progress against patient-defined goals in collaboration with the patient at the start of treatment, during clinical review meetings and at discharge.		[1]
26	1	The team and patient jointly develop a leave plan, which is shared with the patient and their carer (with the patient's consent), that includes: • A risk assessment and risk management plan that includes protective factors and an explanation of what to do if problems arise on leave; • Conditions of the leave; • Information on medication; • Contact details of the unit and crisis numbers.		[1] [2]
27	1	Staff agree leave plans with the patient's carer where appropriate, allowing carers sufficient time to prepare.		[1]
28	1	When patients are absent without leave, the team (in accordance with local policy): • Activate a risk management plan; • Make efforts to locate the patient; • Alert carers, people of concern and the relevant authorities; • Complete an incident form.		[1] [2]
29	1	Patients are offered a pre-arranged 1-hour session at least once a week with a nominated member of their care team to discuss progress, care plans and concerns.		[1]
30	1	Actions from reviews are fed back to the patient and carer (with the patient's consent) and this is documented.		[1]
31	1	Patients are involved in decisions about their level of observation by staff, where appropriate. *Guidance: Patients are supported to understand why they are under the level of observation and how it can be reduced.*		[1] [2]
32	1	When medication is prescribed, patients are supported to understand: • What medication they are taking; • What the benefits are; • What the common side effects are; • Whether the medication is being prescribed off label or in high dose; • How it will work with other medicines; • A timescale for medicine to be stepped down or stopped. *Guidance: Medication is prescribed in line with the principles of STOMP, where appropriate.*		[1] [2] [11]
33	1	Patients have their medications reviewed at least weekly. Medication reviews include an assessment of therapeutic response, safety, management of side effects and adherence to medication regime. *Guidance: Side effect monitoring tools can be used to support reviews.*		[1]

34	1	Patients have their PRN medication reviewed weekly, with consideration of the frequency dose and reasons.		[1]
35	1	The indication(s) and rationale for prescribing psychotropic medication is clearly stated and documented including whether the medication is being used off label, polypharmacy or high dose; how long the medication should be taken for; the strategy for reviewing the prescription and stopping the medication. *Guidance: In line with STOMP guidance in prescribing psychotropic medication.*		[11]
36	1	Review and evaluation of the need for continuation or discontinuation of the psychotropic drug should be undertaken in line with diagnostic review or whenever there is a request from patients, carers or other professionals.		[11]
37	1	Patients who are on units for long periods of time, who are prescribed mood stabilisers or antipsychotics, have the appropriate physical health assessments at the start of treatment (baseline), at 6 weeks, at 3 months and then annually unless a physical health abnormality arises.		[1] [2]

Section 3: Referral, Transfer and Discharge

No.	Type	Standard	Principle	Ref
38	2	The team invites a community team representative and commissioners to attend and contribute to ward rounds and discharge planning, where appropriate.		[2]
39	2	Discharge planning is initiated at the first multi-disciplinary team review and a provisional duration of admission is set.		[1] [2]
40	1	Patients have a discharge plan, which reflects their individual needs. Staff members collaborate with patients and their carers (with the patient's consent) when developing the discharge plan and they are offered a copy: *Guidance: The plan includes details of:* • *Transition arrangements from the unit;* • *Current care plan;* • *How services will proactively work together (and carers, with the patient's consent) to support the transition;* • *What to do in a crisis;* • *Medication including monitoring arrangements;* • *Details of when, where and who will follow up with the patient.*		[1] [2]

41	1	Where there are delayed transfers/discharges: • The team can easily raise concerns about delays to senior management; • Local information systems produce accurate and reliable data about delays; • Action is taken to address any identified problems.		[10]
42	1	Mental health and learning disability practitioners engage in a thorough assessment of the patient's personal, social, safety and practical needs, in collaboration with the patient, to reduce the risk of suicide on discharge.		[1] [2]
43	1	Patients and their carer (with the patient's consent) are supported to attend a discharge meeting and are involved in decisions about discharge plans. *Guidance: A named nurse is allocated to support the discharge process.*		[2] [10]
44	2	A discharge summary is sent within a week to the patient's GP and others concerned (with the patient's consent), including why the patient was admitted and how their condition has changed, diagnosis, medication and formulation.		[1]
45	1	The team makes sure that patients who are discharged from the unit have arrangements in place to be followed up within 3 days of discharge.		[1]
46	1	Patients admitted to a unit outside the area in which they live have a review of their placement, in line with national timeframes. *Guidance: This will occur at a minimum every 3 months, in line with national guidelines.*		[1] [2]
47	1	When patients are transferred between units there is a handover which ensures that the new team have an up-to-date care plan and risk assessment.		[19]
48	1	Teams provide specific transition support to patients when their care is being transferred to another unit, to a community team for people with learning disabilities, or back to the care of their GP. *Guidance: The team provides transition mentors, transition support packs or training for patients, carers and staff on how to manage transitions.*		[1] [2]
49	1	When staff members are concerned about an informal patient self-discharging against medical advice, the staff members undertake a thorough assessment of the patient, taking their wishes into account as far as possible.		[1]
50	1	The team follows a joint working protocol with primary health care teams. *Guidance: This includes the team informing the patient's GP:* • *If an annual health check is overdue;* • *If there are significant changes in the patient's mental health or medication;* • *If the patient has been referred to another team.*		[12] [16]

51	2	There are care pathways in place to support patients when attending local generic health services. *Guidance: This includes joint working with liaison nurses within hospitals.*		[12] [16]
52	1	There are care pathways in place to support patients to access other mental health services. *Guidance: This includes inviting the mental health service to attend ward rounds and take part in joint care planning.*		[12] [16]
53	2	The team follows a joint working protocol with social care services.		[12] [16]
54	1	The service has a care pathway for women who are pregnant or in the postpartum period. *Guidance: Women who are over 32 weeks pregnant or up to 12 months postpartum period should not be admitted to the unit unless there are exceptional circumstances.*		[1]
55	2	The team supports patients to attend appointments with their community GP whilst on the unit if they are admitted in the local area.		[1] [2]

Section 4: Patient and Carer Experience

No.	Type	Standard	Principle	Ref
56	1	On admission to the unit, patients feel welcomed by staff members who explain why they are on the unit. *Guidance: Staff make use of the patient's hospital passport/communication profile where available to establish correct communication strategies. Staff members show patients around and introduce them to other patients, offer them refreshments and address them using the name they prefer.*		[1] [2]
57	1	Patients are supported to access advocacy services including Independent Mental Health Advocates (IMHA) and Independent Mental Capacity Advocates (IMCA). *Guidance: Staff members check if patients have an advocate and support in the application process.*	 	[1] [2]
58	1	The unit uses interpreters who are sufficiently knowledgeable and skilled to provide a full and accurate translation. The patient's relatives are not used in this role unless there are exceptional circumstances.		[1]

59	1	Staff members are easily identifiable, photographs of staff with their names and role are visible on the unit.		[2]
60	1	Patients know who the key people are in their team and how to contact them if they have any questions. *Guidance: Patients are supported to understand the role of each person involved in their care.*		[1] [2]
61	1	Staff members treat all patients and carers with compassion, dignity and respect.		[1]
62	1	Patients feel listened to and understood by staff members.		[1]
63	1	The unit can demonstrate that it promotes culturally and spiritually sensitive practice. *Guidance: This is taken into consideration within care planning and treatment and the unit links in with external agencies to meet any unmet needs.*		[12]
64	1	Patients and staff members feel safe on the unit.		[1]
65	1	For physical examinations, all patients are given the option to have an impartial observer to act as a chaperone. *Guidance: A chaperone should usually be a health professional who is familiar with the examination procedure. Any appropriate requests for a specific gender of healthcare professional should be accommodated as far as possible.*		[14]
66	1	To reduce the use of restrictive interventions, patients who present with behaviours that challenge are supported to identify: • What causes distress, triggers and early warning signs (through the use of alternative and augmentative communication when necessary) • Make advance statements about the use of restrictive interventions through positive behaviour support plans.	 	[1] [2] [18]
67	1	Staff members respect the patient's personal space, e.g. by knocking and waiting before entering their bedroom except in emergencies or where there are concerns about the patient's wellbeing.		[1]
68	1	Patients and carers are provided with accessible information about the patient's mental illness, behaviours that challenge, autism, sensory needs and physical health needs. *Guidance: Information could be provided in a 1:1 meeting with a staff member, a ward round or in a psycho-education group.*		[8] [16]

69	1	Information provided to patients is available in an accessible format. *Guidance: Information can be provided in languages other than English and in formats that are accessible for people with sight/hearing/ cognitive difficulties and learning disabilities. This could include easy read, audio and video materials, using symbols and pictures, communication passports and signers. This information is in line with national accessible information standards.*		[8]
70	1	There are processes in place to facilitate the understanding of information given to patients throughout their time on the unit. *Guidance: Staff routinely check patients' understanding of information provided.*		[8]
71	1	Patients have access to safe outdoor space every day.		[1]
72	1	Every patient has a 7-day personalised therapeutic/recreational timetable of activities to promote social inclusion, which the team encourages them to engage with. *Guidance: This includes activities such as education, employment, volunteering and other occupations such as leisure activities and caring for dependants.*		[1]
73	2	Patients are supported to engage in psychoeducation on topics about activities of daily living, for example interpersonal communication, relationships, coping with stigma, stress management and anger management.		[1] [2]
74	2	There is a minuted community meeting that is attended by patients and staff members. The frequency of this meeting is weekly, unless otherwise agreed with the patients on the unit. *Guidance: This is an opportunity for patients to share experiences, to highlight issues of safety and quality on the unit and to review the quality and provision of activities with staff members. The meeting should be facilitated by a professional who understands group dynamics.*		[1]
75	2	Patients are consulted about changes to the unit environment.		[1]
76	1	Patients and carers are asked for their feedback about their experiences of using the service and this is used to improve the unit. *Guidance: Patients are supported to express their views, through communication adjustments and support that meets their individual need.*	 	[1] [2]

77	1	Patients use mobile phones, computers (which provide access to the internet and social media), cameras and other electronic equipment on the unit, subject to risk assessment and in line with local policy. *Guidance: Staff members ensure the use of such equipment respects the privacy and dignity of everyone on the unit and know how to manage situations when this is breached.*		[1]
78	2	Patients have access to relevant faith-specific support, preferably through someone with an understanding of mental health and learning disabilities. *Guidance: Patients are supported to maintain pre-existing links with their faith community where possible.*		[1] [2]
79	1	The team supports patients to access support with finances, benefits, debt management and housing.		[1]
80	2	The team provides information and encouragement to patients to access local organisations for peer support and social engagement. This is documented in the patient's care plan and may include access to: • Voluntary organisations; • Community centres; • Local religious/cultural groups; • Peer support networks; • Recovery Colleges.		[1]
81	1	Patients are offered personalised healthy lifestyle interventions such as advice on healthy eating, physical activity and access to smoking cessation services. This is documented in the patient's care plan.		[1]
82	2	Health promotion principles are embedded on the unit and education is offered to patients on the importance of keeping healthy and remaining active. *Guidance: Patients have access to a range of physical activities based on individual needs and interests.*		[2] [9]
83	1	Carers (with the patient's consent) are involved in discussions and decisions about the patient's care, treatment and discharge planning.		[1]
84	2	The team provides each carer with carer's information. *Guidance: This may be in the form of a carers pack and includes:* • *Names of key staff members and who to contact for questions, concerns or in an emergency;* • *How to stay in contact with their loved one whilst they are on the unit;* • *Information on sharing information with carers;* • *Information on family advocacy;* • *Local sources of advice and support such as local carers' groups, carers' workshops and relevant charities.*		[1] [2]

85	1	Carers are supported to access a statutory carers' assessment, provided by an appropriate agency.		[1]
86	2	Carers have access to a carer support network or group. This could be provided by the unit or the team could signpost carers to an existing network. *Guidance: This could be a group or network which meets face-to-face or communicates online.*		[15]
87	2	Carers are offered individual time with staff members, within 48 hours of the patient's admission to discuss concerns, family history and their own needs.		[2]
88	2	Carers feel supported by staff members.		[1]
89	2	The unit has a staff member designated as the carer lead or champion.		[15]
90	2	The service has a strategy for carer engagement. The strategy describes measures taken to proactively support: • A carer's own needs around information and support; • How they can be involved in the care of their loved one; • Opportunities to be involved in service developments, training and improvements.		[20]

Section 5: Environment and Facilities

No.	Type	Standard	Principle	Ref
91	1	The unit has clear and accessible signage.		[2]
92	1	Patients are cared for in the least restrictive environment possible, while ensuring appropriate levels of safety.		[1]
93	1	Staff members, patients and visitors are able to raise alarms using panic buttons, strip alarms, or personal alarms and there is an agreed response when an alarm is used.		[1]
94	1	A collective response to alarm calls is rehearsed at least 6 monthly.		[1]
95	1	Emergency medical resuscitation equipment is available immediately and is maintained and checked weekly, and after each use.		[1]

96	1	The unit is a safe environment with no ligature points, clear sightlines (e.g. with use of mirrors) and safe external spaces.		[1]
97	1	An audit of environmental risk is conducted annually, and a risk management strategy is agreed. *Guidance: This includes an audit of ligature points.*		[1]
98	1	Laundry facilities are available to all patients and their clothes are washed separately.		[2]
99	1	Male and female patients have separate bedrooms, toilets and washing facilities.		[1]
100	1	The unit has at least one bathroom/shower room for every three patients.		[1]
101	2	Every patient has an en-suite bathroom.		[1] [2]
102	2	All patients have single bedrooms.		[1]
103	2	Patients are able to personalise their bedroom spaces. *Guidance: Patients are able to put up their own photos, pictures and posters reflecting their likes and interests.*		[1]
104	2	All patients can access a charge point for electronic devices such as mobile phones.		[1] [2]
105	2	Staff members and patients can control heating, ventilation and light. *Guidance: For example, patients are able ventilate their rooms through the use of windows, they have access to light switches and they can request adjustments to control heating.*		[1]
106	1	Patients are supported to access materials and facilities that are associated with specific cultural or spiritual practices, e.g. covered copies of faith books, access to a multi-faith room, access to groups.		[1]
107	2	All patients can access a range of current culturally specific resources for entertainment, which reflect the unit's population. *Guidance: This may include recent magazines, daily newspapers, board games, a TV and DVD player with DVDs.*		[1]
108	2	The unit has a designated room for physical examination and minor medical procedures.		[1]
109	1	There is a separable gender-specific space which can be used as required.		[1]

110	2	There are facilities for patients to make their own hot and cold drinks and snacks which are available 24 hours a day. *Guidance: Patients have lockers available to store personal food and drinks, based on risk and individual plans.*		[1] [2]
111	1	Patients are provided with meals which offer choice, ensure a nutritional and balanced diet and specific dietary requirements and which are also sufficient in quantity. Meals are varied and reflect the individual's cultural and religious needs.		[1]
112	2	Staff members ask patients for feedback about the food and this is acted upon.		[1]
113	2	The unit has at least one quiet room or de-escalation space other than patient bedrooms.		[1]
114	1	In units where seclusion is used, there is a designated room that meets the following requirements: • It allows clear observation; • It is well insulated and ventilated; • It has adequate lighting, including a window(s) that provides natural light; • It has direct access to toilet/washing facilities; • It has limited furnishings (which includes a bed, pillow, mattress and blanket or covering); • It is safe and secure – it does not contain anything that could be potentially harmful; • It includes a means of two-way communication with the team; • It has a clock that patients can see; • Therapeutic and meaningful activities are available in line with individualised risk assessment.		[1] [6]
115	1	In units where long term segregation is used, the area used conforms to standards as prescribed by the Mental Health Act Code of Practice. *Guidance: This includes patients having access to meaningful and therapeutic activity and outdoor space.*		[6]
116	2	There is a designated space for patients to receive visits from children, with appropriate facilities such as toys and books.		[19]

Section 6: Staffing and Training

No.	Type	Standard	Principle	Ref
		The multi-disciplinary team consists of staff from a number of different professional backgrounds that enables them to deliver a full range of treatment and therapies appropriate to the bio-psychosocial needs of patients on the unit. The team includes:		
117	1	Consultant psychiatrist(s)		[16]
118	1	Registered specialist learning disability and/or mental health nurse(s)		[16]
119	1	Specialist pharmacist(s)		[1]
120	1	Healthcare assistant(s) *Guidance: This includes support workers, occupational therapist assistants, and psychology assistants.*		[16]
121	1	There is a psychologist who is part of the MDT. They contribute to the assessment and formulation of the patients' psychological needs and the safe and effective provision of evidence based psychological interventions. *Guidance: Psychologists are HCPC registered.*		[1]
122	1	There is an occupational therapist who is part of the MDT. They work with patients requiring an occupational & sensory assessment and ensure the safe and effective provision of evidence based occupational interventions. *Guidance: Occupational Therapists are HCPC registered.*		[1] [2]
123	1	There is a speech and language therapist who is part of the MDT. They work with patients requiring communication and/or dysphagia assessment and intervention and ensure safe and effective provision of evidence-based interventions. *Guidance: Speech & Language Therapists are HCPC registered.*		[2]
124	2	Social worker(s)		[16] [10]
125	2	Dietician(s)		[2]
126	2	Arts therapist(s)		[1] [2]

127	1	The unit has a mechanism for responding to low/unsafe staffing levels, when they fall below minimum agreed levels, including: • A method for the team to report concerns about staffing levels; • Access to additional staff members; • An agreed contingency plan, such as the minor and temporary reduction of non-essential services.		[1]
128	2	The unit is staffed by permanent staff members, and unfamiliar bank or agency staff members are used only in exceptional circumstances, e.g. in response to additional clinical need.		[1] [5]
129	1	The team including bank and agency staff are able to identify and manage an acute physical health emergency.		[1]
130	1	There is an identified duty doctor available at all times to attend the unit, including out of hours. The doctor can attend the unit within 30 minutes in the event of an emergency.		[1]
131	2	Appropriately experienced patient or carer representatives are involved in the interview process for recruiting potential staff members.		[1]
132	1	New staff members, including bank staff, receive an induction based on an agreed list of core competencies. This includes: • Arrangements for shadowing colleagues on the team; • Jointly working with a more experienced colleague; • Being observed; • Receiving enhanced supervision until core competencies have been assessed as met.		[1]
133	1	All clinical staff members receive clinical supervision at least monthly or as otherwise specified by their professional body. *Guidance: Supervision should be profession specific as per professional guidelines and provided by someone with appropriate clinical experience and qualifications.*		[1]
134	2	All staff members receive line management supervision at least monthly.		[1]
135	1	All staff members receive an annual appraisal and personal development planning (or equivalent). *Guidance: This contains clear objectives and identifies development needs.*		[1]
136	2	Staff members are able to access reflective practice groups at least every six weeks where teams can meet together to think about team dynamics and develop their clinical practice.		[1] [2]
137	1	The unit actively supports staff health and well-being. This includes: • Providing access to support services; • Providing access to physical activity programmes; • Monitoring staff sickness and burnout; • Assessing and improving morale; • Monitoring turnover; • Reviewing feedback from exit reports and taking action where needed.		[1]

138	1	Staff members are able to take breaks during their shift that comply with the European Working Time Directive. *Guidance: They have the right to one uninterrupted 20-minute rest break during their working day if they work more than 6 hours a day. Adequate cover is provided to ensure staff members can take their breaks.*		[1]
139	1	When the team meets for handover, adequate time is allocated to discuss patients' needs, risks and management plans.		[1]
140	2	Unit-based staff members have access to a dedicated staff room.		[1]
141	1	Staff members feel able to challenge decisions and to raise any concerns they may have about standards of care. They are aware of the processes to follow when raising concerns or whistleblowing.		[1]
	Staff receive training consistent with their role, which is recorded in their personal development plan and is refreshed in accordance with local guidelines. The training includes (standards 142 – 152):			
142	1	The use of legal frameworks, such as the Mental Health Act, the Mental Capacity Act and the Human Rights Act (or equivalents).		[1] [2]
143	1	Physical health assessment. *Guidance: This could include training in understanding physical health problems, undertaking physical observations and when to refer the patient for specialist input.*		[1]
144	1	Safeguarding vulnerable adults and children. *Guidance: This includes recognising and responding to the signs of abuse, exploitation or neglect.*		[1]
145	1	Risk assessment and risk management. *Guidance: This includes assessing and managing suicide risk and self-harm; prevention and management of behaviour that challenges.*		[1]
146	1	Recognising and communicating with patients with cognitive impairment, communication difficulties or learning disabilities within the context of person-centred care.		[1] [2]
147	1	Statutory and mandatory training. *Guidance: This includes equality and diversity, information governance and basic life support.*		[1]
148	1	Autism awareness training.		[6]

149	1	Restrictive practice training. *Guidance: Staff are trained in preventative and reactive approaches. This training is certified as complying with the Restraint Reduction Network training standards.*		[17]
150	2	Trauma-informed approaches to care.		[6]
151	2	Epilepsy training.		[2]
152	2	Carer awareness, family inclusive practice and social systems, including carers' rights in relation to confidentiality.		[1]
153	1	Staff know how to prevent and respond to sexual exploitation, coercion, intimidation and abuse on the unit.		[1]
154	1	The team are knowledgeable about, and sensitive to, the needs of patients from minority groups. This may include: • Black, Asian and minority ethnic groups; • Asylum seekers or refugees; • LGBTQ+ community; • Travellers.		[16]
155	1	The team effectively manages behaviours that challenge on the unit: • Staff members can evidence that if restrictive interventions are used then they represent the least restrictive option to meet the need; • Individualised support plans, incorporating positive behaviour support plans, are implemented for all people who use services who are known to be at risk of being exposed to restrictive interventions; • Providers report on the use of restrictive interventions; • Advance statements are used to identify the patient's wishes and feelings; • During and after the use of physical restraint, the patient's physical condition (including vital signs and airway status) should be monitored and recorded and any deterioration is responded to. *Guidance: Interventions and procedures used align with the Mental Health Act Code of Practice (2015), Towards Safer Services (RRN, 2019) and Positive and Proactive Care (DoH, 2014).*		[5] [18] [20]
156	1	Staff members do not restrain patients in a way that affects their airway, breathing or circulation.		[1]
157	1	The team uses seclusion or segregation only as a last resort and for brief periods only.		[1]

158	1	All staff members who administer medications have been assessed as competent to do so. Assessment is done using a competency-based tool. This assessment is repeated at least once every three years.		[1]
159	1	All staff involved in administering or prescribing rapid tranquillisation, or monitoring patients to whom parenteral rapid tranquillisation has been administered, have received training in immediate life support.		[2]
160	1	All staff undergo specific training in therapeutic observation, as part of their induction on the unit. This training includes: • Principles around positive engagement with patients; • When to increase or decrease observation levels and the necessary multi-disciplinary team discussions that should occur relating to this; • Actions to take if the patient absconds.		[1]
161	1	All staff members who deliver therapies and activities are appropriately trained and supervised.		[1]
162	2	Experts by experience are involved in delivering and developing staff training.		[1]
163	1	Staff members follow a protocol when conducting searches of patients and their personal property.		[19]
164	1	Staff members follow inter-agency protocols for the safeguarding of vulnerable adults and children. This includes escalating concerns if an inadequate response is received to a safeguarding referral.		[5]

Section 7: Governance

No.	Type	Standard	Principle	Ref
165	2	Services are developed in partnership with appropriately experienced patient and carers who have an active role in decision making.		[1]
166	1	The environment complies with current legislation on disabled access. *Guidance: Relevant assistive technology equipment, such as hoists and handrails, are provided to meet individual needs and to maximise independence.*		[1]
167	1	There is a system in place to respond to themes and trends in safeguarding alerts/referrals and there are mechanisms to share learning. *Guidance: An organisational action plan is in place to address any issues raised, including where training needs are identified.*		[5]

168	1	The unit has mechanisms to review data at least annually about the people who are admitted. Data are compared and action is taken to address any inequalities in care planning and treatment. *Guidance: This includes data around the use of seclusion and length of stay in the unit for different groups.*		[6] [13]
169	1	The multi-disciplinary team collects audit data on the use of restrictive interventions and actively works to reduce its use year on year. *Guidance: Audit data are used to compare the unit to national benchmarks where possible.*		[1]
170	1	If long term segregation is used on the unit, mechanisms are in place for regular monitoring. *Guidance: The use is monitored in weekly multi-disciplinary team meetings or at external reviews.*		[6]
171	1	The safe use of high-risk medication is audited at a unit level, at least annually. *Guidance: This includes audit of the use of medications such as lithium, high dose antipsychotic drugs, antipsychotics in combination, benzodiazepines.*		[1]
172	2	A range of local and multi-centre clinical audits is conducted, which include the use of evidence-based treatments, as a minimum.		[10]
173	1	Clinical outcome measurement, and progress against user defined goals is collected at two time points (admission and discharge) as a minimum, and at clinical reviews where possible.		[1]
174	1	Systems are in place to enable staff members to quickly and effectively report incidents and managers encourage staff members to do this.		[1]
175	1	Staff members, patients and carers who are affected by a serious incident including restrictive practice and rapid tranquilisation are offered post incident support. *Guidance: This includes attention to physical and emotional wellbeing of the people involved and post-incident reflection and learning review.*		[1] [18]
176	1	Lessons learned from untoward incidents and complaints are shared with the team and the wider organisation. There is evidence that changes have been made as a result of sharing the lessons.		[1]
177	1	When mistakes are made in care this is discussed with the patient themselves and their carer, in line with the Duty of Candour agreement.		[1]
178	1	There is a visiting policy which includes procedures to follow for specific groups including: • Children; • Unwanted visitors (i.e. those who pose a threat to patients, or to staff members).		[19]

179	2	The team use quality improvement methods to implement service improvements.		[1]
180	2	The team actively encourages patients and carers to be involved in quality improvement initiatives.		[1]

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Working together Excellence Openness & Honesty Compassion

We Matter

Learning Disability Service Model
For Northern Ireland

Final
Version 5.0 May 2021

Learning Disability Service Model
"We Matter"

EQUALITY STATEMENT

In line with Section 75 of the Northern Ireland Act 1998, Learning Disability Services will be provided and available to all irrespective of gender, ethnicity, political opinion, religious belief, disability, age, sexual orientation, dependant and marital status.

Learning Disability Services have a duty to each and every individual that they serve and must respect and protect their human rights. At the same time, Learning Disability Services also have a wide social duty to promote equality through the care it provides and in the way it provides care. This includes addressing the needs of those groups or sections of society who may be experiencing inequalities in health and wellbeing outcomes.

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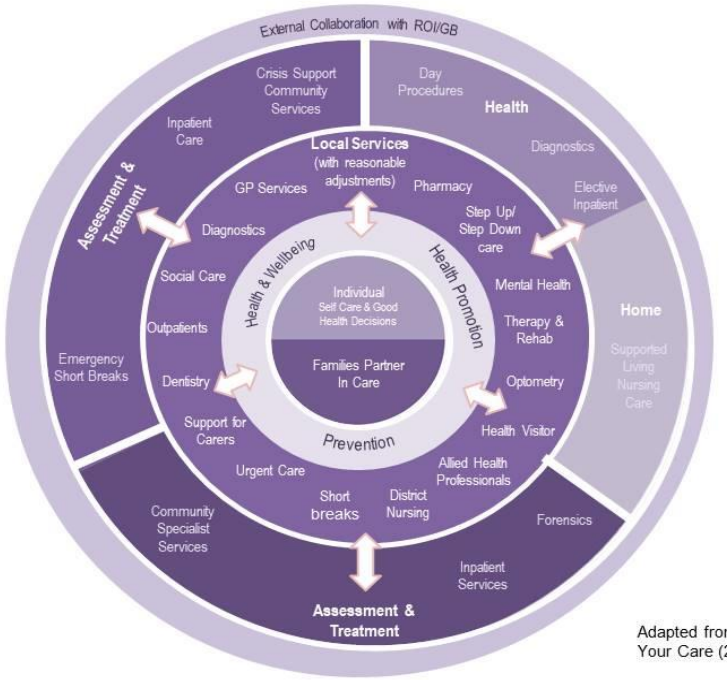
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Citizenship – Social Inclusion – Choice – Partnerships – Empowerment

We Matter

"As an individual with a learning disability I will be respected and empowered to lead a full and healthy life in my community. I will be supported to make choices and decisions in my life that enable me to develop, live a safe, active and valued life."

An Integrated Model for Learning Disability Services



Adapted from Transforming Your Care (2011)

Meaningful Life and Citizenship

"I live in a society that respects my right to work, learn and enjoy my life."

(PFG 1, 2 , 4)

Health and Wellbeing

"I can live a healthy life."

(PFG 3, 4.& 8)

Home

"I am supported to live in my home."

(PFG 3, 4)

Life Changes

"I am prepared and supported through important changes in my life."

(PFG 11)

Carers and Families

"My carers are supported to help me live my best life."

(PFG 1, 2)

Specialist Assessment & Treatment

"I will have access to high quality, compassionate assessment and treatment services when required."

(PFG 4,& 8)

Contents

Foreword

1 **Introduction**

1.1 Executive Summary

1.2 Background and Strategic Context

1.3 Our Scope

1.4 How the Model was Developed

1.5 Our Service Model Vision

1.6 Our Values and Principles for Action

1.7 Our Purpose

2 The Integrated Model of Care

2.1 Pathways of Care / Support Pathways

3 Our Key Ambitions and Outcome Measures

3.1 Key Ambition 1 – Life Changes

3.1.1 Introduction

3.1.2 Outcome Measures

3.2 Key Ambition 2 - Health & Wellbeing

3.2.1 Introduction

3.2.2 Outcome Measures

3.3 Key Ambition 3 - Carers and Families

3.3.1 Introduction

3.3.2 Outcome Measures

3.4 Key Ambition 4 - Meaningful Lives and Citizenship

3.4.1 Introduction

3.4.2 Outcome Measures

3.5 Key Ambition 5 - Home

3.5.1 Introduction

3.5.2 Outcome Measures

3.6 Key Ambition 6 – Specialist Assessment and Treatment

3.6.1 Introduction

3.6.2 Outcome Measures

4 How will the Model be taken Forward – Delivery Plan

4.1 Reporting Infrastructure

4.2 Outcomes Based Reporting

5 References (outstanding)

6 Annexes

7 Appendices

Foreword

[DN: to be completed on behalf of Minister Swann]

1. INTRODUCTION

1.1 Executive Summary

"This new service model has the potential to not just improve my life and how I access services, but will improve the lives of thousands of people with a learning disability, their families, friends ,carers and communities".

Peter Livingstone,
Mencap NI Inclusion Consultant
Member of the HSCB Project Steering Group

The NI Executive and leading organisations across Health and Social Care (HSC), community and voluntary sectors and individuals and carers are committed to transforming care for individuals with learning disabilities.

We have made progress under Bamford and Equal Lives, but much more needs to be done.

"We Matter" Adult Learning Disability Model for NI, thereafter known as 'the Model', is a strategic document which outlines a new outcomes based approach for Learning Disability services in Northern Ireland. The Model which has 6 Key Ambitions and 25 Outcome Measures builds on all the positive work to date whilst also describing what actions are required of services in order to provide quality, safe, compassionate and consistent support to individuals with a learning disability and their carers across the region.

Most importantly it outlines the following:

- what individuals with learning disabilities can properly expect of services – using an outcomes based approach;
- how this will be delivered – using an integrated approach supported by pathways of care depending on assessed needs;
- how it will be measured in order to ensure consistent, high-quality, cost-effective care.

The case for change for the Model is to address a number of on-going key challenges identified by those who use the system and who provide service, and include;

- reducing inequalities and improving health and social wellbeing for individuals with a learning disability;

- increasing levels of complexity of need;
- transitions between services including between children's and adult services and community to acute settings;
- the reduction of delayed discharges from hospital;
- lack of appropriate accommodation for people within the community;
- the provision of short breaks;
- support for older carers;
- data mapping and supporting resource mapping which can identify key health and social care needs of adults with learning disabilities to inform future commissioning and service planning;
- workforce development and training required to support the delivery of effective and efficient services; and
- clear strategic commissioning and procurement processes which are based on analysis of need and support a market of voluntary and independent sector organisations to provide the services.

A number of recent strategic developments, directives and more recent challenges, have highlighted a need to review Adult Learning Disability service provision. These include:

- The outcomes of the *Bamford Review of Mental Health and Learning Disability*, and the associated *Bamford Action Plan (2012-2015);*
- The *Review of Adult Learning Disability Community Services (Phase II)* (October 2016);
- The draft *Programme for Government (2016-2021);*
- The 10 year approach to transforming health and social care*: Health and Wellbeing 2026: Delivering Together* (2016);
- The *Mental Capacity Act (Northern Ireland) 2016*; and
- Recommendations for the Reform of Adult Social Care, outlined in *Power to People: Proposals to reboot adult care and support in Northern Ireland* (2017).

The model outlines a roadmap for transforming learning disability services in Northern Ireland within a projected timeframe of 3-5 years.

The Model has been co-produced after engaging with over 3,600 service providers, carers and service users. It is the result of an extensive programme of engagement, workshops, meetings and surveys (Feb. 2019–March 2020).

It will be led by a Learning Disability Transformation Taskforce (LDTT) bringing together senior responsible owners from all organisations working in Learning Disability.

The Model is informed by six Key Ambition Statements (with 25 key Actions) derived initially from Equal Lives, Former Department of Health and Social Services and Public Safety (DHSSPS 2005) and ratified through engagement with key stakeholders across the region. These statements are Life Changes, Health and Wellbeing, Carers and Families, Meaningful Life and Citizenship, Home and Specialist Assessment and Treatment.

It is grounded in the Programme for Government (PFG) Outcome Measures (2016–2020) as set out overleaf. It sits alongside a high level Delivery Plan and fully costed Implementation Plan for commissioners.

It is intended to provide greater autonomy, choice and independence for individuals with learning disability, their family and carers.

The Vision, Key Ambition Statements, Key Outcome Measures and Key Actions detailed in the Model represent a collective view on what is required of services to improve the lives of individuals with learning disabilities, their families and carers.

We will set up workstreams to adopt what is already good practice in the system at pace, test innovation and get the basics right. The workstreams will support a strong interconnected governance structure that holds the delivery programme to account, and ensures that a partnership and co-produced approach is transparent.

We are committed to provide a new Model built on the foundation of Bamford, but much more transformational, as we move into the future. We want individuals with a learning disability to be respected and empowered to lead a full and healthy life in their community. We want to support them make choices and decisions in their life that enable them to develop and to live a safe, active and valued life.

The Review of Adult Social Care noted “our vision is to place the person receiving care and support at the centre, building on their strengths and as far as possible, complementing family and community resources”. The call for partnering in care and support was evidenced very clearly during this engagement process and will continue as we move into the implementation phase.

A whole systems response is key to delivering the Model and will ensure a joined up approach to services which places quality of life outcomes at the heart of all we do, including all other ongoing work within Learning Disability Services.

Most importantly, the Model has been developed in recognition that citizens live within a whole system sector and needs to take a wider look at what is required from other public sector organisations including for example, Department for Education

(DE), Department for Communities (DfC), Department for Economy (DOE). The Programme of Government outcomes are critical to this transformation agenda. It is essential that DoH, other Government Departments, HSC organisations, voluntary and community sectors, private sector and carers work together providing support jointly to deliver the necessary change. These are described in Section 1.2 Background and Strategic Context (page 11).

Part of the work of the Learning Disability Transformation Taskforce (LDTT) will be to ensure that there will be joined up work with Children's Disability Services during the implementation phase, and this will be set out in the Delivery Plan.

The Model will also describe a number of transformational change ideas to help achieve the vision set out over the next 3-5 years and provide a road map to enable the dynamic change that will be required. These include a Learning Disability Systems Leader/Champion similar to the Mental Health Champion, a Learning Disability People's Parliament, a Learning Disability Network / Observatory, a regional website, a Regional Learning Disability Housing Lead, a Regional Informatics Framework and Register, a Learning and Development Framework, a Learning Disability Carer Consultancy model, and pathways of care for individuals based on their assessed needs.

Details of each of these transformational ideas can be found in Appendix 1 and further work will be required during the Delivery Plan phase.

The work of the Learning Disability Transformational Taskforce will include identifying innovation and opportunities to scale and spread pockets of good practice. It will ensure everyone will receive the same standard of good practice service no matter where they live in NI.

The Model will be supported by two additional documents which will be published separately.

- An Easy Read version of the Model which will be co-produced with individuals with lived experience and their families / carers.
- A Strategic Delivery Plan (SDP) which sets out the key actions and processes to achieve the Model is implemented and will measure it against key indicators developed across each of the 6 Key Outcomes. This is set out in Annex A.

The COVID-19 pandemic has, and will continue to, have an acute impact on individuals with learning disabilities and their carers and staff who support them. We in HSC and society in general, must learn and adapt from the first 'Covid-19 Wave' during 2020.

Partnership working is crucial to both maximise the use of community assets and to draw on the insight and expertise of partners to manage the Pandemic. Covid rebuild plans will be developed alongside individuals, families, carers, voluntary community sector (VCS) organisations as well as learning disability providers.

1.2 Background and Strategic Context

The Model is designed to improve the wellbeing of all individuals with a learning disability and support their carers to ensure individuals with a learning disability will be respected and empowered to lead a full and healthy life in the community, and will be supported to make choices and decisions in their life that enables them to develop and live a safe, active and valued life in Northern Ireland.

There are a number of relevant policy and strategic developments in Northern Ireland which underpin the Adult Learning Disability Service Model. A full summary can be found at Annex B.

As described in the Foreword, the Model needs to be set in the wider context of the 12 Programme for Government, which informs what we want public services in Northern Ireland to look like. These are:

1. We prosper through a strong, competitive, regionally balanced economy.
2. We live and work sustainably - protecting the environment.
3. We have a more equal society.
4. We enjoy long, healthy, active lives.
5. We are an innovative, creative society where people can fulfil their potential.
6. We have more people working in better jobs.
7. We have a safe community where we respect the law and each other.
8. We care for others and we help those in need.
9. We are a shared, welcoming and confident society that respects diversity.
10. We have created a place where people want to live and work, to visit and invest.
11. We connect people and opportunities through our infrastructure.
12. We give our children and young people the best start in life.

It is imperative that the LDTT sets out an infrastructure to ensure partnership working takes place for all key actions outside of the scope of HSC services.

Up to now Equal Lives represented the key strategic driver to shape delivery of services for individuals with learning disabilities and/or autism in Northern Ireland.

It has underpinned the development of the Model and states that individuals with a learning disability using public services should expect to be;

- be encouraged and supported to look after their own health and wellbeing, both mental and physical, and build up emotional resilience;
- be supported, as far as possible, in their own homes and communities, making best use of self-directed help;
- be supported, through effective collaboration between Government Departments and their agencies, in their life choices and in day to day activities of engaging in education, training, work and leisure;
- be consulted on and be able to influence the provision of services to meet their needs;
- be encouraged to access help at as early a stage as possible; and
- be supported towards personal fulfilment and full citizenship.

These overarching ambitions of Bamford remain relevant and lots of positive developments have taken place, but we want to move on. The Model will outline what a good service should look like for the future, using a human rights and person centred approach, an integrated model of care and sets out a number of Key Ambitions.

What is a Learning Disability?

A Learning Disability is a life-long condition which is known to affect three different areas of life:

- how I understand information;
- how I develop independent life skills;
- how I make social connections.

Learning disability criteria is described by British Psychological Society (2015). There are three core eligibility criteria for a diagnosis of learning disability:

- Significant impairment of intellectual functioning (defined as IQ quotient of below approximately 70, taking confidence intervals into consideration);
- Significant impairment of adaptive behaviour/social functioning (these terms are often used interchangeably);
- Onset before adulthood.

All three criteria must be met for a person to be considered to have a learning disability.

Mencap define a learning disability as having *'*a reduced intellectual ability and difficulty with everyday activities – for example, household tasks, socialising or managing money – which affects someone for their whole life.'

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

Every individual with a learning disability, like all citizens, is unique, and shares the same aspirations and needs. The needs of individuals who have a learning disability cover a wide spectrum with regards the support they may require. Like all citizens, this may change in increase with age, supports therefore will need to be tailored to the individual – some requiring minimal support and some with complex needs requiring on-going significant support. Some individuals who have a learning disability may also have other conditions too such as autism. Many will also have communication difficulties. Sometimes a learning disability will be apparent, but this is not always the case. The term Intellectual Disability is often used in other countries but Learning Disability is most widely used and accepted term in Northern Ireland, chosen as the preferred term set out in Equal Lives (2005).

HSC Trusts currently require a diagnosis of learning disability to access services and support. The scope of the Model will be broader to include those individuals who do need the formal criteria and may be best matched within this POC of care when considering issues of: safeguarding, mental health and /or autism. It will be necessary for Trusts to find the best match between mental health and learning disability.

The social model of disability is being proposed for use, an approach which proposes that what makes someone disabled is not their medical condition, but the attitudes and structures of society.

Adopting a human rights and person-centered approach is fundamental to the Model. This will promote a needs-led model and not one dependent upon clinical diagnostic criteria.

The Mental Capacity Act for People with a Learning Disability will also be important. This approach will help ensure that people who may lack capacity to make decisions on their own get the support they need to make those decisions. Where they are not

able to make their own decision, the Mental Capacity Act says a decision must be made that is in their 'best interests'.

The Model will also take cognisance of the new Adult Safeguarding/Protection Bill for Northern Ireland which will also help protect individuals with learning disability and other vulnerable members of society.

Legislative Context

The Model does not attempt to review or comment on legislation. Key developments in international, European, UK, and Northern Ireland law have been examined and discussed at length as part of the Bamford Review of Mental Health and Learning Disability (Northern Ireland) an independent review of mental health and learning disability law, policy, and service provision that was initiated in 2002 and reported in 2007. Its portfolio of publications includes, among others, reports titled: A Comprehensive Legislative Framework (DHSSPS, 2007a) and Human Rights and Equality of Opportunity (DHSSPS, 2007b). Further discussion can be found in Appendix 2.

Prevalence

When reviewing relevant literature there remains a gap in that no one data system is able to provide an overall population within Northern Ireland. It is hoped that the forthcoming system known as 'Encompass' may resolve this matter. A more detailed exploration of prevalence can be found at Appendix 3.

A review of the available data on learning disability across the UK shows that statistics vary widely across the region and by source. The numbers outlined in Appendix 3 are approximate, rely on data collated from a range of sources that categorise information differently, and typically do not include information on people who are not known to the health and social care system.

Mencap (2016-17), identify that there are approximately 1.4 million individuals with a learning disability in the UK, of which approximately 1,119,000 are adults, or 2.16% of the adult population. The prevalence of learning disability among children across the UK is believed to be slightly higher, at 2.5% of the child population as a whole: it may be anticipated therefore that a slight rise in learning disability prevalence among adults may be anticipated in the future.

The numbers outlined below are approximate, rely on data collated from a range of sources that categorise information differently, and typically do not include information on people who are not known to authorities

Table 1: Adults with a Learning Disability in the UK – Estimated Numbers

REGION	ESTIMATED NUMBERS
England	Estimations range from **930,400** (Public Health England, 2016) to **939,338** (Mencap, 2016-17)
Wales	Estimations range from **11,410** (Statistics for Wales, 2018) to **53,681** (Mencap, 2016-17) - **60,000** (Welsh Government, 2018)
Scotland	Estimations range from **23,446** (National Statistics Scotland, 2018) to **26,786** (ENABLE Scotland, n.d.)
Northern Ireland	Estimations range from **7,198** (McConkey, 2013) to **30,814** (Mencap, 2016-17) (All Party Group on Learning Disability, 2018)

The Northern Ireland Census (2011) also indicates that around 2% of the population or around 40,000 people (including children, young people, and adults) may have a learning disability. We await the 2021 Census, expected to be published in 2022 to note any changes in these figures.

Inequalities

Many individuals with a learning disability still face discrimination, marginalisation, and barriers to opportunities, which impact negatively on social integration, ability to work, and mental health. Please see a more detailed analysis of inequalities in Appendix 4.

Resources

The Northern Ireland Assembly Research and Information Service (2017) has noted that funding for learning disability services and support is lower in Northern Ireland than any other region of the UK, “with only 6% of the total Health and Social Care spending being allocated to learning disability in 2016..”, and “..although overall spending on learning disability in Northern Ireland increased by 15% between 2010 and 2015..”, the number of people here with learning disabilities also continues to rise.

Carers

The Northern Ireland Assembly Research and Information Service (2017) noted that "Informal carers provide much needed health and social care support to those with learning disabilities." Citing research conducted by Carers UK and the University of Sheffield in 2015, the service observes there are around "220,500 informal (unpaid) carers in Northern Ireland providing support worth an estimated £4.6 billion per year (around the same as the entire Northern Ireland health budget). Around 9% of these provide care for someone with a learning disability with many carers in poor health themselves."

The predominance care provision is in the home with 75% of individuals living with a member of their family noted by the Regulation Quality Improvement Authority Community Review of Services 2016.

Caring for Carers, Recognising, Valuing and Supporting the Caring Role, (2006) define carers as "people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member."

Some of the key challenges noted by carers during the process included more involvement in decisions about care; better transition arrangements; the need for a Regional Scoring Tool for bed based breaks; improved communication; the frustration around having to fight for services; the lack of autism support; the need for more emergency short breaks; more domiciliary short breaks and emerging nursing beds; and challenges around Self Directed Support (SDS). Carers also noted that current domiciliary provision does not always meet the needs of those with behaviours that challenge.

Workforce

The learning disability workforce, like others, is facing significant challenges. We need to support our current workforce and bolster it through increasing the number of qualified, competent and confident Multi-Disciplinary Teams (MDT) staff and support networks, and a supportive infrastructure.

Some of the key workforces challenges noted during the engagement process included; appropriate workforce and skill mix to respond effectively to needs; additional staff training in day care; training to respond therapeutically to behaviours that may challenge supported by Specialist MDT workforce planning predictions to

meet the rising and increasing needs of individuals with complex presentations; recruiting staff to work in learning disability services, and in particular, staff who have specialist skills; recruitment shortage in rural areas; and challenges for independent and private sector organisations to source staff to support individuals with behaviours that challenge or forensic backgrounds.

A Training and Development Framework is recommended, which incorporates a coherent workforce model and tiered training for staff at all levels and includes shared training and development for all providing support and services to individuals with a learning disability. Both the Department of Health Workforce Review and the Social Work Strategy Workforce Review will be key drivers for this framework.

Part of this framework should consider a Regional Workload Management Framework. The Remain Open But Stable (ROBS) is currently being tested in the Western HSC Trust to inform job plans, and will aim to reduce levels of staff burnout, sickness and even moves out of services. Staff wellbeing is more important now than ever.

The 'Learning Together Working Together' framework which presently operates in mental health services is an exemplar model and could usefully be adapted for learning disability services for all organisations.

Current Services

Learning disability services across NI offer a range of services including; supported living accommodation; nursing home care; residential home care; inpatient services; buildings-based day care; day opportunities; domiciliary care; short breaks; shared care; adult placements and SDS. These services work to complement each other and it is the intention that the Model will develop even stronger partnerships in care with all of the organisations to support the integrated approach set out.

There are a number of key actions in the Model which call for further investment into both statutory and non-statutory services to ensure we realise the vision we have set out in the Model.

The intention is to ensure that care and support to individuals and their families is available consistently across Northern Ireland based on the assessed needs of both individuals themselves and support to carers, to ensure individuals live full and meaningful lives.

The Model sets the direction for a system which encourages personalised support. This means that individuals with learning disabilities, their families and carers should have more choice and control over the high quality services they use.

Further work in this area will be taken forward in the Work Streams.

Personalised Support

Personalised support, in the form of SDS, including Direct Payments, is promoted currently across all Trusts. Each Trust has an SDS Action Plan for all Programmes of Care which is reported monthly to the Health and Social Care Board (HSCB) in terms of activity, and reported annually under the delegated statutory functions process. This odel/approach remains a priority for HSC services.

SDS is a flexible way of providing social care support, which gives people more choice over the way their care and support needs are met. It aims to give people more control over how their support is arranged and managed. This includes deciding the kind of support they want, when they want to use it and who will provide it. SDS is available to those who have been assessed as being in need of social care support.

Following an assessment, a personal budget will be agreed to meet identified support needs. It is provided by the individual's local HSC Trust to organise and purchase care and support around the following package of care options:

- Direct payment
- Managed Budget
- Trust Arranged Service
- Cost Neutral

For those using and benefitting from SDS and Direct Payments, it is well received and spoken of warmly, however for others the process is lengthy and arduous.

During the engagement process carers and staff spoke of a process that was difficult to understand, daunting; taking charge of tax matters with an employee and recruiting a carer/personal assistant. Whilst the processing of weekly pay and tax for an employee can be dealt with by the Centre for Independent Living, that did not address concerns regarding recruiting someone in a rural location or for someone with behaviours that challenge. The rate of pay is regionally agreed with and reviewed annually by the HSCB, however, carers and staff remain concerned that this was not attractive to recruit and retain potential carers. Carers and staff indicated difficulty in accessing appropriate carers within a predominately rural area. It also

requires enough flexibility to extend its potential use for employment or education opportunities for individuals, and in relation to caregiving arrangements during any emergency situations

Generally carers thought the concept was good but difficult to navigate. Staff involved in the process asked if any future review of criteria could include provision for accessing health professional assessment e.g. occupational therapy or podiatry. As SDS includes Direct Payments, it would be recommended that the criteria are reviewed.

It is important that service providers in these sectors are seen as partners in the delivery of support and care, and that a diverse, vibrant and sustainable market is encouraged so there are different types of provider organisations for people to choose from. This will be further explored during the Implementation Phase of the Model.

Commissioners will need to work collaboratively with individuals, their families and carers people and providers to understand what is needed, and how to support the market so providers can offer the services people need and want, now and in the future. It also means encouraging collaboration and partnership to create a choice of appropriate, quality and affordable services.

The Impact of COVID-19

The COVID-19 pandemic has impacted on individuals with learning disabilities and their carers and staff who support them. It is recognised that the cessation of services, in March 2020, placed a further burden on individuals and carers due to limited alternatives being available.

Access to beds, short breaks, both planned and emergency, day opportunities and day care, etc. were stood down during the first lockdown in March 2020, with all services were impacted. Help and support were available but had to be limited compared with usual provision,

Front line staff responded to the pandemic by ensuring critical services such as inpatient/supported living and crisis response services were sustained, following Public Health Agency (PHA) guidance relating to infection protection and control. Services adapted using a blended care and support model through the use of IT for virtual ward rounds and community assessments. It is important to note that the HSC offices have remained open through COVID-19, with collapsed services via non face to face contacts, and use of IT.

Minister for Health Robin Swann has indicated how the HSC and society in general must learn and adapt from the 'Covid-19' during 2020. COVID-19 remains in general circulation at the time of writing this report and it is therefore important adherence to Public Health guidance continues to be implemented. Those providing support to an individual, should use their usual methods of communication to help them continue to understand the restrictions.

Important areas relating to COVID-19 management include helping individuals understand the virus; social distancing guidance and support; managing relationships; staying well; healthcare issues; advance planning; any legislative impacts; safeguarding and, most unfortunately, death and bereavement.

It has become so important to think about what family members enjoy normally what strategies and plans typically work when things are not going well, and to continue to provide calm and reassuring support. Much has been changed by COVID-19, but the personality, preferences and interests of the individual will likely not have done.

Individuals with learning disabilities are likely to be worried about their own health, and that of their loved ones, while also having routines interrupted, and access to friends or colleagues halted. Those providing support to them will be concerned about their own and their family's health too, and may be facing knock-on effects of the pandemic such as lost income or jobs.

It is important that individuals are supported to maintain their relationships with family, friends and partners.

Despite everyone's best efforts, individuals may experience loneliness as a result of the reduction in opportunities to socialise, connect with people, take part in physical activity and everyday cultural and faith experiences. They may experience anxiety about the virus outbreak. NI Direct, HSC websites and local organisations continue to offer useful resources to support them. There are also excellent resources in the PHA COVID 19 Library to support families and organisations working with individuals to support their needs.

Contingency planning is also hugely important as it is likely to be a difficult time for families and carers, as well as for the individual themselves. This is understandable and carers, where possible, should do what they can to take care of themselves as well as the person they support. It is also important that staff and non-staff make arrangements to reach out to carers during this difficult time. Local voluntary and community organisations continue to offer advice for carers on protecting their mental wellbeing.

Families noted that the use of Direct Payments and SDS (and stimulation of the market to generate more choice) will underpin some of the learning/changes arising from COVID-19 going forward, which we must embrace. The use of these payments needs to flex to support the needs of individuals and their families, should we incur further COVID-19 waves into the future.

In preparing for and responding to COVID-19, organisations working in learning disability services continue to make decisions in the context of reduced capacity and increasing demand. Partnership working is crucial to both maximise the use of community assets and to draw on the insight and expertise of partners. Response plans should be developed alongside individuals, families, carers, voluntary and community sector (VCS) organisations as well as learning disability providers.

Services that a VCS partner may be well placed to provide, which would help to maintain safety in the community, include: peer support, family/carer support, befriending, telephone or social media outreach. In addition, they may work as part of crisis teams to provide telephone support and listening support.

Providers will need to maximise the use of digital and virtual channels to manage the impact of self-isolation on staff and patients, for example, by enhancing single point of access (SPA) lines to make them available 24/7 and review information on their websites to ensure it is clear. Robust access assessment arrangements will also be important to ensure the most acutely unwell patients receive the care they require in a timely way.

Evidence of these new ways of working are cited in many publications written about the first wave of COVID-19, and important lessons have been learned for future responses.

1.3 Our Scope

The Model is for all who access, develop and deliver services for individuals with learning disabilities and their families/carers. Whilst it specifically focuses on responsibilities for HSC, Department of Health (DoH) and HSC providers, including the voluntary and community sector providers as well as private sector providers, it also considers key actions for other Government Departments including Department of Education (DE), Department of Communities (DfC) and Department of the Economy (DOE),. It will provide a platform to link partners together to identify key objectives and work effectively to provide services, share skills and knowledge and build on a shared value base in line with legislation and policy guidance.

The Model will focus on the following key groups:

- **Individuals Diagnosed with a learning disability:**
  - who live in Northern Ireland;
  - who may have mild, moderate or severe learning disability and need support.

- **Family and Carers**

- **Staff who provide care to individuals with a learning disability:**
  - HSC Trusts;
  - local communities;
  - Independent community, voluntary and private organisations.

Whilst the Model is not specifically relating to children and young people, it is required, as per legislation under the Children's Services Co-operation Act (2015) and the Special Educational Needs Disability Act (NI) 2016 that there will be joined up work with Children's Disability Services during the Implementation Phase, and will be set out in the Delivery Plan.

1.4 How the Model was Developed

The Model provides recommendations for future service delivery aimed at improving outcomes for individuals, carers and support to staff/organisations working across Northern Ireland.

It has been developed through engagement with individuals living with a learning disability families and carers and Health and Social Care practitioners, and supported by key policies and best available evidence.

The following engagement took place:

- Over 190 engagement events were hosted across Northern Ireland (March – December 2019), of which 2860 individuals attended and/or responded to.

- A regional online survey was rolled out, delivering 794 responses from those living with a learning disability, families and carers and staff working in disability services.

- A series of visits to service providers both statutory and independent sector providers were held as well as meetings with individuals who used learning

disability services, carers, staff and representatives from professional organisations to listen to what they felt were important now and in the future.

- Three regional workshops with local service provider organisations were also facilitated by Association for Real Change (ARC) NI.

- In summary, 3,654 responses were received to identify key priorities for the Model. This feedback has been instrumental in developing key priorities for action for the next 3-5 years.

- Details about ideas and recommendations are formulated in the Strategic Delivery Plan.

The engagement process repeatedly reinforced the requirement for a Model that is responsive to the unique environment and challenges in Northern Ireland. We therefore opted to create the Model from the ground up, rather than import one from another region.

In developing the Model, however, a detailed analysis of the service delivery policy and models in England, Wales and Scotland was carried out to explore key points of learning/reference arising from other models and strategic developments in the other UK nations. A summary is set out below and more detail can be found at Annex C.

Region	Analysis
England	Overall, the strategic documentation in relation to the English learning disability service model offers a systematically developed framework underpinned by a strong value base and commitment to standards and quality. In context, this model is designed for implementation through joint commissioning rather than integrated health and social care service delivery: as such the model reads as a high-level framework for action and accountability.
Wales	Overall, the Welsh learning disability service model offers a streamlined, value-oriented framework underpinned by clearly defined processes. Notably, the model and service improvement recommendations place particular emphasis on communication, effective working relationships at all levels across the system, and staff training, development, and support. The emphasis of these 'softer' skills/elements within the programme of change is distinctive.

Scotland	Overall, the Scottish learning disability service model offers an accessible framework for action that is readily understood by a lay person, and firmly grounded in the day-to-day life, challenges, and opportunities facing people with a learning disability. This grounded approach embodies the underlying value base and mission of the strategy i.e. to improve the *quality of life* for people with learning disabilities. The model is also notable for the synergy it highlights between national outcomes for the population as a whole, and the specific objectives and outcomes it projects for people with learning disabilities.

- A regional reporting structure was established to develop the Model (see Appendix 8 for details). Five key groups were as follows: Project Board
- Project Steering Group
- Regional Service User Reference Group
- Expert Panel for review of Assessment and Treatment
- Project Implementation Team comprising of Project Manager and 5 Trust Project Leads

The Project Board reported to the Transformation Implementation Group (TIG) via the Mental Health and Learning Disability Improvement Board, led by the Director of Social Care and Children's Service, HSCB.

The Project Steering Group was represented by the Department of Health and Professional Leads for Learning Disability. Social Care Leads for Learning Disability from the HSCB, Assistant Director of Nursing, PHA, HSC Trusts Assistant Directors, ARC NI, service user representation, carer representation and Regional Project Manager.

A regional Project Team, led by the regional Project Manager and five HSC Trust Project Leads developed a structured engagement with all stakeholders, seeking a strategic response to the key challenges as described on page 6.

It is important to note that Project Leads were recruited at different times during 2019, which resulted in a staggered commencement to the project across the region. The nature of temporary funding also had an impact on retention of staff as two Trusts saw the movement of Project Leads to permanent posts during the timeframe.

1.5 Our Service Model Vision

The vision for the Model is set out below:

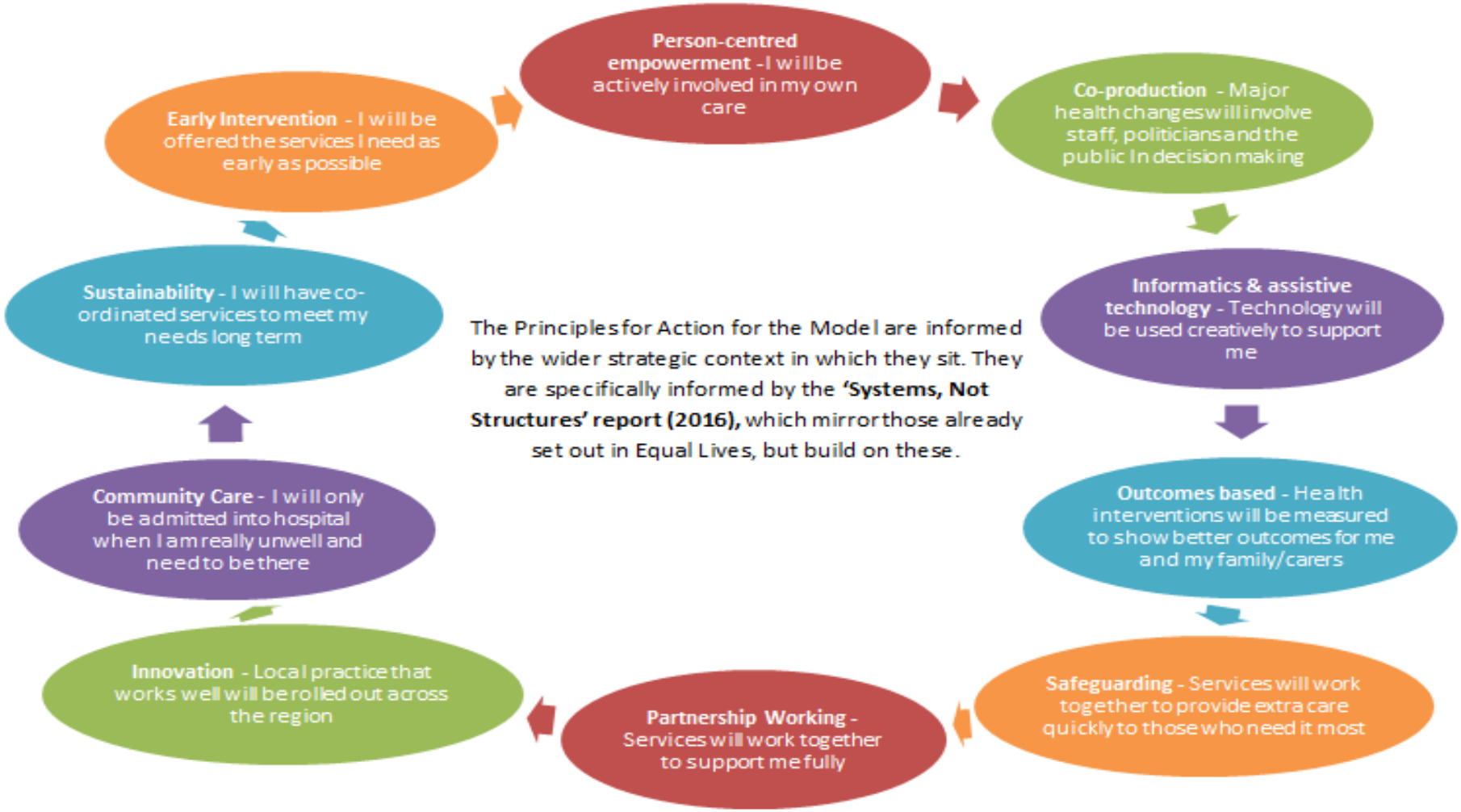
"As an individual with a learning disability, I will be respected and empowered to lead a full and healthy life in my community. I will be supported to make choices and decisions in my life that enable me to develop, and live a safe, active and valued life."

Values

The Model is first and foremost grounded in our HSC values of working together, excellence, compassion and open and honesty. These also mirror the Equal Lives values, which "We Matter" has evolved from.



1.6 Our Values and Principles for Action



The Scottish Governments PANEL Principles (2015) are also important for our Model in Northern Ireland as they will also ensure that the needs and rights of individuals with learning disabilities are reflected as paramount throughout this model.

These outcomes are embedded within the context of the Scottish Public Sector Reform agenda and have validity in NI:

PANEL Principles	
Participation	Everyone has the right to participate in decisions which affect them. Participation must be active, free, and meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.
Accountability	Accountability requires effective monitoring of human rights standards. For accountability to be effective there must be appropriate laws, policies, administrative procedures and mechanisms of redress in order to secure human rights.
Non-discrimination and equality	Human Rights based approach means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights.
Empowerment	People should understand their rights, and be fully supported to participate in the development of policy and practices which affect their lives. People should be able to claim their rights where necessary.
Legality	The full range of legally protected human rights must be respected, protected and fulfilled. A human rights based approach requires the recognition of rights as legally enforceable entitlements, and is linked in to national and international human rights law.

1.7 Our Purpose

The purpose of the Model is to outline what individuals with learning disabilities expect of services, how services will achieve this and how they will be measured to ensure high quality, cost effective care.

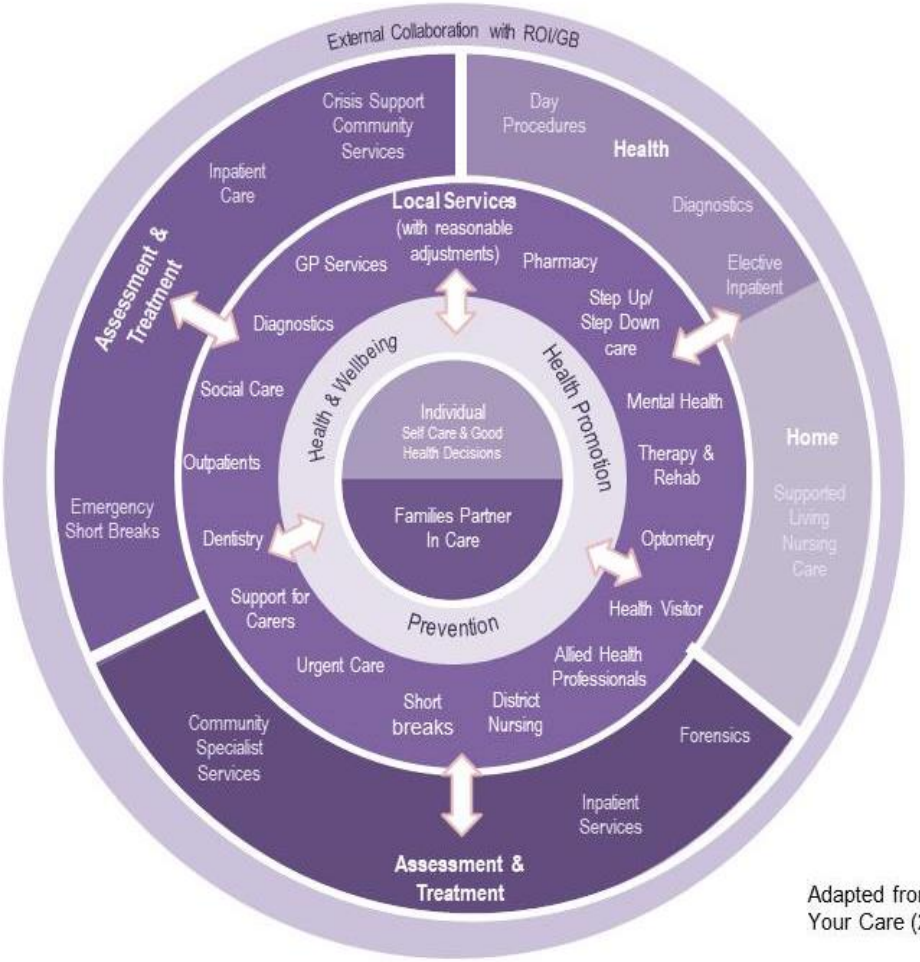
The Model will provide more autonomy, choice and independence for individuals and support to their families and carers.

The Model describes a range of services and supports that should be in place for individuals with learning disability. Depending upon their needs, individuals and their families will have access to services and support that is right for them and also be supported to navigate their way through the system, as their needs change.

2. THE INTEGRATED MODEL OF CARE

Set out in Transforming Your Care (2011) the integrated model of care is grounded in 12 principles for change, most importantly placing the individual at the centre of the model and providing the right care in the right place at the right time. The model will ensure that individuals with learning disabilities will have opportunities to make decisions that help maintain good health and wellbeing and all providers of services will provide the tools to do this.

Services will be provided locally and will regard home as the hub and be enabled to ensure individuals can be cared for, based on their assessed needs.



Adapted from Transforming Your Care (2011)

Where possible a mainstream service approach will be adopted, which entails facilitating access to generic/universal services for individuals with learning disability. Two important factors to ensure equitable access for individuals with learning disabilities are appropriately resourcing 'reasonable' adjustments and standardised pathways to care.

Reasonable adjustments ensure that care received by individuals with learning disabilities is appropriate and high quality. These are small but significant changes to the way a service or practitioner interacts with an individual in order to make the service suitable for them, e.g. changes to environment, length of appointment and communication styles. Reasonable adjustments must always be tailored to the individual's level of functioning and specific needs.

The Model offers a range of care based on the premise that individuals with learning disabilities will lead fulfilling lives in the community. The various elements of the Model recognise the range of levels of need for those with mild to moderate needs who manage and thrive with support of family, friends and mainstream HSC services, to those who require more intensive and specialist supports in community and inpatient environments. The Model aims to offer the most effective intervention which supports the individual to remain at home.

Access to services will be based on assessed needs of local populations and commissioned accordingly, to ensure equity and access of care.

In responding to changing need, crisis or circumstance, the Model will offer a speedy response with the flexibility to move between the range of support available at each element.

Individuals with learning disabilities may require access to services across a number of different elements simultaneously. Key workers will co-ordinate access to a range of services based on an individual's needs. This will require explicit links and interfaces between different pathways of care in order to provide an integrated approach. Organisations will work together in a more integrated way and be supported by pathways of care.

2.1 Pathways of Care/Support Pathways

Pathways of care/support pathways as they are usually referred to, describe the nature and anticipated care and support journey for an individual. Pathways of care/ support pathways will be developed during the Implementation Phase and set out in

the Delivery Plan. A thematic Work Stream will be engaged to do this work. A care pathway example, *"Sample Pathway of Care for Transitions"* is set out in Appendix 7.

Organisations working in learning disability services already use this care pathway/ support pathways approach but it is the intention of this Model to ensure consistency, standardisation of approach and equity across Northern Ireland for all our citizens.

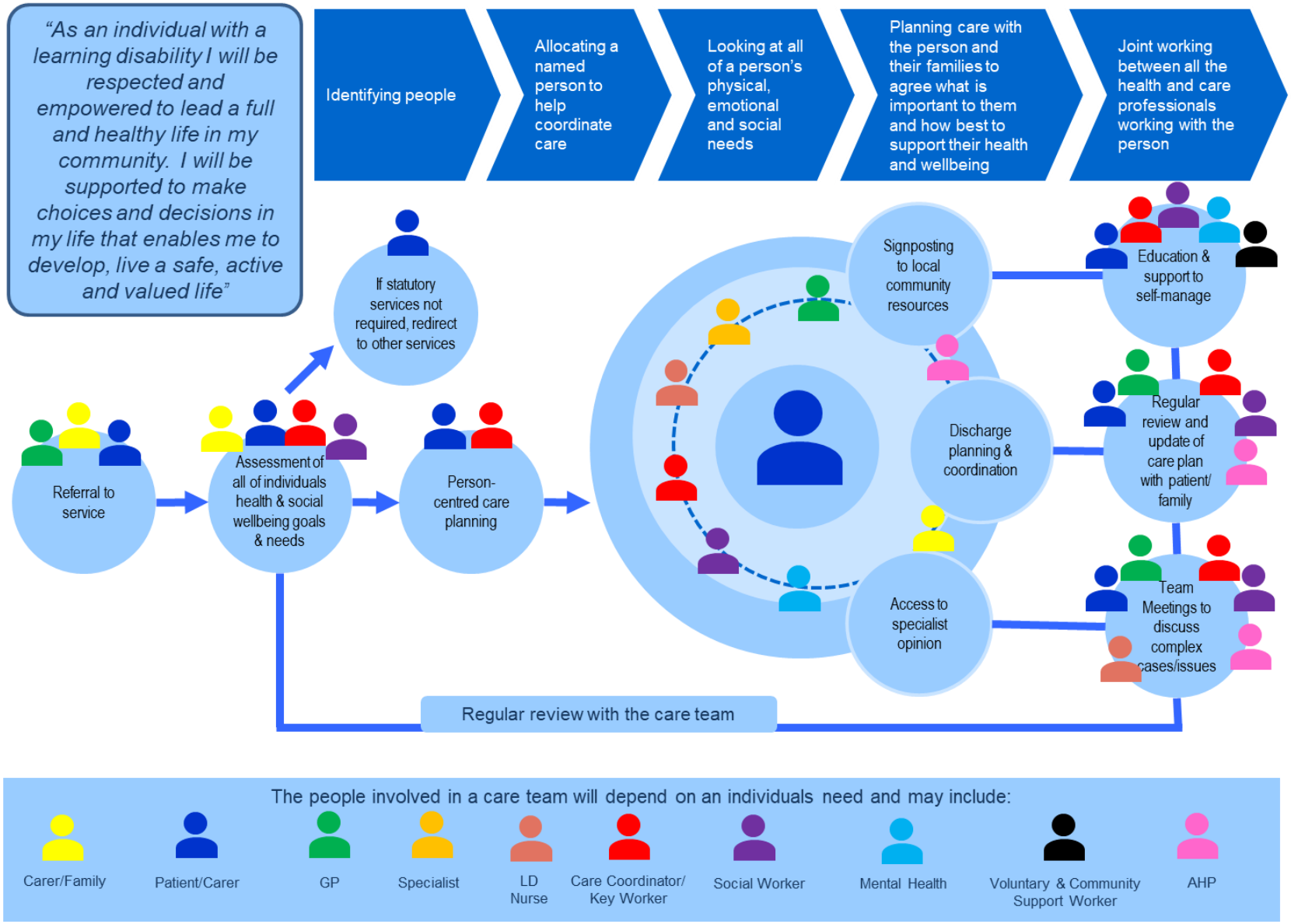
The *You in Mind Mental Health* suite of Care Pathways offers an example in practice, and it is anticipated that a similar suite of regional standardised pathways of care will be developed for learning disability services.

The pathway(s) of care/ support pathways will explain how individuals with learning disabilities and their families can access services to ensure individuals themselves live a *"safe, active and valued life"* as described in the Vision Statement, across the 6 Key Ambition Statements using the Integrated Model of Care. Care and support will be delivered in a co-ordinated and integrated way, and have consensus and support from all key stakeholders. They will be co-produced with individuals and their families will put the individual themselves at the heart of all decision making and will be needs-led and rights based.

This approach ensures there is agreement on standardised referral and care and treatment, to define where and when particular individuals should be referred to services, and what services they will choose, want and need. They should link to each other across the range of services seamlessly described above and also identify and work with outside HSC services.

Each pathway of care/ support pathway will have an agreed referral flow diagram, as per the example set out in Appendix 7. They will be designed to be flexible and will have agreed protocols for referral, eligibility and joint working arrangements in order to deliver a seamless and co-ordinated programme of care. An example is also set out below. This approach was adopted from a similar model in existence in the Lambethand Southwark local care network.

PATHWAY OF CARE APPROACH



3. OUR KEY AMBITIONS AND OUTCOME MEASURES

In order to achieve the vision set out in the Model, a number of Key Ambition Statements and associated Outcome Measures have been developed. These will guide the transformation of services, and be supported by the ideas for transforming the way we work noted on page 10 and further described in Appendix 1

The next section of the Model sets out each of the 6 Key Ambition Statements in full, including each Statement, Introduction, and Outcome Measures.

Appendix 6 sets out some of the Key Challenges associated with each of the 6 Key Ambition Statements expressed during the regional engagement process, and described in the extensive literature search carried out during the Project:

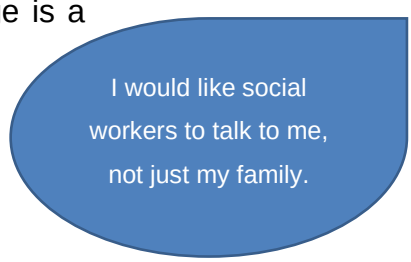
It is anticipated that the Key Actions set out in this Model will not be implemented immediately; a phased approach (3-5 years) will be required and will be set out in the Strategic Delivery Plan (SDP).

3.1 Key Ambition 1- Life Changes

Key Ambition Statement 1: *I am prepared and supported through important changes in my life.*

3.1.1 Introduction

Everyone will go through changes in their lives. A life change is a phrase used to reflect different stages of my life. This is sometimes called “Transitions” and is normally associated with moving from children’s to adult services. This is only one of many life changes that occur. We also change throughout our lives, as we and our parents grow older.



As I go through life, I may try new things, make new friends, go to school, get a job, move house, get married. These are important changes in my life. Sometimes I can plan these on my own; for some I may need support from my family or other health and social care staff such as when a family member dies.

3.1.2 Outcome Measure - What Success Looks Like

- Individuals with a learning disability who require assessed health and social care services will receive these using a single, lifelong care model, which is flexible and responsive to their needs.

- Every individual who receives services will be involved in co-producing a comprehensive, holistic Life Plan/ Goals, or Service User Care Plan.

- Every individual will have their needs assessed using a rights based and person centred model. This will ensure that services are targeted according to the assessed needs of individuals and will be informed by a regionally agreed and standardised approach.
- Every individual in receipt of services will have a Key Contact Person/Link Worker to offer support if needed through all life changes. They will enable the person to support and signpost the individual to other agencies that can help them achieve their Life Plan goals.

- For children and young people with a long term accommodation need after aged 16, planning should commence early and in a timely manner with Department for Communities for a home suitable into adulthood.

3.2 Key Ambition 2 – Health and Wellbeing

Key Ambition Statement 2 : *I will live a happy, healthy and active life*

3.2.1 Introduction

Knowing how to stay healthy and take steps to care for myself is important to me. There are things I can do to keep myself healthy. I can eat healthy foods and make sure that I do activities, for example, if I can walk or do sports. I should do these regularly and make sure to get outdoors. Spending time with friends and family who make me laugh and who I like can help take care of my emotional health.

"If I'm in busy environment it can be helpful to be seen first or last so fewer people and there is less noise so that upset can be kept to a minimum" (Service User/Carer, WHSCT)

I know myself. My GP is there for me if I need medical help or my GP can ask other health care staff to help too. Health and social care staff will communicate with me directly in a way I understand. They will work with me and my family or someone I

choose to have with me to understand and consider my care and treatment needs. They can offer me help and guidance when I have to attend hospital appointments. My hospital passport is really helpful in helping me to do this too. My Hospital (Health) Passport will help to let hospital staff know all about my abilities and needs. It will help them give me better care when I am in hospital. I will make sure my information is up to date. My Hospital (Health) Passport is owned and kept by me.

3.2.2 Outcome Measures - What Success Looks Like

- Individuals will have the same access to health and social care services with consideration given to reasonable adjustments. They will have access to integrated, community-based health and well-being multi-disciplinary team support in their local areas.

    - Individuals will receive a comprehensive Annual Health Check by a GP.

    - Individuals will have a Health and Social Wellbeing Action/Support Plan which is focused on prevention and early intervention activities, will be person-centred and flexible and be supported by Multi-disciplinary Teams who are appropriately trained. This will include a dedicated Management Plan for any specialist treatment/support/health conditions.

    - Individuals will have access to a Healthcare Facilitator who will support them to identify health and social wellbeing goals and how these will be met. They will offer clear, accessible and practical information about keeping fit and healthy and will include suitable health and wellbeing programmes available through general HSC services and community partners. This will form a key part of the individual's overall Life Plan/Service User Care Plan.

    - Individuals will be supported to access acute general hospital appointments when required. They should have access to an acute Hospital Liaison Service. This is particularly important for those with communication difficulties or specific environmental challenges. Where appropriate an individual's Health Passport will be used to help general HSC services make reasonable adjustments for the individual.

3.3 Key Ambition 3 – Carers and Families

Key Ambition Statement 3: *My carer is supported to help me live my best life.*

3.3.1 Introduction

Family means the people who have known me since I was a child. This can be parents, grandparents, sisters, brothers, cousins, nieces, nephews, aunts and uncles. Sometimes friends or neighbours who we have known our whole lives also feel like family. Not everyone has a large family, but we all belong somewhere. A family often knows me best. They understand me. They know about things that have happened in my life, and they know what I like and what I don't like. Many family members are also carers.

"Family Carers are presently providing the bedrock of social care; they know their family member better than anyone and need recognition as partners." (Carer)

3.3.2 Outcome Measures - What Success Looks Like

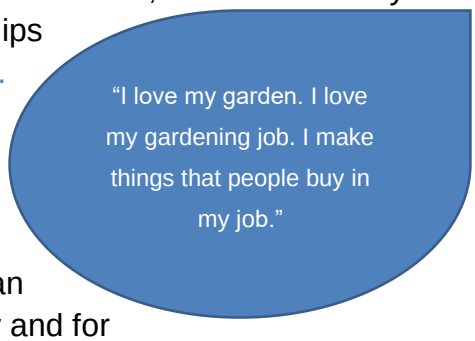
- Family and carers will be offered flexible practical and emotional support to carry out their care giving role, including signposting and support networks.
- Family and carers will be offered a Carer's Support Assessment of their own needs using a standardised Regional Scoring Tool i.e. NISAT / Carer's Conversation Wheel and a Carer Support Plan will be developed.
- When a short break is needed carers will be offered a flexible choice based on assessed need with clear, transparent regional standardised criteria and a menu of options available.
- Family and carers will be offered support by HSC staff to plan for the future life changes of the individual they care for.
- Carers will have access to a local independent advocacy service, when required

3.4 Key Ambition 4 - Meaningful Lives and Citizenship

Key Ambition Statement 4 : *I live in a society that respects my rights and choices as a citizen - where I am enabled to have choices to learn, work, and enjoy my life.*

3.4.1 Introduction

Engaging in meaningful activities and have opportunities to learn, contribute to my neighbourhood, work and build friendships or relationships in my life are important for good health and well-being. As an equal citizen I am entitled to access a range of public and health and social care services that enable me to lead a fulfilling and purposeful life.



I share my life with my family and friends. My friends can come from anywhere. Some people make friends easily and for others it's more difficult. Having places to meet with my friends and make new ones is important to me. Activities in my community can offer me these opportunities. I will have access to a range of opportunities to lead a full life. This will improve the quality of my life.



3.4.2 Outcome Measures - What Success Looks Like

- An Individual's Life Plan/Service User Care Plan will be reviewed with them on an annual basis.
- Individuals will have access to a local independent advocacy service, when required.
- Individuals will have access to activities and services in the community that are meaningful and purposeful. They will have choice and control over the activities in which they participate in.
- Individuals will have training, education and employment opportunities in their local area. This will be developed in partnership with other relevant government departments and providers.
- SDS will be flexible to allow individuals to realise their wishes, goals and dreams for a meaningful life.

3.5 Key Ambition 5 - Home

Key Ambition Statement 5*: I am supported to live in my home.*

3.5.1 Introduction

Home is the place where I can relax and be me, it is important that my home meets my needs. Having the right home helps me do as much as I can for myself, and enable me to be independent should I wish to be. The right type of house in the right place is important to me.

"I like having my own front door key and living on my own. I like being able to go out on my own when I want."
(Individual who accesses services)

I want to have the opportunity to talk regularly about where I live and my housing needs. If I move to a different type of home, I want to be supported to make choices about where I live. I will have housing options made available to me in my preferred location. Organisations will explain clearly and involve me, my family carer and or advocate in the decisions that need to be made. Like everyone else in society, I want to live in an ordinary house.

3.5.2 Outcome Measures - What Success Looks Like

- Individuals will be supported to remain in their own home for as long as possible. This should include considering the assessed present and future needs of the individuals and their environment. These will be included as their Home Plan in the individual's overall Life Plan/Service User Care Plan.

- When a change of home is being considered, the individual, with their family/and or their advocate, will be included in the decision making process about where they live and with whom. They will be offered a regular needs assessment and personal choices relating to their Home Plan and will be reflected in their overall Life Plan.

- Individuals will have access to the same housing options as any other citizen. HSC staff will support the individual to anticipate their future housing needs and liaise with housing services to plan for these at an early stage, making best use of emerging assistive technology.

3.6 Key Ambition 6 - Specialist Assessment and Treatment

Key Ambition Statement 6: *I will enjoy the highest attainable standard of physical and mental health possible and have access to high quality, compassionate, assessment and treatment services, when required.*

3.6.1 Introduction



For me to live a happy, healthy and active life I will be supported by my GP and health care facilitator in primary care, and have access to a team of support professionals in the community close to where I live. However, there may be times when I might need more specialist assessment and treatment services to help me and my carers when I am going through difficulties. This might be because I have a mental health problem, or that I have some behaviours which are difficult for me to manage due to an Autistic Spectrum Disorder, for example. It might also be because I have committed a crime or at risk of committing a crime.

It is important for me to get the right specialist support at the right time. Mental and physical health and communication problems can be more frequent among individuals with a learning disability. If something is wrong or doesn't feel right there are people who can help solve the problem and help me manage my behaviour.

3.6.2 Outcome Measures - What Success Looks Like

- I can remain at home or in a homely setting wherever possible, and I will have access to community based assessment and treatment services so that I am not admitted to hospital if I can be supported to stay at home.

- If I need to be admitted to hospital I will be supported to leave in the shortest time possible. A plan will be put in place to make sure I leave hospital at the right time for me.

4. HOW THE MODEL WILL BE TAKEN FORWARD - STRATEGIC DELIVERY PLAN (SDP)

The Model sets out the vision for the future of learning disability services in Northern Ireland. Publication is only the beginning of the process. There are a number of key mechanisms that now need to be put in place to ensure it is implemented. We call this the Strategic Delivery Plan (SDP).

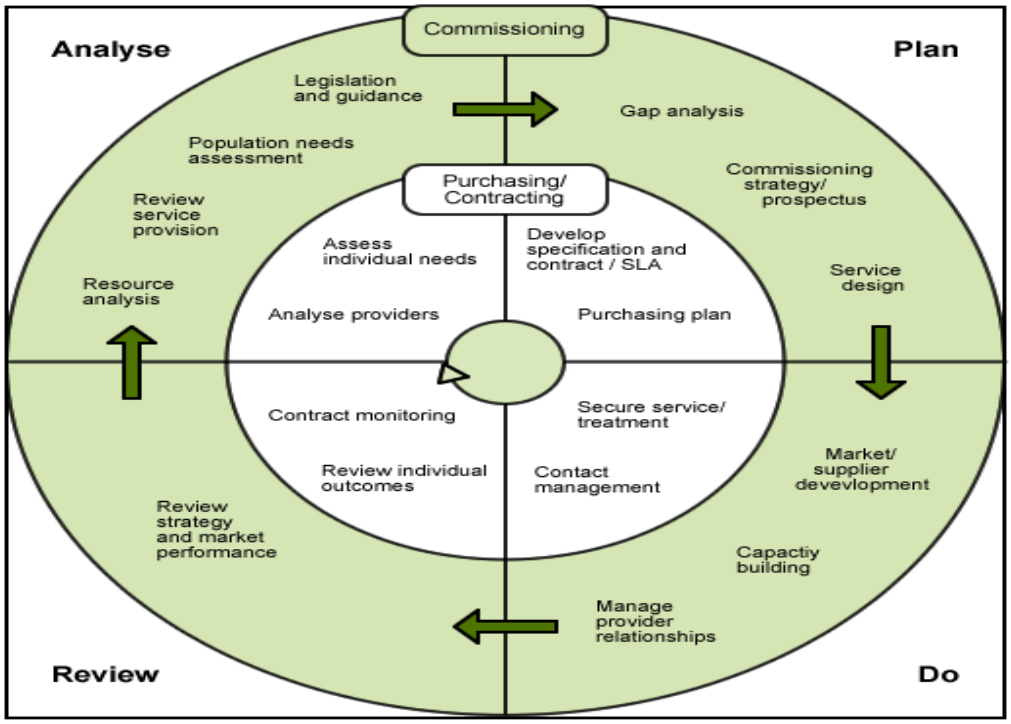
The SDP will be remain a live document and sets out key outcome measures and key actions as described in the Model, as well as how we report progress, defines lead responsibility, identifies resource implications and sets timeframes. A phased approach to delivery is described and will be closely monitored and reviewed to reflect strategic priorities and available resource.

The key outcomes in the SDP recognise the importance of 'Quality of Life' and 'Health and Wellbeing', and in particular, to enable individuals with learning disabilities to live safe, active and valued lives.

Detailed action plans will be developed by the project manager and members of thematic work streams and will be based on the key outcomes/ actions of the SDP. Key Performance Indicators (both qualitative and quantitative) will also be established to effectively monitor the success at delivering the key outcomes. The thematic work streams will be set up in discussion with the Learning Disability Transformation Taskforce (LDTT).

The SDP will also draw on the Institute of Public Care (IPC) Joint Commissioning Model, as also set out in the Scottish "Keys to Life" model, to describe strategic commissioning as "all the activities involved in assessing and forecasting needs, linking investments to agreed desired outcomes, considering options, planning the nature, range and quality of future services, and working in partnership to put these in place;" 'joint commissioning' is "where these actions are undertaken by two or more agencies working together, typically health and other Government Departments, and often from a pooled or aligned budget."

While health and social care are integrated in Northern Ireland, this model offers a structured framework for considering the process that applies to commissioning and monitoring services.



In order to progress the key action as described within the Model, local Action Plans will be developed within each HSC Trust area specifically for learning disability and led by Local Transformation Taskforce(s). The composition of the groups should be 'multi-agency multi-spread' and have individuals living with a learning disability, their families and their carers at the heart of the decision making process. This will be the output of what is more commonly referred to as the 'strategic commissioning' process. Strategic commissioning is the term used for all the activities involved in assessing and forecasting needs, linking investment to agreed outcomes, considering options, planning the nature, range and quality of future services and working in partnership to put these in place.

4.1 Reporting Infrastructure

Whilst all Government Departments have a part to play in an individual's life, in terms of service provision, the Department of Health has a primary responsibility for the delivery of this Model. There must be, however, accountable co-operation, collaboration and partnership working across all Departments if the Model is to be implemented in full.

Whilst awaiting the formation of a cross-Departmental group for Learning Disability, the existing Mental Health and Learning Disability Improvement Board will oversee the implementation of the Model against the key Ambitions, Outcome Measures and Key Actions set out in the Strategic Delivery Plan (SDP).

The LDTT will be established to oversee all developments relating to both the Model itself, and other future developments relating to learning disability in general. A Terms of Reference for the group will be written. This group will include assistant directors, clinical leads, Department of Health policy and professional leads, voluntary sector representation, individuals with lived experience, carers, and will have HSC oversight and other key stakeholders.

A Learning Disability Champion and Care/ Service User Reference group will sit independently alongside the LDTT and provide an advisory role from service users and carers with lived experience.

The group will convene a number of Thematic Work streams based around the Key Ambition Statements and other associated priorities, to take forward the Strategic Delivery Plan. (See Appendix 8 for details of proposed reporting arrangements).

A Project Manager employed by the HSCB will oversee the implementation of the Model in partnership with all the key stakeholders, on behalf of the LDTT. The Project Manager will report directly to the Social Care Lead for Learning Disability.

4.2 Outcomes Based Reporting

Similar to the Programme for Government (PfG) and to other strategies and models being developed at present, the Outcomes Based Accountability (OBA) approach will be employed to implement and monitor the Model going forward, focusing our attention on the results we plan to achieve through the Implementation Phase.

For each Key Ambition set out in the Model we will ask the three key OBA questions:

- How much did we do?
- How well did we do it?
- Is anyone better off?

The “We Matter” Plan on A Page illustrates this, as shown in Annex D.

For our Key Ambition Statements, Outcome Measures and Key Actions we will report on progress ‘using OBA terminology’ or ‘turning the curve’ i.e. the actions we need to take to improve the lives of individuals with a learning disability.

To ensure consistency of approach, the LDTT will adopt the same reporting mechanisms and templates as currently used by Adult Mental Health Services, to report progress on the Model to the Mental Health and Learning Disability Improvement Board using the Outcomes Delivery Plan template, as per Annex A. This will ensure consistency of approach across Programmes of Care.

5. REFERENCES

To be completed in due course

6. ANNEXES

Annex A – “We Matter” Adult Learning Disability Service Model Strategic Delivery Plan

Annex B - Health and Social Care Policy: Summary Overview 2011 – 2019

Annex C – Key Elements of Regional Models – England

Annex D – Key Elements of Regional Models – Wales

Annex E – Key Elements of Regional Models - Scotland

Annex D – “We Matter” Plan on A Page

Annex A – "We Matter" Adult Learning Disability Service Model Strategic Delivery Plan

The following Strategic Delivery Plan sets out the key actions and processes to ensure the Model is implemented. We will measure it against Outcome Measures and Key Actions developed across each of the 6 Key Ambition Statements:

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
Life Changes ***I am prepared and supported through important changes in my life.***	**1.1**	Individuals with a learning disability who require assessed health and social care services will receive these using a single, lifelong care model, which is flexible and responsive to their needs.	• We will develop a rights based and person centred lifelong care pathway for learning disability services. A lifelong care plan will be created together with individuals and their respective carers and families and will include key transitions. • We will ensure services are adequately resourced with Transition Workers/Adult Link Workers to support ALL transition points and across all agencies. • We will continue to co-operate with the Education Authority and Department of Communities to provide health and social care services to individuals with a learning disability in Education and further education.	**LDTT** **LDTT** **DoH/DE**	**TBC** **Scoping Exercise required**	**Year 1** **Year 2** **Year 1**
	1.2	Every individual who receives services will be involved in co-producing a comprehensive, holistic Life Plan/ goals.	• We will design and develop a co-produced, standardised Life Plan Tool for regional use. • We will design and implement a Transition Pathway for all transition points.	**LDTT** **LDTT**		**Year 1** **Year 1**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
	1.3	Every individual will have their needs assessed using a rights based and person centred model. This will ensure that services are targeted according to the assessed needs of individuals and will be informed by a regionally agreed and standardised approach.	• We will ensure there is a regionally agreed rights based and person centred model using a thresholds of need approach. • We will ensure there are care pathways and associated supports for all individuals who are assessed under the rights based and person centred thresholds of need approach.	**LDTT** **LDTT**		**Year 1** **Year 1**
	1.4	Every individual in receipt of services will have a Key Contact Person/Link Worker to offer support if needed through all life changes. They will enable the person to support and signpost the individual to other agencies that can help them achieve their Life Plan goals.	• We will co-produce regionally consistent easily accessibly information and communications resources on services from diagnosis/birth of a child to support transition process from childhood to adulthood, and other life changes • We will consider the recommendations and roll out of the Future Planning Programme (Taggart et al.) for carers and HSC providers. • We will scope out community resources to ensure they are meeting older individuals needs and those requiring physical rehabilitation in hospital and the community. • We will ensure the Regional Dementia Care Pathway is implemented. • We will ensure the provision of palliative care services to all individuals with a learning disability	**LDTT** **LDTT** **LDTT** **PCOP** **HSCTs**	**£100k** **Scoping Exercise £20k** **Scoping Exercise**	**Year 1 & 2** **Year 1** **Year 1** **On-going** **On-going**
	1.5	Children and young people with a long term accommodation need	• We will **engage with other Government Departments** and agencies in relation to	**DoH/DE/ DfC/**		**Year 1**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
		after aged 16, planning should commence in partnership with Department for Communities in a timely manner, for a home suitable into adulthood.	education, leisure, employment, accommodation and training opportunities in support of goals to set out in an individual's Life Plan to ensure that they plan inclusively.	**DoE/ Voluntary Sector**		
Health and Wellbeing ***I will live a happy, healthy and active life***	**2.1**	Individuals will have the same access to health and social care services with consideration given to reasonable adjustments. They will have access to integrated, community-based health and well-being multi-disciplinary team support in their local areas.	• We will ensure that health and social wellbeing goals will be included in the Life Plan and programmes are inclusive and resourced at a local level. (possible expansion of DES) • We will explore and pilot a Health and Wellbeing Co-ordinator post in each locality to oversee and monitor Health and Social Wellbeing Action/Support Plans, including partnerships with other Government Departments. • We will ensure that there is regionally consistent and appropriately resourced staffing of Multi-disciplinary Teams. These staff should ensure that general HSC services provide equity of access and equality of outcomes for individuals with learning disabilities. • We will pilot specialist Learning Disability support in Integrated Care Multi-Disciplinary Teams.	**LDTT** **LDTT/ Voluntary Sector** **LDTT** **LDTT/IC**	 **Pilot x 1 locality (2 x Band 6)** **Scoping Exercise** **Pilot (1 x Band 7 per Trust)**	**Year 1 & 2** **Year 1** **Year 2** **TBD**
	2.2	Individuals will receive a comprehensive Annual Health Check by a GP.	• We will fully implement recommendations from Hospital Passport Phase II Evaluation. • We will ensure that the Encompass Programme design for Learning Disability Services incorporates a mechanism to record and monitor health and social care data, as part of an	**LDTT** **LDTT**		**Y1 & 2** **TBD**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
			individual's Annual Health Check.			
	2.3	Individuals will have a Health and Social Wellbeing Action/Support Plan which is focused on prevention and early intervention activities, will be person-centred and flexible and be supported by Multi-disciplinary Teams who are appropriately trained. This will include a dedicated Management Plan for any specialist treatment/support/health conditions	• We will develop a Positive Behaviour Support framework for use in both Community Specialist Services (community and inpatient) and in Community Learning Disability Teams, where appropriate. • We will ensure each HSC Trust has an Epilepsy Nurse Specialist. • We will ensure there are healthcare pathways for both specialist learning disability and general specialist services. • We will consider the creation of a LeDeR project to review and monitor performance against premature deaths, as part of the Learning Disability Observatory/Network Transformational Change project.	**LDTT** **LDTT** **LDTT** **LDTT**	**Scoping Exercise to determine required budget** **Band 7 x 5 HSCTs** **TBC**	**Year 1 & 2** **Year 1** **Year 1** **Year 2**
	2.4	Individuals will have access to a Healthcare Facilitator who will support them to identify health and social wellbeing goals and how these will be met. They will offer clear, accessible and practical information about keeping fit and healthy and will include suitable health and wellbeing programmes	• We will evaluate and, based on findings, explore the role of multi-disciplinary Healthcare Facilitators, and include a pilot Healthcare Assistant role.	**LDTT**	**Band 4 x 5 HSCTs**	**Year 2**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
		available through general HSC services and community partners. This will form a key part of the individual's overall Life Plan.				
	2.5	Individuals will be supported to access acute general hospital appointments when required. They should have access to an acute Hospital Liaison Service. This is particularly important for those with communication difficulties or specific environmental challenges. Where appropriate an individual's Hospital Passport will be used to help general HSC services make reasonable adjustments for the individual	• We will ensure that a regional Acute Hospital Liaison Service is established. • We will ensure there is adequate investment in hospital estates to fully achieve reasonable adjustments and communication standards.	**LDTT** **LDTT**	**4 x Band 7's** **TBD**	**Year 1** **On-going**
Carers and Families ***My carer is supported to help me live my best life.***	**3.1**	Family and carers will be offered flexible practical and emotional support to carry out their care giving role, including signposting and support networks.	• We will develop a Regional Carer Support Plan for carers that will include physical, social, emotional and carer supports. • We will produce a communication and information resource, including a co-produced regional website. This will provide information about services regionally and locally. • We will co-produce a regional programme to share relevant health and social care training to support carers in their role.	**LDTT** **LDTT** **LDTT**	**TBC** **£50-100k** **£150k**	**Year 1** **Year 1 & 2** **On-going**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
	3.2	Family and carers will be offered a Carer's Support Assessment of their own needs using a standardised Regional Scoring Tool i.e. NISAT / Carer's Conversation Wheel and a Carer Support Plan will be developed for Carers.	• We will work with other agencies to offer access to local Carer Support Networks.	**LDTT/ Voluntary Sector**	**£200k**	**Year 1 & 2**
	3.3	When a short break is needed carers will be offered a flexible choice based on assessed need with clear, transparent regional standardised criteria and a menu of options available.	We will consider the findings of the Review of Short Breaks (2019), and agree and implement regionally consistent criteria for short break options. • We will review and deliver planned short breaks options for individuals and carers based on assessed need. • We will develop a regionally agreed pathway and criteria for emergency short breaks.	**LDTT** **LDTT** **LDTT**	**Scoping Exercise** **Scoping Exercise**	**Year 1** **Year 1** **Year 1**
	3.4	Family and carers will be offered support by HSC staff to plan for the future life changes of the individual they care for.	• Based on findings from the evaluation of the Carer Consultant Role in Belfat HSC Trust, HSC will consider and introduce any recommendations for scale and spread across Northern Ireland to ensure a Carer Consultancy Model is in place. • We will consider the recommendations and roll out of the Future Planning Programme (Taggart et al.) for carers and HSC providers • We will ensure that the Shared Lives NI framework is developed further and utilised as a	**LDTT** **LDTT** **Shared Lives**	**£200k** **As per 1.4** **Nil**	**Year 1 & 2** **As per 1.4** **On-going**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
			highly personalised alternative to residential and other forms of care.			
	3.5	Carers will have access to a local independent advocacy service, when required.	• We will ensure that there is regional consistency in contractual independent advocacy services and explore a range of different models/approaches.	**LDTT/ Voluntary Sector**	**TBC(Enhance existing contracts depending upon model of choice)**	**Year 1 & 2**
Meaningful Lives and Citizenship ***I live in a society that respects my rights and choices as a citizen - to learn, work, and enjoy my life*.**	**4.1**	An Individual's Life Plan will be reviewed with them on an annual basis.	• We will ensure that Royal College of Speech and Language Therapists Five Communication Standards (2013) are adopted by all organisations.	**LDTT**		**On-going**
	4.2	Individuals will have access to a local independent advocacy service, when required.	• We will ensure that there is regional consistency in contractual independent advocacy services and explore a range of different models/approaches.	**LDTT/ Voluntary Sector**	**Scoping Exercise**	**Year 1 & 2**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
	4.3	Individuals will have access to activities and services in the community that are meaningful and purposeful. They will have choice and control over the activities in which they participate in.	• We will ensure adherence to the regulations and guidance set out in the Mental Capacity (Deprivation of Liberty) Regulations (Northern Ireland) (2019), and ensure there is education and support packages for carers and staff for implementation. • We will contract activities and services from local health and social care providers in line with assessed need. This will involve regional operational consistency and flexibility in approach. • We will ensure full implementation of the Regional Day Opportunities Review (2016). • We will undertake a Day Care scoping exercise to determine current and future needs. • We will develop peer support networks for individuals in their own communities. • We will commission research focusing on individual's sense of well-being with specific focus on loneliness and sense of connection. • We will implement the Regional Forensic Care Pathway.	**DoH** **LDTT/ Voluntary Sector** **HSCTs** **LDTT** **Voluntary Sector** **DoH** **FMCN**	**Nil** **TBC** **TBC** **Cost neutral** **£250k** **£30k** **TBD**	**On-going** **Years 1-3** **On-going** **Year 1** **Year 2** **Year 2** **TBD**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
	4.4	Individuals will have training, education and employment opportunities in their local area. This will be developed in partnership with other relevant Government Departments and providers.	• We will explore the role of a Day Opportunities Hub Co-ordinator or sometimes known as a Community Navigator, to work in partnership with other agencies/Government Departments to develop and sustain a range of flexible and appropriate programmes, in areas such as volunteering, education, training and employment. • Public, independent and voluntary sector organisations will develop mechanisms and agree targets for providing appropriate job opportunities for individuals with a learning disability. • Public, independent and voluntary Sector organisations will ensure that individuals with a learning disability have access to a range of transport options for social, leisure, health, training, day opportunities, volunteering and employment opportunities. This will require collaborative working and resources from across Government Departments.	**LDTT/ Voluntary Sector** **DoH/DfC** **DoHDfC/ DoE**	**2 x Band 6's per locality (10)**	**Year 1 & 2** **Year 1 & 2** **Year 1 & 2**
Home	**5.1**	Individuals will be supported to remain in their own home for as long as possible. This should include considering the assessed present and future needs of the individuals and their environment. These will be included as their	• We will develop a regional standardised Home Plan template for individuals. • We will offer early assessment of health and social care needs in relation to future housing demand. • We will explore the potential for pilot projects to test out new innovative models for example,	**LDTT** **LDTT** **DfC**		**Year 1** **Year 1** **Year 1 & 2**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
I am supported to live in my home		Home Plan in the individual's overall Life Plan	nursing/ MDT supports aligned to private tenancies. • We will continue to explore and scope out the use of technological solutions to support community living, with key partners. • We will work with Department for Communities to explore broadening the definition used in the Disabilities Facilities Grant to improve accessibility for an individual with a disability, to include physical needs of those individuals who have behaviours that challenge, dementia and those with autism.	**All** **DoH/DfC**		**Year 1 & 2** **Year 1**
	5.2	When a change of home is being considered, the individual, with their family/and or their advocate, will be included in the decision making process about where they live and with whom. They will be offered a regular needs assessment and personal choices relating to their Home Plan will be reflected in their overall Life Plan.	• We will continue to work in partnership with Department for Communities (DfC) to explore and offer flexible housing options for individuals with learning disability to support future planning based on specific projected housing need and demand.	**DoH/DfC**	**TBD**	**On-going**
	5.3	Individuals will have access to the same housing options as any other citizen. Health professionals, such as Occupational Therapists will support the individual to anticipate	• We will engage with Department of Communities to ensure that the Housing Adaptation Officer role continues to develop appropriate housing specifications for individuals. • Public Sector bodies will work in partnership to	**DfC** **DoH/DfC**	**50% funding per locality** **50% funding £50k**	**Year 2** **Year 2**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
		their future housing needs and liaise with housing services to plan for these at an early stage, making best use of emerging assistive technology.	develop a Regional Learning Disability Housing Lead role with funding control/influence of build and design to meet the accommodation needs of individuals with learning disability, whether general or bespoke housing.			
Specialist Assessment and Treatment ***I will enjoy the highest attainable standard of physical and mental health possible and have access to high quality, compassionate, assessment and treatment services, when required***	**6.1** **6.2**	If I need specialist services related to my learning disability this should be provided in the least restrictive setting possible and ideally in the community. I can remain at home or in a homely setting wherever possible, and I will have access to community based assessment and treatment services so that I am not admitted to hospital if I can be supported to stay at home.	Work is currently underway to develop Community based assessment and treatment services for people with a learning disability and/or complex needs, Autistic Spectrum Disorders and those within the criminal justice system. This work will link to the consideration of acute hospital provision for individuals who require specialist hospital admission due to mental health problems or behaviours that challenge. The key recommendations of this work will feature in the Model's Delivery Plan, and will be published later in the year as an Annex to the Model itself.	**CAT Task & Finish Group**	**TBC**	**In line with Model implementation timeframes**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
Ideas for Transforming Change						
Learning Disability Champion		Outcome measures to be determined by thematic work stream.	• DoH to explore role and function	**DoH**	**£150k**	**Year 1**
Learning Disability Innovation Fund		Outcome measures to be determined by thematic work stream.	• Design Application Process • Develop Application criteria • Design Evaluation process	**DoH**	**TBD Mental Health £500k**	**Commence in Y2**
Learning Disability Network/ Observatory		Outcome measures to be determined by thematic work stream.	• Communications Thematic Work Stream to scope and cost the model • Employ a Network Co-Ordinator	**HSCB**	**Band 7 + B3**	**Year 2**
Design Regional Register/ Database		Outcome measures to be determined by thematic work stream.	• Design Team in place • Engage with Encompass to develop specification	**HSCB/HSCTs**	**Band 5 LD Informatics x 5 Trusts**	**Year 1**
Design a standard Minimum Data Set and Associated Informatics Framework to Support the Collection of Data to Deliver the Model		Outcome measures to be determined by thematic work stream.	• Informatics Thematic Work Stream to develop and pilot template • Engage with Encompass to develop specification	**HSCB/HSCTs**	**As above**	**Year 1**
Develop Standardised Reporting Documentation and Systems		Outcome measures to be determined by thematic work stream.	• Informatics Thematic Work Stream to scope, design and test • Engage with Encompass to develop specification	HSCB/HSCTs	As above	**Year 1** **On-going**
‘ We Matter’ Training		Outcome measures to be	• Task & Finish Group set up to design and			**Year 1 & 2**

Ambition Statement	No	Outcome Measures	Key Actions	Lead	Resource Requirements	Implementation Phase
and Development Framework and Regional Shared Knowledge Network		determined by thematic work stream.	cost framework	DoH/HSCB / PHA	TBC (check 'Working Together, Learning Together Framework in MH Services')	
Information Resources/Guide		**Outcome measures to be determined by thematic work stream.**	• Communications Thematic Work Stream to explore digital and hard copy resources	All	As per 3.1	**On-going**
Regional Website		**Outcome measures to be determined by thematic work stream.**	• Communications Thematic Work Stream to explore and cost options	All	As per 3.1	**On-going**
People's Parliament		**Outcome measures to be determined by thematic work stream.**	• Scoping exercise to explore options	HSCB Project Mgr	TBC	**Year 1 & 2**

Reporting Progress

For each Key Outcome set out in the Model we will ask the 3 key OBA questions:

- How much did we do?
- How well did we do it?
- Is anyone better off?

Example

Key Outcome 1 – Life Changes							
	KEY ACTIONS	**HOW MUCH WILL WE DO?**	**HOW WELL WILL WE AIM TO DO IT?**	**HOW WILL WE KNOW IF ANYONE IS BETTER OFF?**	**HOW WILL WE MEASURE IT**	**WHEN?**	**OWNERS**
1.1							
1.2							

The “We Matter” Plan on A Page at **Annex E** also sets out a High Level example of this type of OBA reporting.

Annex B - Health and Social Care Policy: Summary Overview 2011 – 2019

REF	POLICY / STRATEGY	RELEVANT INFORMATION
1	*Quality 2020: A 10-Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland* (DHSSPS, 2011b)	• Underpinned by **3 core themes**: ○ Safety ○ Effectiveness ○ Patient and Client Focus
2	*Transforming Your Care: A Review of Health and Social Care in Northern Ireland* (DHSSPS, 2011a)	• Proposes model for future service delivery (see Figure 3 below) and 99 recommendations for change across 16 themes, including the following with relevance to learning disability: ○ Quality and outcomes to be the determining factors in shaping services. ○ Confirming the closure of long-stay institutions in learning disability and mental health with more impetus into developing community services for these groups ('resettlement' - see section 3.14 above). • Identifies 12 principles for change: ○ Placing the individual at the centre of any model by promoting a better outcome for the service user, carer and their family ○ Using outcomes and quality evidence to shape services ○ Providing the right care in the right place at the right time ○ Population-based planning of services ○ A focus on prevention and tackling inequalities ○ Integrated care – working together

REF	POLICY / STRATEGY	RELEVANT INFORMATION
		○ Promoting independence and personalisation of care ○ Safeguarding the most vulnerable ○ Ensuring sustainability of service provision ○ Realising value for money ○ Maximising the use of technology ○ Incentivising innovation at a local level • Highlights the need for a new service framework setting out standards of care for those with learning disability. This was subsequently published in 2015 (see section 3.16 below).
3	*Making Life Better: A Whole System Strategic Framework for Public Health 2013-2023* (DHSSPS, 2014)	• Vision: A whole system approach to increasing personal control, improving health and wellbeing, reducing health inequalities across the population: "*All people are enabled and supported in achieving their full health and wellbeing potential. The aims are to achieve better health and wellbeing for everyone and reduce inequalities in health.*"
4	*Systems, Not Structures – Changing Health and Social Care (The Bengoa Report)* (DOH, 2016)	• Guided by 'The Triple Aim': ○ Improving the patient experience of care (including quality and satisfaction); ○ Improving the health of populations; and ○ Achieving better value by reducing the per capita cost of health care. • Key observation: (despite the commitments/vision outlined above) *"The present model of care in Northern Ireland is not delivered on a population agenda. It is struggling to provide continuity of care in an organised way and the organisations delivering it are still operating in silos. There is a need to move away from hospital centred care to a more integrated model."* • Provides a succinct transformation model that may be useful in the development of the new Adult Learning Disability Service Model (see Figure 4 below). • Makes 14 recommendations for transformation focused on three components for practical implementation which, though they have different life spans, are noted to be urgent and connected, and should be launched simultaneously:

REF	POLICY / STRATEGY	RELEVANT INFORMATION
		○ Driving the system towards Accountable Care Systems (integrating – by agreement, and without the need for structural reform – the 'provider sector', to take collective responsibility for all health and social care for a given population and with a joint capitated budget linked to population based outcomes under agreement with the commissioning system to be decided by the Minister) ○ Aggressively scale up good practice ○ Rationalisation and stabilisation
5	*NI Executive Children's Strategy 2019-2029*	• Key strategic driver which requires the NI Executive to promote co-operation across relevant bodies and to adopt a strategy to improve the wellbeing of all children and young people • *Will require all authorities to co-operate in the delivery of transition provision from Children's to Adult Services*
6	*Health and Wellbeing 2026 – Delivering Together* (DOH, 2017)	• Policy response to Bengoa Report and recommendations for transformation. • Identifies 18 actions to be taken forward over the first 12 months, including consultation on transformation of adult social care services (no specific reference to learning disability) • Aligns to Draft Programme for Government (see section 3.20 below).

Annex C - Key Elements of Regional Models – ENGLAND

The key documents and strategic developments outlined below have informed and driven the **Transforming Care** process, which has been undertaken following the Department of Health investigation in 2012 into staff abuse of patients with learning disabilities and autism at Winterbourne View Hospital. Collectively, the documents reviewed comprise the overarching strategic direction and priorities of NHS England and its partners in relation to the delivery of learning disability services in England.

These developments are presented in a logical order in terms of the sequence of information and ideas discussed, rather than chronological order by publication date.

1 *Transforming Care For People With Learning Disabilities – Next Steps* (Association Of Directors Of Adult Social Services Et Al, 2015)

1.1 This report is issued by the Transforming Care delivery board. It outlines key steps envisaged to establish the basis for long-term transformation. These steps are organised into five work streams, shown in Table 1 below.

Table 1: NHS England Transforming Care Work Streams

REF	WORK STREAM	DETAILS
1	**Empowering people and families**	Consulting on a range of measures to strengthen people's rights in the health and care system
2	**Getting the right care in the right place**	Developing a clearer model for health and care services, describing outcomes to be achieved with associated performance indicators, what kind of services should be in place (both inpatient capacity and community-based support), and service standards.
3	**Regulation and inspection**	Tightening of regulation and inspection of providers, and strengthening providers' corporate accountability, responsibility, and management to improve quality of care.
4	**Workforce**	Improving care quality and safety by raising workforce capability.
5	**Data and information**	Ensuring the right information is available at the right time to the people who need it – this focus underpins all the work stream activity described above.

1.2 The document also includes a summary overview of the report produced by Sir Stephen Bubb on behalf of NHS England (the Bubb report) in November 2014, which makes recommendations for organisations across the health and social care system for accelerating the transformation process. These recommendations cover four key areas, as follows:

- Strengthening the rights of people with learning disabilities and their families.
- Improving commissioning, with the introduction of a mandatory commissioning framework (as per the Ensuring quality services report discussed at 3.2 below).
- Closing inpatient institutions.
- Building capacity in community services.

2 *Ensuring Quality Services: Core Principles For The Commissioning Of Services For Children, Young People, Adults And Older People With Learning Disabilities And/Or Autism Who Display Or Are At Risk Of Displaying Behaviour That Challenges* (NHS England et al, 2014)

2.1 This 'Core Principles Commissioning Tool' reflects extensive engagement and consultation for service improvement conducted as part of the Transforming Care process.

2.2 The document describes 14 core principles that "should be present across all education, health, and social care services being accessed by children, young people, adults, and older people with learning disabilities and/or autism who either display or are at risk of displaying behaviour that challenges" (p.7).

2.3 The core principles are underpinned by a consistent emphasis on the value of involving service users, carers, and staff in the development of improved services. Table 2 below shows the 14 themes covered by these principles.

Table 2: NHS England Core Principles Commissioning Tool

REF	PRINCIPLE
1	Positive Behavioural Support
2	A whole systems life course approach
3	Prevention and early intervention
4	Family, carer and stakeholder partnerships
5	Function based holistic assessment
6	Behaviour that challenges is reduced by better meeting needs and increasing quality of life
7	Support for communication
8	Physical health support
9	Mental health support
10	Support for additional needs
11	Specialist local services
12	Safeguarding and advocacy
13	Workforce
14	Monitoring quality

2.4 The authors argue the application of these principles should result in:

- Improved quality of life for the service users and their families.
- Reduced prevalence and incidence of behaviour that challenges among these service users.
- Reduced numbers of individuals placed in restrictive settings inappropriate to their needs.
- Reduced incidence of inappropriate use of psychoactive medication, restraint, and seclusion to manage behaviour that challenges.

2.5 The document includes an extensive reference list of relevant background information, online resources, and further reading. In addition, a useful synopsis of the 'Detailed Pathway and Policy Specification' recommending specific actions for individuals and organisations is included in the Appendix. All of this information forms the basis for subsequent strategy and implementation developments, discussed below.

3 Building The Right Support: A National Plan To Develop Community Services And Close Inpatient Facilities For People With A Learning Disability And/Or Autism Who Display Behaviour That Challenges, Including Those With A Mental Health Condition (NHS England et al, 2015)

3.1 This document builds upon the developments outlined above to outline the NHS England agenda for achieving what it describes as a necessary “change in culture” and “shift in power to individuals” to deliver sustainable positive change in the delivery of improved, person-centred services for individuals with a learning disability and/or autism.

3.2 Key points that stand out in this document include:

- An emphasis on the “highly heterogeneous” or diverse characteristics of the population referred to as ‘people with a learning disability and/or autism’. The authors argue that it is important to respect and reflect that diversity in the improved service model.
- A focus on reducing the need for inpatient services, which is quantified over time and sets a target for “closing, at minimum, between 35%-50% of inpatient provision nationally by March 2019” (p. 27).
- An overview of the proposed new service delivery model, underpinned by nine core principles – this is published in more detail alongside the document – see point 2.4 below.
- The description of new Transforming Care Partnerships – collaborations of Clinical Commissioning Groups, local authorities, and NHS England specialised commissioners – to drive forward the programme of change by implementing the new service delivery model.

3.3 The vision set out in this document is to deliver a service model that can better meet the complex and diverse needs of this heterogeneous population, both now and with increasingly positive impact in the future.

4 Supporting People With A Learning Disability And/Or Autism Who Display Behaviour That Challenges, Including Those With A Mental Health Condition: Service Model For Commissioners Of Health And Social Care Services (NHS England Et Al, 2015)

4.1 This document describes in detail the new service delivery model outlined at point 3 above.

4.2 This model builds on previous service commitments to focus on rights, independence, choice, and inclusion for people with a learning disability and/or autism. It promotes a vision of a whole-system response that enables effective multi-disciplinary and multi-agency working to deliver access to high quality services and support based on individual need.

4.3 In line with the provisions of the Children and Families Act 2014[1] and the Care Act 2014,[2] which focus on outcomes, personalisation, and wellbeing, this model focuses on strengthening support in the community and preventative support to avoid crises and enable people to be active members of their communities.

4.4 The model was developed by a reference group of stakeholder leads. Through a process of engagement, NHS England, the Local Government Association, and the Association of Directors of Adult Social Services consulted with clinicians, commissioners, providers, families, and people with a learning disability and/or autism. The document clarifies that NHS England anticipates the model should be implemented over a 3 year period following its publication. It is therefore currently due for review/evaluation.

[1] See: http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted
[2] See: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

4.5 The model is underpinned by a human rights-oriented value base of five 'golden threads' as outlined in Table 3 below.

Table 3: NHS England Service Model: Vision / Value Base

REF	VALUE	DETAILS
1	**Quality of life**	People should be treated with dignity and respect – there should be a focus on supporting people to live in their own homes, supported by local services
2	**Keeping people safe**	People should be supported to take positive risks whilst ensuring they are protected from potential harm – there should be a culture of transparent and open reporting, ensuring lessons are learned and acted upon
3	**Choice and control**	People should have choice and control over their own health and care services – people should be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interests involving them as much as possible and those who know them well
4	**Support and interventions**	These should always be provided in the least restrictive manner – where an individual needs to be restrained either for their own protection or the protection of others, restrictive interventions should be for the shortest time possible and using the least restrictive means possible
5	**Equitable outcomes**	Individual outcomes should be comparable with the general population, addressing the determinants of health inequalities, and delivered as far as possible by mainstream services adjusted where necessary in line with Equality Act legislation[3]

4.6 These values inform nine core principles around which the model is organised, and which set the direction for specific actions required by health and social care commissioners.

4.7 A distinguishing element of these core principles is that they acknowledge a small percentage of people with a learning disability and/or autism engage in behaviour that may lead to contact with the criminal justice system, and potentially diversion to a hospital setting, and that the specific needs of this

[3] See: https://www.legislation.gov.uk/ukpga/2010/15/contents

group have not always been recognised. Core Principle 8, "*If I need it, I get support to stay out of trouble*," addresses this point specifically.

4.8 The nine core principles are outlined in Table 4 below.

Table 4: NHS England Service Model: Core Principles

REF	PRINCIPLE	SUMMARY NOTES
1	**I have a good and meaningful everyday life**	Everyone should: • be included in activities and services that enable them to lead a good and meaningful everyday life; • have access to education, training, and employment (including supported internships) which they can access in their local area; and • have the opportunity to develop and maintain good relationships with other people.
2	**My care and support is person-centred, planned, proactive, and coordinated**	• Local health and care services should develop a dynamic register based on sophisticated risk stratification of their local populations. • Everyone should have a single person centred care and support plan. • Everyone should be offered a named local care and support navigator or keyworker.
3	**I have choice and control over how my health and care needs are met**	• Everyone should receive information about their care and support in formats that they can understand (see Accessible Information Standard[4]). • Individuals, and where appropriate families/carers, should be integral partners in care and planning discussions. • People should have access to different types of independent advocacy.
4	**My family and paid support and care staff get the help they need to support me to live in the community**	All families or carers who are providing care and support for people who display behaviour that challenges should be offered: • practical and emotional support and access to early intervention programmes; • carers' assessment and advocacy support; and

[4] See: https://www.england.nhs.uk/ourwork/accessibleinfo/

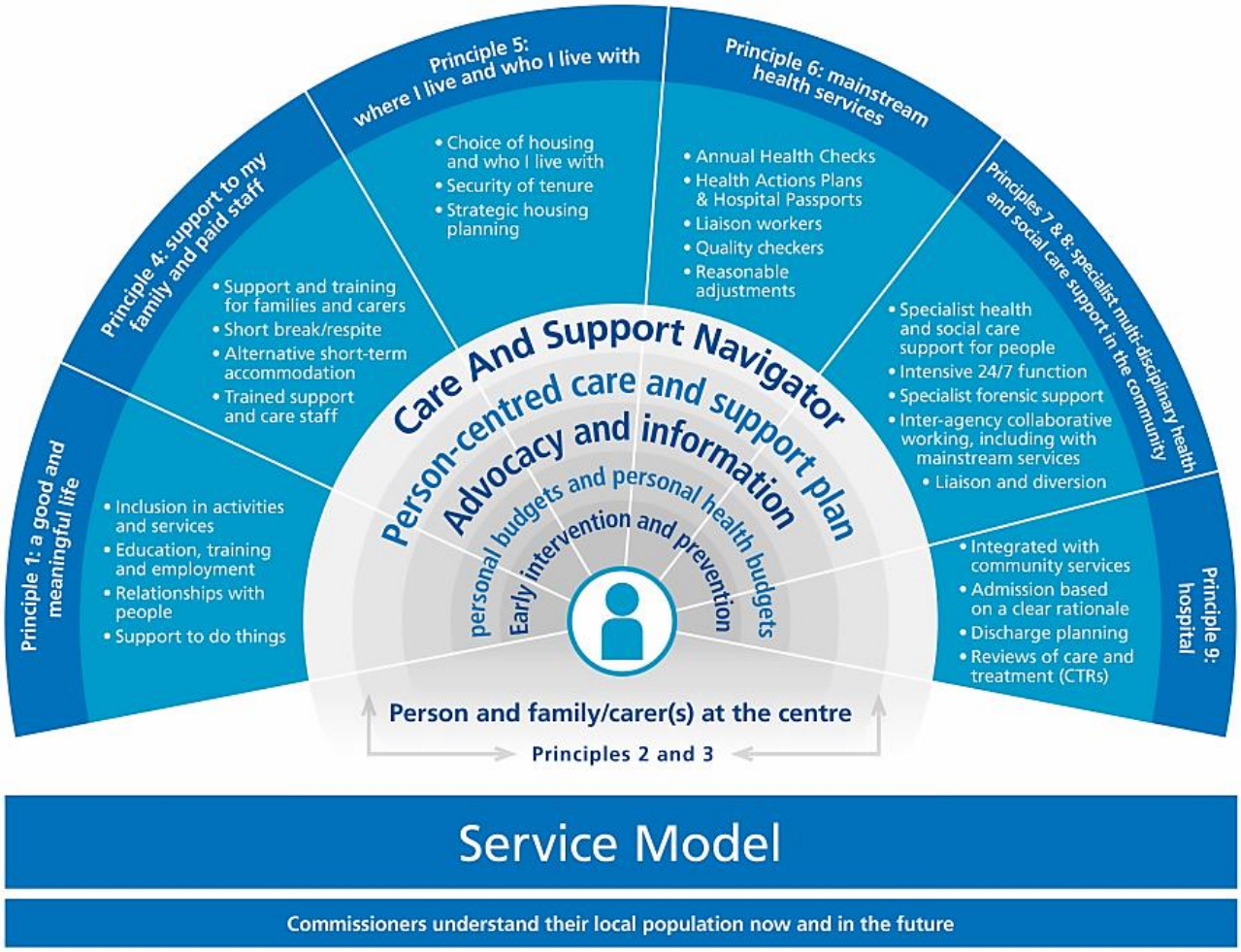
REF	PRINCIPLE	SUMMARY NOTES
		• access to suitable short breaks/respite. In addition: • Alternative short term accommodation should be available to people. • Everyone in receipt of a social care package should have access to paid, and suitably trained and experienced support and care staff. • Local authorities should use Market Position Statements with an explicit focus on people with a learning disability and/or autism, and preferred providers with minimum standards and competencies.
5	**I have choice about where I live and who I live with**	• People should be offered a choice of housing, including small-scale supported living. • Everyone should be offered settled accommodation. • Commissioners should work closely with housing colleagues to ensure future needs of this group are understood, considered, and planned for strategically as part of local housing strategies.
6	**I get good care and support from mainstream health services**	• Everyone with a learning disability over age 14 should be offered an Annual Health Check, have a Health Action Plan, and where appropriate, a Hospital Passport to help mainstream NHS services make reasonable adjustments to meet specific needs and ensure equitable health outcomes. • Everyone should expect NHS services to employ clearly identified and readily accessible healthcare liaison workers with specialist knowledge and skills in working with people with a learning disability and/or autism. • Everyone should expect quality checker schemes and annual audits to be implemented, ensuring mainstream health services serve them appropriately, evaluate delivery and outcomes, and deliver real improvements.
7	**I can access specialist health and social care support in the community**	• Everyone should have ready access to integrated, community-based, specialised multidisciplinary health and social care support for people with a learning disability and/or autism that is responsive to the needs of the individual. • Anyone who required additional support to prevent or manage a crisis should have access to hands-on intensive 24/7 multi-disciplinary health and social care support at home or in other appropriate community

REF	PRINCIPLE	SUMMARY NOTES
		settings. • Interface between specialist routine multi-disciplinary support services and intensive support should be seamless
8	**If I need it, I get support to stay out of trouble**	• People who have/may be at risk of coming into contact with the criminal justice system should have access to the same services aimed at preventing or reducing anti-social or offending behaviour as the rest of the population, and should expect those services to identify and make reasonable adjustments for people with a learning disability and/or autism. • Liaison and diversion schemes, ensuring clear pathways to health and social care services, should support people through the youth/criminal justice system. • People should have access to specialist multidisciplinary health and social care support when (at risk of) coming into contact with the criminal justice system.
9	**If I am admitted for assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to**	• Everyone who is admitted to a hospital setting should expect this to be integrated into their broader care and support pathway, and to experience a focus on independence and recovery. • People admitted to hospital on the basis that they present an immediate risk to themselves or those around them should have access to high quality assessment and treatment in non-secure hospital services with the clear goal of returning them to live in their home. • Admission to secure inpatient services should only occur when a patient is assessed as posing a significant risk to others. • Admissions should always be with a clear stated purpose and set of expected outcomes. • For all inpatient provision, secure or not, children admitted to hospital should be placed in an environment suitable for their age and must have access to education. • For adults, provision of single-sex accommodation is essential.

4.9 The nine core principles are summarised in the Service Model diagram shown in Figure 1 below.

5 Overall, the strategic documentation in relation to the English Learning Disability Service Model offers a systematically developed framework underpinned by a strong value base and commitment to standards and quality. In context, this Model is designed for implementation through joint commissioning rather than integrated health and social care service delivery: as such the model reads as a high-level framework for action and accountability.

Figure 1: NHS England Service Model (2015)[5]



[5] Excerpted from: *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition: service model for commissioners of health and social care services* (NHS England et al, 2015) (p.12).

ANNEX D: Key Elements of Regional Models – WALES

The strategic approach of the Welsh government to addressing need in relation to learning disability is underpinned by the *Social Services and Well-being 2013 Bill.* This legislation places statutory responsibility on local government and its partners to develop **outcomes-based services** that **emphasise personal independence** and aim to **prevent or reduce the requirement for targeted services and long term or institutional care.**

The following documents provide the overarching framework for adult learning disability services in the region.

1 Sustainable Social Services for Wales: A Framework for Action (Welsh Government, 2011)

1.1 This overarching strategic framework is proposed as a response to the dual challenges of increasing demand and expectations from service users and carers, and ongoing austerity. It sets an agenda for transformation, change, and modernisation across social services, promoting renewal and innovation in response to these challenges, rather than retrenchment and minimisation. This framework informs and shapes the process and recommendations in the two documents discussed below.

2 Transforming Learning Disability Services in Wales (SSIA & Welsh Government, 2014)

2.1 This report provides information on the programme for transforming learning disability services in Wales, the analytical models used in the programme, and the implications for the future of Learning Disability services in Wales. The programme was developed to help councils and their partner agencies to assess current learning disability provision and practice across Wales and identify a sustainable service model for the future.

2.2 Values and principles: The programme is founded on the values and vision established in historic strategic planning and service development in relation to learning disability in Wales, summarised in Table 1 below.

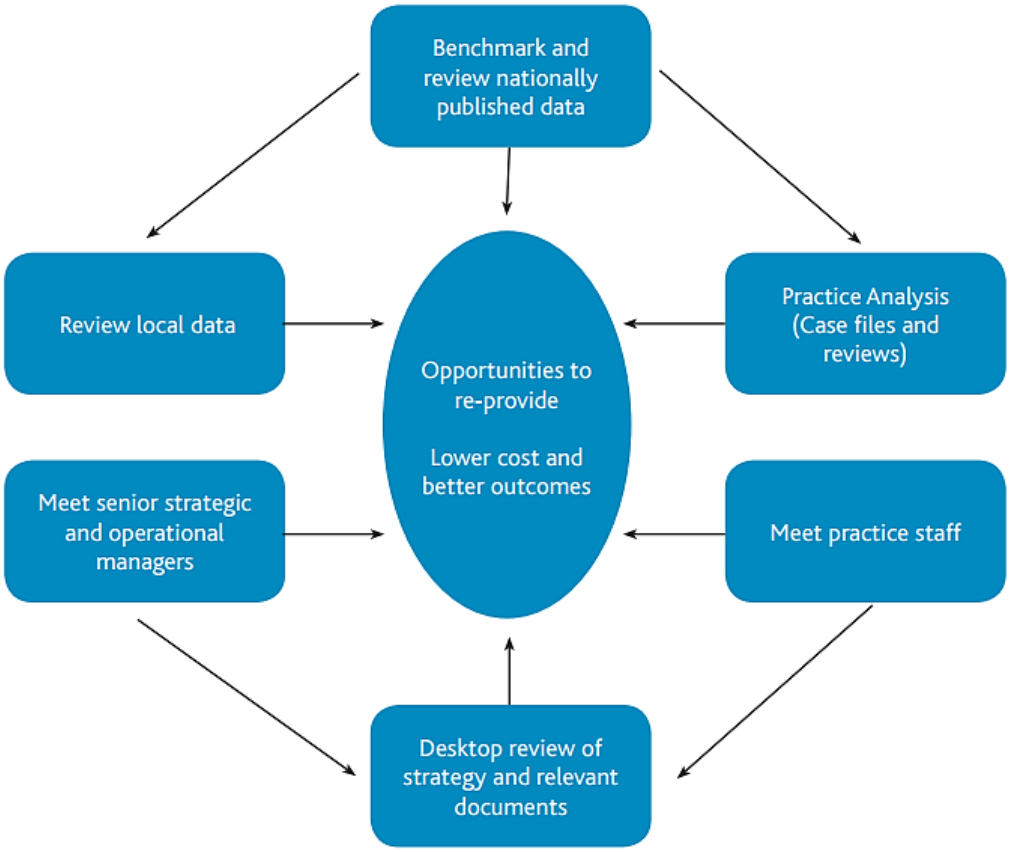
Table 1: Welsh Government: Learning Disability Strategy Values/Principles

REF	VALUE / PRNCIPLE
2001 policy document: 'Fulfilling the Promises' ***People with a learning disability have the same value and status as everyone else, and have equal rights to:***	
1	Good health
2	Good housing
3	Protection from harm
4	Safety and financial security
5	Opportunities to obtain meaningful work
6	Positive roles in their families and communities
7	Opportunities to learn and improve skills
8	Civic rights
2007: Welsh Government Statement on Policy and Practice for Adults with a Learning Disability ***All people with a learning disability are full citizens, equal in status and value to other citizens of the same age. They have the same rights to:***	
9	Live healthy, productive, and independent lives with appropriate and responsive treatment and support to develop their maximum potential
10	Be individuals and decide everyday issues and life-defining mattes for themselves, joining in all decision-making which affects their lives, with appropriate and responsive advice and support where necessary
11	Live their lives within their community, maintaining social and family ties and connections which are important to them
12	Have the support of the communities of which they are a part and access to general and specialist services that are responsive to their individual needs, circumstances, and preferences

2.3 Analytical models adopted in this new programme include:

a) The Opportunity Assessment model is a three-pronged approach to assessing provision based on: existing service data; commissioning and delivering strategies; and current practice using case files and engagement with practitioners. This approach underpins the whole programme, and is shown in Figure 1 below.

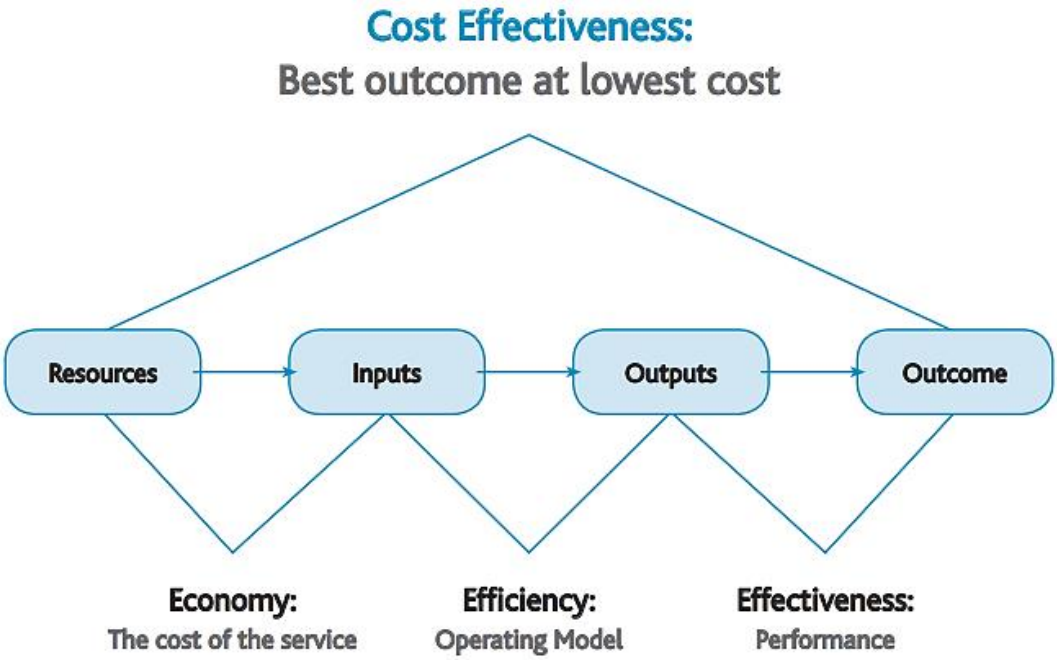
Figure 1: Alder's Opportunity Assessment Approach (SSIA Wales)[6]



[6] Excerpted from: *Transforming Learning Disability in Wales* (SSIA & Welsh Government, 2014) (p. 7)

a) A useful model for conceptualising Cost Effectiveness, shown in Figure 2 below.

Figure 2: Cost Effectiveness Model (SSIA Wales)[7]

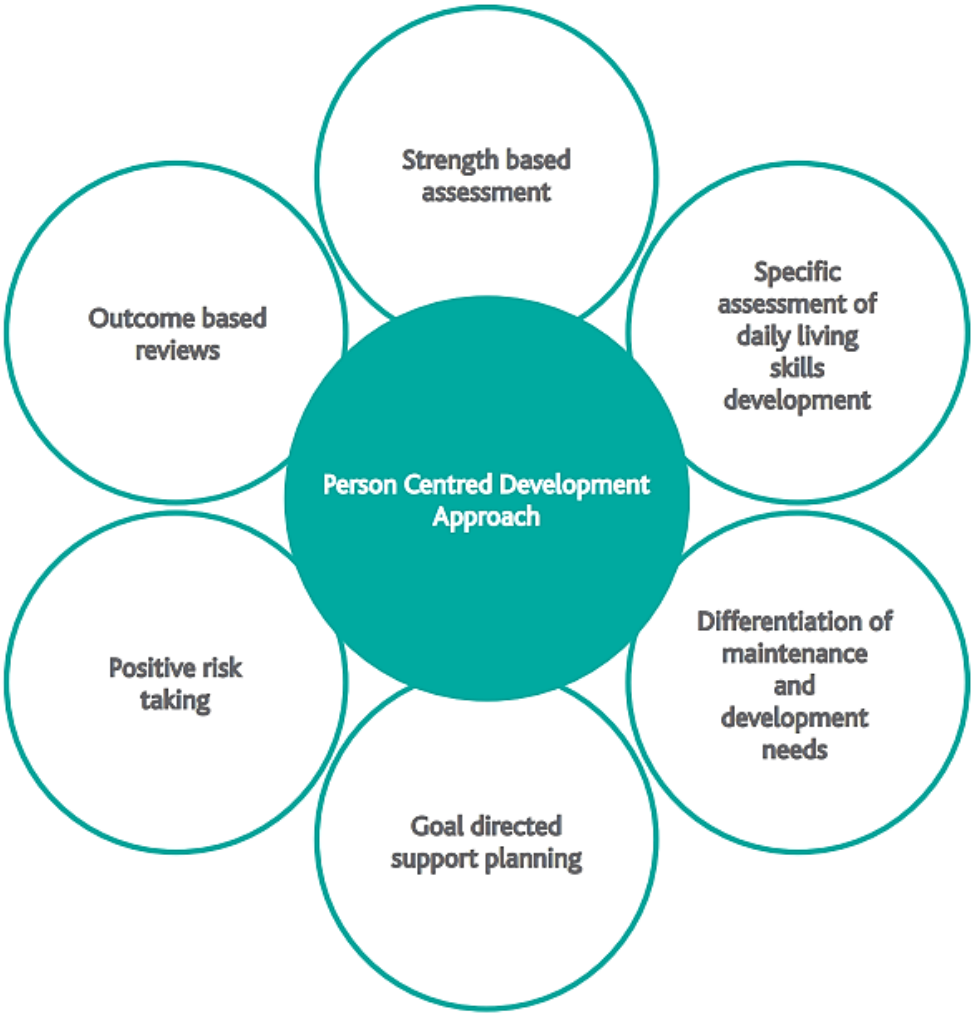


a) The framework proposes a Progression Model, which it describes as a person-centred developmental approach that takes a long-term view of the future accommodation and support needs of the individual, and seeks to help a person realise their aspirations for independence. Crucially, the model assumes that people prefer to be less, rather than mode, dependent, and that most people with a learning disability are able to learn at their own pace. The model also takes account of the fact that people can lose skills, for example through progressive conditions such as dementia

The aim of implementing this approach is to deliver a reduction in costs as independent living skills are gained and the need for/provision of support diminishes. The model is built on six principles, as shown in Figure 3 below.

[7] Excerpted from: *Transforming Learning Disability in Wales* (SSIA & Welsh Government, 2014) (p. 8)

Figure 3: Progression Model: Implications for Practice[8]



2.4 **Recommendations:** The programme recommends embedding the principles of the Progression Model into routine practice, and notes that that future work on the planning, commissioning, and delivery of learning disability services in Wales should take an integrated approach across the NHS and local government. The full list of seven recommendations is shown in Table 2 below.

[8] Excerpted from: *Transforming Learning Disability in Wales* (SSIA & Welsh Government, 2014) (p. 19)

Table 2: Recommendations: *Transforming Learning Disability Services in Wales*

REF	RECOMMENDATION
1	The Progression Model should be adopted as the future model for learning disability services throughout Wales and implementation should be undertaken on a regional basis.
2	Future work should develop on the basis of a genuinely integrated approach, across the NHS and Local Government, to the planning, commissioning, and delivery of learning disability services in Wales.
3	People with a learning disability, their families, carers, and communities, including the voluntary sector, should be engaged in this work at local levels.
4	Further work must be undertaken with Health Boards to ensure joint planning and joint commissioning at a regional level for learning disability services and to better understand the resources, particularly Continuing Health Care funding, that supports people with a learning disability.
5	A new and different conversation and relationship needs to be undertaken with providers of services to ensure they are delivering on new models of support.
6	Managers and staff within local authorities must engage in this change process from the onset and senior management support and commitment is also crucial. Assessment must focus on outcomes and must be reviewed and monitored regularly. This model requires a significant change in approach for staff and so may necessitate additional or different training.
7	Additional short-term capacity may be required to analyse case management information. Implementation of the whole programme may require specialist skills, as well as initial resources, which should be recouped in full implementation.

3 *Learning Disability: Improving Lives Programme* (Welsh Government, 2018)

3.1 This programme links to both the Transforming Learning Disability Services (2014) agenda, and the overarching health and social care strategy, A Healthier Wales (2018).

3.2 The programme aims to identify improvements in five key areas:[9]

- **Early Years:** reducing ACEs and improving the ability of parents with a learning disability to bring up their children.
- **Housing:** new models of supported housing will be developed, helping people to live closer to their friends and families.
- **Social Care:** making sure everyone who needs it has access to good quality care and support which is focused on their needs.
- **Health:** through reasonable adjustments to mainstream services and access to specialist services when needed.
- **Education, Skills and Employment:** supporting young people to make the most of their potential, and when they become adults ensuring they have the right support to allow them to live successful lives, providing targeted careers advice and making sure more people with a learning disability have paid jobs.

3.3 The programme makes detailed recommendations across each of these five areas. These can be summarised into three key priorities:

- **To reduce health inequalities** through adjustments to mainstream services and access to specialist services on need
- **To improve community integration** by increasing housing options closer to home, integrated social care, health and education, and increased employment and skills opportunities
- **To enable improved strategic and operational planning** and access to services through streamlined funding, better data collection, partnership working, more training and awareness

3.4 A Learning Disability Ministerial Advisory Group has been established by the Government to support the programme implementation, including people with a learning disability, families, carers, local authorities, the health sector, and charities.

[9] See: https://gov.wales/newsroom/health-and-social-services/2018/learning-disability/?lang=en

4 **Overall, the Welsh learning disability service model offers a streamlined, value-oriented framework underpinned by clearly defined processes.**

Notably, the model and service improvement recommendations place particular emphasis on communication, effective working relationships at all levels across the system, and staff training, development, and support. The emphasis of these 'softer' skills/elements within the programme of change is distinctive.

ANNEX E: Key Elements of Regional Models – SCOTLAND

The overarching strategic statement and policy direction for learning disability services in Scotland is *The Keys to Life* (2013) document discussed below.

While an initial impression of the document may be that it is very detailed and lengthy, closer reading reveals a comprehensive and considered approach to every aspect of the lives of people with learning disabilities, centred on developing an improved understanding of maximising quality of life. The strategy is notable among all of the four nations' policy statements for both:

- The **depth and breadth of the consideration of issues relevant to people with a learning disability** across the lifespan; and
- The **resources made available to the public** to understand and access the document, in particular via the **dedicated website**: https://keystolife.info/

1 *The Keys to Life: Improving quality of life for people with learning disabilities* (Scottish Government, 2013)

1.1 The strategy focuses on tackling health inequalities for people with a learning disability, addressing the poor health and early mortality characteristic of this population. This focus is reflective of a broader focus on tackling the equality gap across other Scottish policy areas.

1.2 In keeping with the NHS England and Welsh Government core values, the Scottish strategy is underpinned by rights-based principles as shown in Table 1 below.

Table 1: Scottish Government: Learning Disability Strategy Values/Principles

REF	VALUE / PRINCIPLE
1	Everyone – including people with learning disabilities – should be able to contribute to a fairer Scotland where we tackle inequalities and people are supported to flourish and succeed.
2	People with learning disabilities should be treated with dignity, respect and understanding. They should be able to play a full part in their communities and live independent lives free from bullying, fear and harassment.

1.3 The delivery approach is founded on a well-defined landscape of relationships and functions which the strategy describes as a whole system, whole population, whole person approach. This is outlined in Table 2 below.

Table 2: Scottish Government: The 'whole system, whole population, whole person approach' [10]

REF	COMPONENT	DESCRIPTION
1	**Whole System**	Incorporating local and national government, the third and private sectors – and going beyond 'traditional' boundaries of learning disability activity and services (see (5) below).
2	**Whole Population**	Incorporating the whole life journey from childhood to older age.
3	**Whole Person**	Considering the whole person, recognising the capabilities and talents of people with learning disabilities as well as the challenges they face. Understanding how important relationships and communication are for the wellbeing of people with learning disabilities, both personal and professional.
4	**A Rights Based Approach**	Recognising the human rights of people with a learning disability, reflecting the UN Convention on the Rights of Persons with Disabilities and the Scottish National Action Plan on Human Rights (SNAP) commitment to Participation, Accountability, Non-discrimination, Empowerment and Legality (the PANEL approach).
5	**A Fairer Scotland**	Aligned to the Scottish Government's National Performance Framework, *A Fairer Scotland Action Plan* (2016),[11] which commits to building a society that treats all people with kindness, dignity, and compassion.

[10] Excerpted from https://keystolife.info/strategy/our-approach/
[11] See: https://www.gov.scot/publications/fairer-scotland-action-plan/

6	**Collaboration**	Working with key strategic and delivery partners across the third, public, and private sectors, including in particular: **a) The Scottish Commission for Learning Disability**, which "aims to be a knowledge hub offering support, information and new ideas about learning disability in Scotland" (https://www.scld.org.uk/). Its activities include: *promoting engagement and dialogue* (with people with learning disabilities and carers, and professionals, policy officials and service providers); *leading innovation and collaboration* (in service design and delivery, and practice, support, and advocacy); and *building and disseminating evidence* (about lived experiences of people with learning disabilities, and what works to drive better outcomes). **b) The Scottish Learning Disabilities Observatory**, based in the University of Glasgow (https://www.sldo.ac.uk/), which aims to provide better information about the health and health care of people with learning disabilities and autism in Scotland, and to inform actions, practice, and policy to benefit these populations.

1.4 Tables 3 and 4 below outline the key Strategic Outcomes and Ambitions of the strategy.

Table 3: Scottish Government: The Keys to Life – Strategic Outcomes

REF	OUTCOME	DETAIL
1	**A Healthy Life**	People with learning disabilities enjoy the highest attainable standard of living, health and family life.
2	**Choice and Control**	People with learning disabilities are treated with dignity and respect, and protected from neglect, exploitation and abuse.
3	**Independence**	People with learning disabilities are able to live independently in the community with equal access to all aspects of society.
4	**Active Citizenship**	People with learning disabilities are able to participate in all aspects of community and society.

Table 4: Scottish Government: *The Keys to Life* – Strategic Ambitions [aligned to *A Fairer Scotland Action Plan* (2016)[12]]

REF	AMBITION
	OVERARCHING AMBITION: ***Disabled people can participate as active citizens in all aspects of daily and public life***
1	Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation.
2	Health and social care support services are designed to meet - and do meet - the individual needs and outcomes of disabled people.
3	Decent incomes and fairer working lives.
4	Making sure disabled people can enjoy full participation with an adequate income to participate in learning, in education, voluntary work or paid employment and retirement.
5	Places that are accessible to everyone.
6	Housing and transport and the wider environment are fully accessible to enable disabled people to participate as full and equal citizens.
7	Protected rights.
8	The rights of disabled people are fully protected and they receive fair treatment from justice systems at all times.
9	Active participation.

1.5 The structure of the strategy document reflects its comprehensive scope.

Table 5 below provides a summary overview of its key sections: this information could function almost as a checklist of relevant issues and concerns to be taken into account by health and social care services across the individual's lifespan, in line with the strategic values, outcomes, and ambitions outlined above.

On the basis of the information considered in each section, the document includes 52 detailed recommendations that span the ten sections/themes.

[12] See: https://www.gov.scot/publications/fairer-scotland-action-plan/

Table 5: Scottish Government: The Keys to Life – Information Covered in the Strategy

REF	SECTION	KEY SUB SECTIONS
1	**Human Rights**	*"…whatever the individual circumstances of people's lives, including age, gender, ethnicity, disability, religion, sexual orientation, mental health, economic or other circumstances, they should have access to the right health services for their needs."*
2	**Definitions and Numbers**	• Review of current data – who are the people with learning disabilities?
3	**Commissioning of Public Services**	• Joint Commissioning, Integration of Adult Health and Social Care and Commissioning • Care for Older People • Self-Directed Support
4	**Health**	• Scottish Learning Disability Observatory (see Table 9) • Health Inequalities • Healthy Lifestyles – prevention and self help ○ Diet, obesity, weight management, exercise, smoking, drinking • Good quality general health support in the community • Health in Hospital ○ Avoidable hospital admissions ○ Use of A&E ○ Dementia, Palliative Care ○ Bereavement and Loss
5	**Independent Living**	• Mitigating the effects of UK Welfare Reform • Day Opportunities • Housing, Supported Living, Adaptations, Travel/Transport • Advocacy
6	**Shift the Culture and Keeping Safe**	• Relationships ○ Building resilience ○ Friends and partners, Family carers, Paid carers ○ Parents with learning disabilities • Protecting children, young people, adults ○ Early intervention for improved outcomes ○ Legislation ○ Guardianship ○ Abuse
7	**Break the Stereotypes**	• Education • Transitions • Further or Higher Education

REF	SECTION	KEY SUB SECTIONS
		• Employment and Volunteering
8	**People with Profound and Multiple Learning Disabilities (PMLD)**	• Healthcare issues for people with PMLD ○ Invasive Procedures, Annual Health Checks, Oral Healthcare • Transitions for people with PMLD ○ Child to adult services ○ Family home to supported living • Meaningful activities for people with PMLD ○ Further and continuing education ○ Day opportunities ○ Changing Places toilets • Bereavement and loss for people with PMLD
9	**Criminal Justice**	• Criminal Justice Services • Victims and Witnesses • Being Accused or Suspected of Committing a Crime • Legislation • Young People • Prison Health
10	**Complex Care**	• Autism Spectrum Disorder • Mental Health • Delayed Discharge • Out of area placements

1.6 Strategic Commissioning:

The strategy draws on the Institute of Public Care (IPC) Joint Commissioning Model[13] to describe strategic commissioning as "all the activities involves in assessing and forecasting needs, linking investments to agreed desired outcomes, considering options, planning the nature, range and quality of future services, and working in partnership to put these in place;" 'joint commissioning' is "where these actions are undertaken by two or more agencies working together, typically health and local government, and often from a pooled or aligned budget."

[13] This model has also been recommended to the Welsh Government as a good practice model for planning and commissioning care for people with a learning disability – see: https://ipc.brookes.ac.uk/publications/LD_Commissioning__Guidance.html

While health and social care are integrated in Northern Ireland, this model offers a structured framework for considering the process that applies to commissioning and monitoring services.

The model is shown in Figure 1 below.

Figure 1: Institute of Public Care Joint Commissioning Model[14]



1.7 The strategy recommends 10 strategic outcomes to guide joint commissioning in practice. These outcomes relate to statutory bodies' legal obligations and wider national policy priorities. They are summarised in the document as shown in Table 6 below.

[14] Excerpted from *The Keys to Life* (2013) and available here: https://services.salford.gov.uk/solar_documents/nsc2103114.2.doc

These strategic outcomes correlate broadly with the NHS England Service Model Core Principles outlined in Annex 1, Table 4 above.

Table 6: Scottish Government: Joint Commissioning Strategic Outcomes

REF	OUTCOME
1	People have choice and control in their daily lives and are supported to live as independently as they can
2	People enjoy the best possible emotional health and wellbeing
3	People have good things to do that help them achieve their full potential
4	Carers are supported
5	People are safe, respected, and included in their communities
6	People are involved in the planning, development, design and delivery of services that help them to achieve the outcomes they want
7	People are satisfied with their experience of health and social care services
8	Statutory bodies fulfil their statutory legal responsibilities, adhere to meeting quality standards, services are safe and continually improving
9	People working in services are positive about their role
10	Services are efficient and responsive to local people's needs

2 **Overall, the Scottish learning disability service model offers an accessible framework for action that is readily understood by a lay person, and firmly grounded in the day-to-day life, challenges, and opportunities facing people with a learning disability.**

This grounded approach embodies the underlying value base and mission of the strategy i.e. to improve the *quality of life* for people with learning disabilities.

The model is also notable for the synergy it highlights between national outcomes for the population as a whole, and the specific objectives and outcomes it projects for people with learning disabilities.

Draft "We Matter" Plan on a Page

What we'll do

Our Vision:
"As an adult with a learning disability I will be respected and empowered to lead a full and healthy life in my community. I will be supported to make choices and decisions in my life that enables me to develop, and live a safe, active and valued life"

Our Ambition Statements:
AS1- I am prepared and supported through important changes in my life
AS2 – I can live a happy and healthy life
AS3- My carers are supported to help me live my best life
AS4 – I live in a society that respects my right to work, learn and enjoy my life
AS5 – I am supported to live in my home
AS6 – I will have access to high quality. Compassionate, assessment and treatment services, when required

Preoccupations:
Address the growing demand for services and ensures individuals get access to services based on their assessed needs
Support recruitment and retention of staff
Integrating services and supporting joint working across Departments
Securing investment is critical to deliver the Model

Priorities:

To be determined by PSG and MHLDIB

How we'll do it



How we'll know if we've made a difference

Agreed Outcomes as per "We Matter" to be included after PSG meeting on 21-10-20

Three behaviours that underpin everything – PSG to consider

A collaborative, partnership approach will be adopted in all aspects of service provision – development, design and delivery.	Service development and professional practice is evidenced based and informed.	A proactive approach is adopted towards prevention and early intervention.

7. APPENDICES

Appendix 1 – Ideas for Transforming the Way We Work - Implementation Phase

Appendix 2 – Legislation Background

Appendix 3 – Prevalence

Appendix 4 - Inequalities

Appendix 5 – Project Steering Group Reporting Structure

Appendix 6 – Key Challenges To Deliver ‘We Matter’ Ambitions

Appendix 7 – Pathway of Care Example, ‘Transitions from Children’s Disability Services to Adult Learning Disability Services’

Appendix 8 - Proposed Reporting Arrangements for “We Matter”

APPENDIX 1

Ideas for Transforming the Way We Work - Implementation Phase



Consideration to be given to a Learning Disability System's Leader/Champion for Adults and Children who would have oversight of all government departments with a specific brief in relation to Learning Disability. The role should be a non-political office endorsed with cross party support e.g. via the All Party Group on Learning Disability. The Systems Leader will provide oversight of all government departments and promote values within the model wider society, to ensure that the rights of individuals with a Learning disability are upheld, promoted and key performance targets are met per area of need. The Champion will seek to promote, encourage, and maintain high standards and good practices in the delivery of learning disability services and to protect the interests of individuals. This role is primarily to enable the cross linkages and achieve the aspirations of Programme for Government.

Consideration will be given to the setting up of a Learning Disability Network/Observatory to support information sharing, ongoing co-production of services, and research opportunities. Carers and individuals with learning disabilities have been clear and consistent during this engagement in their request to be involved in the decision making process, for their voices to be heard and for more information made available to help inform choices. Co-production recognises the importance of partnership working for service design. Other jurisdictions have responded to these requests by developing effective networks between carers, users, commissioners and community agencies, such as the Centre of Excellence, Scotland These partnerships play an essential role in:

- Contributing to government policies
- Involvement in high quality research both nationally and internationally
- Delivering local training
- Evaluating local implementation of key policy documents
- Promoting greater awareness of learning disability in society

Components of Centre for Excellence

- Inclusive, ongoing network linking research to service delivery.
- to support information sharing, ongoing coproduction of service, and research network

- A formal partnership approach adopted with experts drawn from all stakeholders to inform future planning of services from strategic and government level to local implementation as has already been established in other jurisdictions
- Centre of Excellence developed with key stakeholders to build on evidence base and increase accountability for govt policies and learning and development framework.
- Training, and Knowledge Exchange Partnership for staff (HSC / non HSC staff) and family carers See like dementia center in Scotland.
- Central register/database - Informatics linked with future planning / creation of minimum dataset

The key components of the Learning Disability Network/Observatory will be explored further in the Implementation phase.

Consideration will be given to the feasibility of a regional register/database. A national database of individuals is an essential means of informing future planning and targeting resources. Recent advances in technology and examples of how this is being used successfully in other countries such as Ireland and Scotland adds evidence to the debate. The development of a national database for N. Ireland would provide us with information on prevalence and forecast potential numbers of those requiring services in the future (McConkey and Craig, 2015). We can use this to predict local needs in terms of housing; specialist services to allocate can be equitable resources. The dataset would allow us to measure outcomes on new system initiatives such as suggested within this model and although not immediate, is a sustainable way to evidence outcomes longitudinally. The key components of the Learning Disability Database will be explored further in the Implementation phase.

Many of the indicators that will be set out in the Strategic Delivery Plan (SDP) will likely come from existing data sources. Where there are gaps we will design a standardised Minimum Data Set and associated Informatics Framework to support the collection of data to deliver the Model.

There is a need to develop a Training & Development Framework which incorporates the vision of Health & social care staff training and learning at all levels and includes shared training and development for all providing support and services for an individual with a learning disability including:

- Health & social care staff;
- Service providers;
- Public services;
- General public;
- Carers & families; and
- Individuals with a learning disability.

There is a need for a qualified, competent and confident workforce and support network to support people with learning disabilities and it is crucial to develop an infrastructure to support this. The use of information technology would enable wide reaching opportunities to explore and learn through digital resources alongside face to face and group training. The development and implementation of a Regional Shared Knowledge Network alongside traditional training opportunities could provide a learning platform (Learning zone) to facilitate this idea.

Development of standardised reporting documentation and systems similar to those embedded in mental health services through the You in Mind project, in readiness for one system for NI, delivered through Encompass.

Consideration to be given to the establishment of a Peoples Parliament as a forum to enable individuals with a learning disability to be meaningfully involved in decision making with regard to the planning, design and delivery of health and social care services (and beyond) ultimately to improve quality, safety and to reduce health and social inequalities. Active participation in decision making in all aspects of daily and public life concerns citizenship, enabling a person with a learning disability to play a full part in the community in which they live. It is a cornerstone of a human rights based approach to service planning, design and delivery and aligns completely with

the goal of person centred services where the individual with a learning disability has a voice and is heard.

There is a need for linked up consistent messaging and branding, both to support individuals as well as to raise awareness and the stature of individuals with a learning disability in society. A Regional website is the vehicle for more information on services, policies and legislation that impact on individuals with learning disabilities and their families/carers, and the opportunity to use technology in a different way to connect with others when leaving the home can be challenging due to caring commitments. An interactive website should be developed for N. Ireland that shares, receives information and provides a forum for open debate. The website should also contain updates during the implementation of the Service Model, minutes of public meetings as well as information relevant to adults with learning disabilities and carers. This could fall under the remit of centre of excellence.

Information Resources/Guide should be designed and set out clearly the menu of services available in a way that is inviting for individuals and their families to engage, enabling easier navigation and consent.

APPENDIX 2

Legislation Background

"We Matter" does not attempt to review or comment on legislation. Key developments in international, European, UK, and Northern Ireland law have been examined and discussed at length as part of the Bamford Review of Mental Health and Learning Disability (Northern Ireland) an independent review of mental health and learning disability law, policy, and service provision that was initiated in 2002 and reported in 2007. Its portfolio of publications includes, among others, reports titled *A Comprehensive Legislative Framework* (DHSSPS, 2007a) and *Human Rights and Equality of Opportunity* (DHSSPS, 2007b).

Current legislation requiring reasonable adjustments to be made to mainstream services are contained within section 75 of the Northern Ireland Act 1998, the Good Friday Agreement and other pieces of equality legislation but not one central piece of legislation. This differs from the approach taken in England which uses the Equality Act (2010) as a single framework which merges legislation on anti-discrimination and equalities. The Equality Act (2010) places a legal duty on all service providers to take steps and make further *"reasonable adjustments"* in addition to existing adjustments described within Disability Discrimination Act 1995.

A key action of the Bamford Review was the incorporation of mental health and mental capacity law into a single piece of legislation. This has been achieved under the Mental Capacity Act (Northern Ireland) 2016 and a Deprivation of Liberty Code of Practice (2019) for professionals.

A succinct overview of relevant legislation and official statements pre-dating the Mental Capacity Act (Northern Ireland) 2016 is included in the Bamford report: *Promoting the Social Inclusion of People with a Mental Health Problem or a Learning Disability* (DHSSPS, 2007c) (pp.6-9). This includes discussion of the following:

- Mental Health Declaration for Europe (2005)
- Human Rights Act (1998)
- The Madrid Declaration (2002)
- UN Convention on the Rights of Persons with Disabilities (2006)
- Disability Discrimination (Northern Ireland) Order 2006
- Northern Ireland Act 1998 – Section 75

With particular reference to transitions, or Life Changes as we describe it in the Model, statutory agencies have also specific duties to promote the welfare of children and young people with disabilities, through a number of different pieces of legislation. It is universally agreed that there is a great need for better coordination of supports and services for children and young people with disabilities and their families. Relevant legislation includes:

- UN Convention on the Rights of the Child (1989) – Article 4 requiring Governments to take all appropriate legal, administrative and other measures to implement children's rights
- UN Convention on the Rights of Persons with Disabilities (2006) – ensure that individuals with disabilities are treated equally
- Children Order (NI) 1995 – Article 17a child shall be taken to be in need if he/she is disabled
- Children's Services Co-operation Act (2015) – requires the NI Executive to promote co-operation across relevant bodies and to adopt a strategy to improve the wellbeing of all children and young people
- Special Educational Needs and Disability Act (NI) 2016 – provides for increased co-operation between Education Authority and HSC Services to provide services they have identified to be of benefit to address a child's special educational need (SEN).

Recommendations set out in the NI Executive's Children's Strategy 2019-29, led by the Department of Education (DE), will dovetail into the lifespan approach for children and young people with a learning disability. Outcome measures and key actions relating to Life Changes, transitions from Children's Services to Adult

Learning Disability Services will be monitored by the Learning Disability Transformation Taskforce (LDTT) and through the Children's Strategy reporting arrangements. Key stakeholders from Children's Services and other Government Departments will be represented on the Learning Disability Transformation Taskforce (LDTT).

Safeguarding

Safeguarding means protecting vulnerable adults from abuse or neglect and putting systems in place to prevent abuse or neglect from happening. As a society and those working in health and social care services, we are responsible for any individual who has needs for care and support, is experiencing or is at risk of abuse or neglect. HSC services have a duty of care to individuals with learning disabilities in this regard.

The essence of the Mental Capacity Act promotes individuals' rights; and challenges potential assumptions around choice and control. Principle Four considers that a person can make an unwise decision; this societal perspective which extends to most members of the public has not always been extended to individuals with a learning disability, the right or dignity of risk, challenging the parameters of choice and control. Whilst an outcome may be unwise that does not preclude the Trust or others from a duty to care and risk manage a person's safeguarding needs.

Building on the current models of advocacy already in operation, the development of other forms of advocacy should form part of the Model to ensure that advocacy permeates throughout all areas of planning, practice and approaches; locally and regionally, providing a preventative and protective impact, and support implementation of the Mental Capacity Act.

The role and development of advocacy, set out for example, in the Scottish model, Keys to Life (2016) indicates that numerous forms of advocacy exist and could be developed to improve representation, choice and control to individuals. Individuals engaged during the project were seeking to be included in decision making and being informed especially when seeking or receiving medical care and advice. A

future model should explore methods of providing advocacy and review current methods of investment and / funding source

APPENDIX 3

Prevalence

According to Mencap (2016-17), there are approximately 1.4 million individuals with a learning disability in the UK, of which approximately 1,119,000 are adults, or 2.16% of the adult population. The prevalence of learning disability among children across the UK is believed to be slightly higher, at 2.5% of the child population as a whole: it may be anticipated therefore that a slight rise in learning disability prevalence among adults may be anticipated in the future.

Taking into account the caveats highlighted at point 2.1 above, Table 1 shows the estimated numbers of adults with a Learning Disability across the UK.

Table 1: Adults with a Learning Disability in the UK – Estimated Numbers

REGION	ESTIMATED NUMBERS
England	Estimations range from **930,400** (Public Health England, 2016) to **939,338** (Mencap, 2016-17)
Wales	Estimations range from **11,410** (Statistics for Wales, 2018) to **53,681** (Mencap, 2016-17) - **60,000** (Welsh Government, 2018)
Scotland	Estimations range from **23,446** (National Statistics Scotland, 2018) to **26,786** (ENABLE Scotland, n.d.)
Northern Ireland	Estimations range from **7,198** (McConkey, 2013) to **30,814** (Mencap, 2016-17) (All Party Group on Learning Disability, 2018)

Learning Disability in Northern Ireland

As noted above, the estimated numbers of people, and specifically adults, with a learning disability in Northern Ireland vary according to the source and definitions employed. In 2009, the DHSSPS noted that up to 2% of the population may have a learning disability, with half of those falling into the 0-10 age group (DHSSPS, 2009: 15). This finding correlates with the most recent Northern Ireland Census (2011), which revealed that, at that time, around 2% of the population or around 40,000 people (including children, young people, and adults) may have a learning disability.

HSC Trust Health Care Facilitators (HCF) noted anecdotally there may be a number of individuals attending yearly Health Checks with a GP and Health Care Facilitators (HCF) that may have a diagnosis of learning disability but decline further services, and others that decline diagnostic assessment.

The Northern Ireland Assembly Research and Information Service (2017) has noted that funding for learning disability services and support is lower in Northern Ireland than any other region of the UK, “with only 6% of the total Health and Social Care spending being allocated to learning disability in 2016”, and “although overall spending on learning disability in Northern Ireland increased by 15% between 2010 and 2015, the number of people here with learning disabilities also continues to rise, and it has been highlighted that current one year commissioning is too short to plan long-term strategies for this group.”

Additional funding should be made available to offset the inherent inequalities and disadvantages (e.g. premature deaths and differential health outcomes compared to the general public), allowing services to be targeted and reasonable adjustments made to deliver health improvements; as described within the Marmot Review (2010). The author introduces the concept of “proportionate universalism”, which means that whilst the health service is free to all, it is not used or accessible in an equitable manner just because the door is open, hence the need increased funding for adults with a learning disability.

Care and Carers

The Northern Ireland Assembly Research and Information Service (2017) has also noted that “Informal carers provide much needed health and social care support to those with learning disabilities.” Citing research conducted by Carers UK and the University of Sheffield in 2015, the Service observes there are around “220,500 informal (unpaid) carers in Northern Ireland providing support worth an estimated £4.6 billion per year (around the same as the entire Northern Ireland health budget).

Around 9% of these provide care for 'someone with a learning disability' with many carers in poor health themselves."

Inequalities

Research has shown that individuals with a learning disability in Northern Ireland are a vulnerable group who experience particular health inequalities (Black, 2013). This finding is supported by wider current research and practice in relation to applying a social determinants approach to improving the lives and health outcomes of people with learning disabilities – i.e. understanding and improving the conditions in which people are born, live, and work (Rickard & Donkin, 2018).

This research reveals that, in both Northern Ireland (see: All Party Group on Learning Disability, 2018) and elsewhere (see: Rickard & Donkin, 2018), individuals with a learning disability are more likely than the general population to:

- Grow up in poverty and poor environments, which can limit the ability and freedom to pursue healthy options, be socially included, and/or afford decent housing.
- Can have difficulty forming close relationships in their early years, which can lead to behavioural and mental health problems.
- Have poor educational attainment.
- Experience social isolation and loneliness.
- Experience mental health difficulties.
- Have poor physical health.
- Have a shorter life expectancy: individuals with a learning disability die on average, 15 to 20 years sooner than their peers.

Additional issues pertinent to the lives of individuals with a learning disability in Northern Ireland include:

- **Accommodation:** Around 60% of adults with a learning disability in Northern Ireland live with family carers, while the remainder live in long stay hospitals, residential homes, or supported living schemes. A small

number live independently by themselves. . The RQIA Review of Adult Learning Disability Community Services Phase II (2016) noted a level of approximately 70 % living alone or with family, with numbers fluctuating from 65% to 76% depending on each Trust.

- **Access to employment***:* Only one in ten adults with a learning disability in Northern Ireland is in paid employment. . However there is an important qualification to add. By way of example, according to a report titled "Mapping the Employability Landscape for People with Learning Disabilities in Scotland" identifies employability of learning disability at 7% and 10% in England and Scotland. To qualify these statistics that employment is an umbrella term and does not relate solely to employment in open employment; many are employed within the context of supported employment and that does not mean fulltime either e.g for example: 65%-70% are working less than 16 hours per week. By type of employment 49% were in open employment, 29% were in non-open or sheltered employment and 21% were in employment but not known if open or non-open. This is significant because unemployment has been associated with increased premature mortality and poor mental and physical health as well as increased poverty and associated health impacts.

- **Exclusion and discrimination**: Many people with a learning disability still face discrimination, marginalisation, and barriers to opportunities, which impact negatively on social integration, ability to work, and mental health.

- **Legislation:** Current legislation protecting requiring reasonable adjustment are contained within section 75 of the Northern Ireland Act 1998, the Good Friday Agreement and other pieces of equality legislation but not one central piece of legislation. However within Great Britain stronger legislation has been passed i.e.: the Equality Act 2010, which is a single framework for that brings together all of the antidiscrimination and equality law which applies to both public and private sectors. The Model should consider at least to seek parity with Great Britain or explore

stronger legislation via our own legislative assembly. The Equality Act 2010 places a legal duty on all service providers to take steps and make further *"reasonable adjustments",* in addition to existing adjustments described within Disability Discrimination Act 1995.

- **Access to health and social care**: Research has found that individuals with a learning disability make far less use of their GP than the general population, due to a variety of reasons including, for example, communication difficulties and access issues. Since GPs act as the gatekeepers to the healthcare system and are usually the first point of contact, this trend of low uptake of GP services by individuals with a learning disability can lead to delays in diagnosis and treatment in relation to the full range of physical and mental health and wellbeing needs.
  (see: Black, 2013 – need full Ref)

UK Population Profile:

According to the Scottish Government, 2013 *People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Update Report, w*hile life expectancy is increasing individuals with a learning disability innately it remains shorter by approximately **20 years** when compared to the general population and is shorter for individuals with severe learning disabilities.

The Learning Disability Mortality Review (LeDeR) Annual Report (2018) data suggests a disparity in the age at death for people with learning disabilities (aged 4 years and over) and the general population (all ages) to be 23 years for males and 27 years for females. A person with a learning disability's life expectancy is averaging 70 years of age, with a projected 164% increase in the number of people with learning disabilities aged 80 and over using social care services by 2030 (Emerson & Hatton, 2011). Due to the earlier onset of dementia often experienced by those who also have a learning disability, particularly with Down's Syndrome, the need for services can be required at an earlier age than the majority of the population.

This growing population of older people with learning disability and additional conditions related to ageing brings about new challenges for health professionals and care services.

Individuals with a learning disability have high rates of mental health comorbidity (Deb et al, 2001). Epidemiological studies have suggested a prevalence rate of 31–41% (Cooper et al, 2007; Morgan et al, 2008). For those who are treated within hospital settings, (RCPsych, 2013) mental health co-morbidity ranges from 50- 84%. This is in addition to other comorbid conditions such as autism spectrum disorders, attention-deficit hyperactivity disorder, personality disorders and substance misuse.

For individuals treated within or referred to forensic (i.e. Secure) hospital services for those with learning disability, similarly high figures are reported. Up to half have a personality disorder, up to a third have an autism spectrum disorder, about a third to half have a major mental illness, about a third to half have substance misuse/dependence and about a fifth have epilepsy (Alexander et al, 2002, 2006; Plant et al, 2011). For those people with a learning disability who come into contact with specialist learning disability services, their clinical presentations are often a complex mix of learning disability, mental illnesses, other developmental disorders, personality disorders, substance misuse, and physical disorders including epilepsy.

APPENDIX 4

Inequalities

Many individuals with a learning disability still face discrimination, marginalisation, and barriers to opportunities, which impact negatively on social integration, ability to work, and mental health.

Health Inequalities

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The provision of services to meet the needs of people with mental disorder and/or learning disability who are, or are likely to be, in contact with the criminal justice system requires a co-ordinated multi agency approach. In 2018 the HSCB developed a Forensic Managed Care Network (FMCN) for mental health and intellectual developmental disability. Its infrastructure is made up of a high level Advisory Board and three specific sub groups to take forward the priority areas of work for forensic services. It is important that the FMCN and the six Ambitions set out in the Model provide an integrated approach for people with forensic learning disability across community and inpatient services to ensure that their needs and supports are met. Services will need to work, collaboratively on a multidisciplinary and interagency basis, across community and inpatient services.

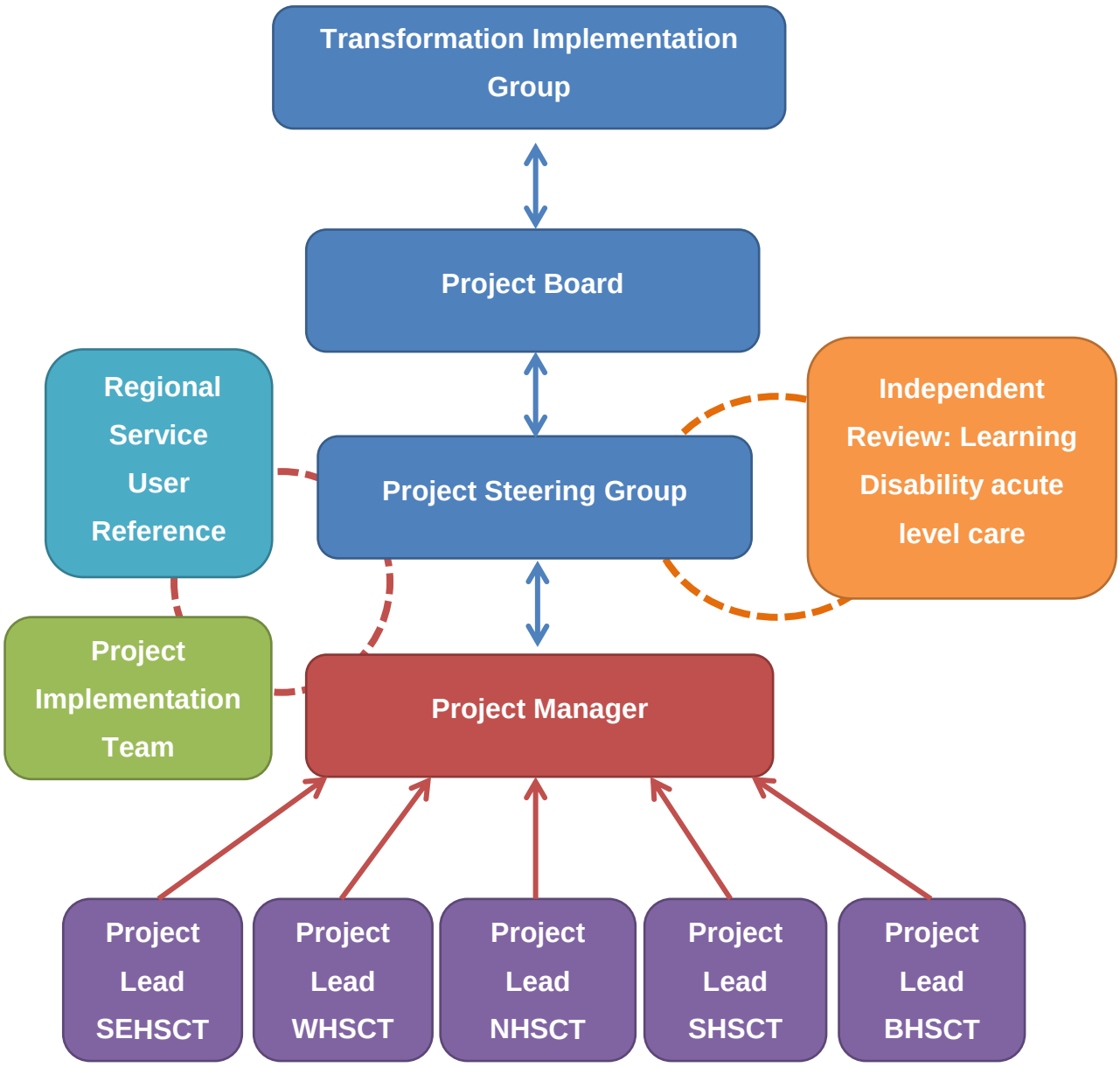
Other Inequalities

There are also a number of other social, emotional and financial factors which impact on the health of people with learning disabilities and research notes that individuals with a learning disability are more likely than the general population to:

- Grow up in poverty and poor environments, which can limit the ability and freedom to pursue healthy options, be socially included, and/or afford decent housing.
- Can have difficulty forming close relationships in their early years, which can lead to behavioural and mental health problems.
- Have poor educational attainment.
- Experience social isolation and loneliness.
- Experience mental health difficulties.
- Have poor physical health.

APPENDIX 5

Project Steering Group Reporting Structure



APPENDIX 6

Key Challenges To Deliver 'We Matter' Ambitions

Life Changes

Ambition Statement 1 - *I am prepared and supported through important changes in my life.*

Within Northern Ireland, Adult Services in each HSC Trust have different provision than Children's Services. Most Trusts have dedicated Transition Workers within Children's Services identifying needs and profile, an eligibility criteria, which is sometimes varied, is applied to determine whether the individual has a diagnosis of learning disability, at which point an adult assessment of need is completed. Keys to Life in Scotland noted a marked reduction in availability of services from Children's to Adult Services. Children's services in NI use a needs-led and whole child model approach, where services are wrapped around a child, based on their assessed needs. Services however, do not follow the child into Adult Services when they transition.

Under the new Special Educational Needs and Disability Act (NI) 2016 there is a call for provision for increased co-operation between Education Authority and HSC Services to provide services they have identified to be of benefit to address a child's special educational need (SEN). Under the Special Education Needs and Disability (NI) Order 2005 (SENCO) Code of Practice, transition planning in schools commences at the first annual review following the 14th birthday. A diagnostic assessment for Learning Disability may be best completed at the same age. Staff reported that they saw benefits in assessment of need commencing at an earlier age, from at least 14. In the development of the Model, individuals and carers acknowledged a need for earlier notification and contact with Adult Services, currently identification of need can occur from 16 and 17 years of age onwards.

Access to Adult Services is currently via an agreed eligibility criteria based on a diagnosis of Learning Disability, which has also not always been completed earlier enough in the transition process.

Currently a diagnostic/ eligibility process should identify those with and without a learning disability, providing an opportunity for an individual and carers to adjust to the outcome. Carers and staff however identified the need to support service users that do not have a learning disability, but still present with vulnerabilities e.g. educational, safeguarding, mental health issues and may also have a diagnosis of autism. Further work is required to explore the profile of need for these individuals and to apply a human rights and person centred approach rather than clinical diagnostic criteria.

Individuals and carers reported ongoing difficulties in navigating the process from Children's to Adults Services, and staff from with Children's Services did not understand Adult Services in the context of: legislation, service provision and issues facing children turning 18. To aid understanding service users, carers and staff all indicated the need for easier access to local information in respect of services available in cities, towns and villages, the creation of a single information platform, preferably online which includes information pertaining to: statutory, non-statutory, council, private and voluntary sector organisations.

As noted within the policy context; legislation and regulations continue to change within Adults Services, and a mechanism to cascade such changes should be provided to children's services to ensure all staff are kept up to date of changes and implications of same e.g. Mental Capacity Act and the provision of short and long term detentions and implications for service user and families. Statutory staff reported that Children's Services seemed not fully informed or up to date of legislative changes from childhood to adulthood; continued updates would assist awareness and work with respective young people during reviews and home visits when preparing for transition.

Whilst there is evidence of good working between Children's and Adults services, challenges remain within the service, it is hoped that earlier assessment of need will assist in identifying the numbers requiring Adult Learning Disability Services but only if subsequent assessment and care planning occurs in a timely fashion. Equal Lives indicted that *"much of planning occurs in the last year at school, which is too late to ensure that a range of options are sampled or explored."* Equal Lives also indicates other options being explored with college, day services and potential employers these will be discussed under supports which are relevant not just at transition to adult services.

Carers attending engagement events spoke of late notification of outcomes within Adult Services and need for earlier decision making, regarding what happens next in the individual's care pathway. Transition from Children's to Adults Services is unlike other transitions within a non-disabled world; this straddles issues of legislation, service provision, change and capacity. Independence, for many is not a progression after acceding the age of 18, the respective individual will continue to need varied supervision and/or 24/7 care and/or support but is treated like an adult.

If the care pathway is agreed by 17 this will allow the individual and families time to access the short breaks when turning 18.

Carers and families stressed the importance of a standardised approach to transitions, better partnership working, adopting a systems-led approach, seamless with a key worker supporting all transition paths.

As an individual gets older and their needs changes, services will respond to other transition points requiring support, these will be reflected elsewhere within this report. For individuals and carers changes in health and age are challenging times. Adjustment to these changes is not easy to manage or navigate. As the age of an individual rises, the ability for a carer to be involved will become harder as they may die before them. Many carers have indicated their desire that housing and future planning occur earlier allowing their involvement in future decision making.

The circumstances and expectations of people with a learning disability have evolved over more recent decades with a greater emphasis on inclusion and community living. While these are welcome developments which raise expectations for opportunities for positive ageing, there remain questions over how support for ageing generations is to be provided in the future. In their systematic review of caring for older people with a learning disability, Innes et al. (2012) have argued that the ageing experience of these individuals with a learning disability should not be seen as exactly the same as those of the general population.

In a small qualitative study of perceptions of active ageing, Buys et al. (2008) noted that with the move away from institutional care, many older service users with a learning disability have had different experiences in the latter part of their lives that have led to new hopes and expectations on their part.

For health and social care service providers, the expanded horizons which have come with the transition towards ageing and inclusion also brings a host of new challenges in terms of lifestyle support issues in order to assist new generations of older people with a learning disability move through this new ‘unknown’ phase of their lives. Today’s generation of older persons with a learning disability are the first for whom transitions are required to support movement from services provided to adult persons, towards provision that is more suited to their changing demographic and health needs.

Many individuals with learning disabilities miss out on the usual milestones of growing older, having a career, getting married, bringing up a family, retiring. It can be challenging for them to recognise that they are getting older. Sometimes they can be so protected by family that they continue to feel like a child and may have no sense of feeling like an adult at all. It is important to help them to learn about older adulthood. It is a life change just like others, with its own challenges, and it is important that they understand and are supported to manage these.

According to Keys to Life (2013), “life limiting illness is more likely in Learning Disability population with an estimated 61% of people with learning disabilities living

with a specific long term illness or additional disability]". The increase in co-morbidity begins to rise from the age of 40 onwards which is significantly earlier than the general population which is similar to aged 65. Whilst the overall age will increase in learning disability it would be important to ensure that a future model enables each service user to enjoy maximum independence for as long as possible, shortening periods of ill health that accompanies ageing.

Whilst ageing can impact on physical and cognitive health, research shows that dementia occurs at an earlier stage and higher frequency within the learning disability population particularly those with Down's syndrome. The standards set out in the Regional Dementia Care Pathway will also apply to individuals with a learning disability.

Research by Tuffrey-Wijne (2017) noted that "all people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care." By way of example, within the SHSCT palliative supportive ranges from district nursing, complex nursing, access to Macmillan/ Marie Curie nursing and the use of a local hospice care. It is expected that communication recommendations will improve an individual's experience during any hospice admissions. Research within Learning Disability is limited, but Tuffrey-Wijne (2017) identified certain key issues:

- Communication difficulties,
- Difficulties around insight and participation in decision making,
- Distress, multiple co-morbidities,
- Complex family and social circumstances and
- Higher levels of behavioural and psychiatric problems.

Tuffrey-Wijne considers that someone with a learning disability has difficulty with equal access, challenges in accessing palliative care and that health professional can misinterpret symptoms of ill-health as matters pertaining to their learning disability. This can result in misdiagnosis, described as "diagnostic

overshadowing." Secondly training, it is important that care staff delivering such services have completed adjustment training.

Health and Wellbeing

Ambition Statement 2 - I will live a happy, healthy and active life

Research has shown that individuals with a learning disability face many health inequalities compared to the general population in terms of health conditions and life expectancy. The 2018 Learning Disabilities Mortality Review (LeDeR) found the average age at death was 60 for men and 59 for women, compared to age of death of 83 for men and 86 for women in the general population. The typical life expectancy overall for general population is lower in NI, however there are no published figures to suggest the same principle applies to the average life expectancy for individuals with learning disability in N.I Individuals with learning disabilities are more likely to experience a range of health conditions. Coronary heart disease is the main cause of death amongst this population, with respiratory disease higher than the general population. There are also increased incidences of psychiatric disorder, dementia and epilepsy. There is also low uptake of health screening including breast, cervical, bowel, and AAA.

Research indicates that individuals with a learning disability are less likely to eat healthy foods and do regular exercise without help and support and therefore are at an increased risk of obesity and diabetes. Individuals with a learning disability face many challenges in maintaining good health and wellbeing because of:

- Not being able to take part or access local exercise classes/programmes in their community;
- Poor communication which impacts on ability to understand;
- Lack of support to help maintain a healthy lifestyle;
- Services unable to make reasonable adjustments;

- Conditions go undetected or are masked with other conditions.

Central to ensuring the health and wellbeing of an individual with a learning disability not only is being healthy, which is a key goal, but having access to services to enable a happier healthier and more active life. It is vital that individuals have access to all health and social care services which are required to improve their health and wellbeing outcomes, including access to the full range of AHP services. Survey responses in relation to health and wellbeing during the consultation phase found signfiicant numbers of carers unhappy with services in this area.

We know that the needs of individuals with a learning disability have changed since the Bamford review in 2005. The range and breadth of health and wellbeing services have evolved in response to need to provide a menu of options available to the individual, carers and families to consider. Day Care Services are moving towards supporting individuals with complex needs whilst Day Opportunities are for individuals assessed as being more independent.

It is important that we consider extending and developing our links with community initiatives and health improvement programmes to ensure that individuals with a learning disability have access to a range of social, physical and emotional health and wellbeing activities which may also help address isolation and loneliness. The DOH “Making Life Better”, a whole system framework for public health, is a key driver to take this forward, including Active Inclusion programmes, and the Take 5 campaign.

Health Care Facilitation was a service commissioned in 2008 to provide Annual Health Checks in GP practices in order to reduce inequality and access to appropriate screening. A 2013 Review identifed the need to record the impact of Annual Health Checks during the course of the year and at the next Review. This aspect of the service remains outstanding at this stage. A co-ordinated informatics response would assist in enabling and measuring the added value of this service.

Throughout the engagement process Case Managers also indicated a desire to be more involved in health improvement and health promotion. Case Managers could be involved in the implementation and monitoring of Health Actions Plans.

To ensure that health improvement is part of not just community teams, Health Action Plans should be linked to the use of commissioned services – either statutory or the independent sector. Examples of Health improvement initiatives specific to learning disability include: fit 4 U, I Can Cook It, Heart Health Toolkit, Understanding Relationships, Walk Leader Training, and Home Accident Prevention. These are all initiatives which have been adopted and offered in Day Services and could be delivered within Community Teams. The Review of Adult Learning Disability services by RQIA (2016) recommended "a plan that can demonstrate measurable evidence of health improvements for adults with learning disability".

One Trust is currently piloting a Health and Wellbeing Coordinator post within Day Services to embed the health and wellbeing agenda across day services and in particular tackle obesity and other long term conditions. The post holder works closely with the Health Care Facilitators. This could be identified as a potential pilot across all Trusts.

Consultation responses also noted greater adjustments required to facilitate attendance at HSC seminars, including longer GP appointment times, countinuity of care by the same GP and a GP flag on Case Notes. Adjustments should not relate solely to GPs but include other providers, e.g., Dentists, Opticians and Acute Services and any other health and social care services attended by individuals with a learning disability. These adjustments should ensure that information is available in a timely fashion.

The consultation process also noted challenges when visiting hospital services, accessing wards, waiting times, for example, Hospital Passports not being read or understood by staff. The recently published 'Regional HSC Passport For People with Learning Disabilities – Phase Two Evaluation' (2020), to review the Hospital Passport introduced by the Public Health Agency in 2017, noted that whilst many

healthcare professsionals across NI welcomed the Hospital Passport and saw real benefits in terms of ensuring reasonable adjustments for individuals receiving healthcare, some challenges remain. Key recommendations have been set out in the Phase II Evaluation and will be set out in the Strategic Delivery Plan.

Carers also reported that when their son or daughter requires admission they would want to stay with them to ensure their needs were supported within a hospital setting. Health care professionals with expertise in Learning Disability e.g., a Learning Disabled Nurse, AHPs with skills and expertise in Learning Disability,are essential to ensure that a individual's needs are communicated, discussed and reasonable adjustments are made.

The Confidential Inquiry Into Premature Deaths of People with Learning Disabilities (2014) noted that whilst ageing can impact on physical and cognitive health, research shows that dementia occurs at an earlier stage and higher frequency within the learning disability population particularly those with Down's syndrome. It is intended that the Regional Dementia Care Pathway will support individuals with a learning disability who develop dementia.

The links between dementia and development of epilepsy and increased occurrence of cognitive decline amongst those with Down's Syndrome is also well recognised.

Future planning and decision making also require consideration as cognitive and physical needs will change as dementia progresses. Appropriate support mechanisms should be available to the individual and their carers.

There is a higher occurrence of epilepsy in learning disability compared to the general population. Frequency changes significantly with age. According to the People with Learning Disabilities in Scotland report (2017), there is an average occurrence of 22% but this rises with age to 31% with those aged 40-49 within learning disability. A specialist epilepsy service is currently operating in one HSC Trust in NI since 2007, which provides assessment, seizure care plans, nurse-led

review clinics, monitors medication, staff support and ongoing range of training packages for staff.

The ESPENTE, Epilepsy Specialist Nurses the Evidence: A systematic mapping review study (2019) carried out by Epilepsy UK concluded that epilepsy specialist nurse is highly valued by patients, their families and other health care professionals. It is important that this service need is reflected in the new Model.

Research within learning disability is limited relating to palliative care, but Tuffrey-Wijne (2017) noted someone with a learning disability can have challenges in accessing palliative care and that health professionals can misinterpret symptoms of ill-health as matters pertaining to their learning disability. This can result in misdiagnosis. It is important that care staff delivering such services have completed adjustment training.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (2014) identified a range of factors that led to premature deaths which occurred and can be attributed to issues arising within the community and hospital. Key factors included: advanced health and care planning, recognising needs and adjusting care, coordination of care, information sharing and record keeping.

The Confidential Inquiry also highlighted the need for appropriate coding and recording of learning disability. In order to measure a reduction in premature deaths it would be necessary that hospitals and coroners service ensure that learning disability is recorded following admission and/ or death. A LeDeR Learning Disability Death Review which ensures that individuals with a learning disability are clearly recorded within respective systems, hospital, community and coroners service to allow learning and research to improve services, should be considered in the new Model and commissioned in the ‘once for NI’ Encompass system.

Carers & Families

Ambition Statement 3 – *My carer is supported to help me live my best life.*

The NI Research & Information Service noted that informal carers provide much needed health and social care support to people with learning disability. There are 220,500 informal carers in Northern Ireland providing support worth an estimated £4.6b per year. Around 9% of these informal carers provide care to someone with a learning disability, with many carers in poor health themselves.

It is recognised that within a person-centred approach family caregivers are partners in provision. Professionals need to support caregivers in this role by working in partnership with them and by providing them with the support they need. Carers work very hard to support each other and work in partnership with HSC organisations to ensure their loved ones have a good quality of life.

According to the Human Rights Commission (2014), carers are not a homogenous group. Carers can be all ages. Each carer is an individual who has his or her own story to tell and has particular needs. Delivering Together (2016) stated we need to ensure carers can access up to date information and crucially consider how we can support carers to live their own lives, need to encourage greater take up of Carer's Support Assessments and expand the options for short breaks, as well as enabling the greater use of personalisation and personal budgets where appropriate.

Although helping others may bring personal satisfaction, carers can face substantial health and financial challenges. According to Taggart et al (2011), there is a plethora of research evidence that documents the stresses and strains that carers experience and the consequential ill-health that often results. In their study, 'Supporting People with Intellectual Disabilities who challenge or who are ageing: A Rapid Review of Evidence', they make reference to the key principles set out in the DHSSPS (NI) Valuing Carers Strategy (2006) which remain fundamental:

- Carers are real and equal partners in the provision of care**.**

- Carers need flexible and responsive support**.**
- Carers have a right to a life outside caring.
- Caring should be freely chosen
- Government should invest in carers.

The Foundation for People with Learning Disability (2015) also noted that parents have often said their hope for the future is that they will outlive their adult son or daughter, but as individuals with learning disabilities are living longer, this is frequently not the case. But in any event, living with fear and worry for the future should not be the way for a family to live.

NICE NG 150 'Supporting Adult Carers' (2020) sets out the standards for support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care.

NICE NG96 "Care and Support of People Growing Older with Learning Disabilities" (2018) also recommends that we review the needs and circumstances of carers at least once a year and give help and information to families and carers, including siblings, as part of planning and providing support for individuals growing older with learning disabilities

Given the increased life expectancy of individuals with a learning disability, many older individuals are now living with family carers and indeed may outlive their parents. The Department of Health in England (2010), through their Valuing People Strategy, placed particular emphasis on policy initiatives in relation to older carers of persons with learning disabilities. Based on the evidence of this review it is recommended that:

- Family caregivers who seem dissatisfied with services they receive should be listened to and their views incorporated into service delivery
- Future planning involving parents and clients in a true person-centred way needs to take place to prepare for transitions and the future
- Attention needs to focus on siblings and their views on being potential future main caregivers (this is an area that would benefit from future research).
- Services should be provided in the home to support families as far as possible and family caregivers should be provided with education, training and support for their caring role.
- Short term respite breaks should be more available and meet the complex needs of people who challenge
- If out of home placements are required these should be available at local level and be for short duration.

Carers NI 'State of Caring- A Snapshot of Unpaid Caring in NI' (2019) represents the most up to date study into unpaid carers. 694 respondents participated in this research and a number of key recommendations were made. These included ensuring that carers did not suffer financial hardship as a result of caring, recognition of the value of carers, funding for older individuals and those with disabilities to access quality affordable care, funding and choice of breaks for carers and to ensure that carers are able to juggle work and care if they wish to.

One such approach is the Shared Lives approach. This matches dedicated host carers who provide support in their own homes to individuals who require day services, short breaks or long term placements. Shared Lives is a regulated approach that provides choice, control and flexible person centred care, enabling individuals to remain living in their communities. It creates and maintains long term sustainable relationships and provides a direct response to managing social isolation. The approach has proved to be a cost effective and highly personalised alternative to residential and other forms of care. It enables health and social care

partnerships to offer better outcomes for the individuals involved and has been reported that individuals feel settled, valued and have improved self-esteem.

The ‘Shared Lives’ model is currently in 4 of the HSCTs and plans are under way to develop a region wide service. Transformational funding was made available to develop a regional framework which includes a standardised approach for any organisation adopting a shared lives NI model. By adopting this approach it is envisaged the Share Lives Model can grow more substantially across Northern Ireland.

Carers noted a number of other key issues during the consultation phase, including the need for a Regional Scoring Tool for bed based breaks, improved communication, services provide by family, the need to have to fight for services and the lack of autism support.

The RQIA Review (2016) also noted the need to increase the uptake and completion of Carers Assessments. Staff indicated that carers found conversations regarding the future challenging, a subject that can be delayed until a crisis.

The Southern Trust Physical Disability Service piloted a new approach called the ‘Carers Conversation Wheel’ and at each Annual Review a conversation should occur regarding future planning.

Other key challenges noted by carers included need for emergency short breaks, domiciliary short breaks and emerging nursing beds.

Carers noted that current domiciliary provision does not always meet the needs of those with behaviours that challenge. The provision of home support via a domiciliary provider could offer another support or alternative support to some carers with sons or daughters that demonstrate behaviours that challenge. For example, a short break of 3 hours in an evening, up to at least 7 days per week. For an individual who presents with behaviours that challenge and / or autism, could be

more settled within their home environment as opposed to moving to a short breaks location.

Carers also noted that Self-Directed Support also proved difficult to achieve in a rural setting. Recruitment and retention within this area of need can be difficult and therefore consideration should be given to the need to consider a specialist provider targeting this need

Carers spoke of the need for a Regional Scoring Tool that would assist staff and carer agreeing the quantity of short breaks needed, based on a regionally agreed schedule to provide a fairer, equitable and standardised approach. This would generate regional data when considering future need.

Current provision in Trusts includes: nursing, residential, shared care and activity based short breaks normally over a weekend. The most recent data from the Health and Social Care Board's Performance Management Service Improvement Directorate shows that regionally, 9,286 adult carers received a short break at Quarter Ending December 2019, a 12% increase from Quarter Ending December 2018. Of these, 1841 were carers of an individual with a learning disability.

Meaningful Lives and Citizenship

Ambition Statement 4 - I live in a society that respects my rights and choices as a citizen - to learn, work, and enjoy my life.

The Regional Learning Disabiity Day Opportunities Model Consultation report (2014) stated that providing opportunities for individuals with learning disabilites to become true citizens in their own communities is the responsibility of us all. Citizenship and Social Inclusion also represent two of the core Equal Lives values drawn from Bamford, which continue to be critical to developing the vision for the Model.

Significant progress has been made over the last ten years to promote a meaningful life for individuals with learning disabilities but challenges still remain, as noted by those who engaged in the consultation process. These include accessible information, advocacy services, day opportunities, education, training and employment, self-directed support, transport and social isolation and lonlieness.Accordng to the report 'Five Communication Standards' by the The Royal College of Speech and Language Therapists (2013), 90% of individuals with learning disabilites have communication problems of differing degrees. The Care Standards for Nursing Homes (2015) Standard 20 also referenced the need for the use of effective communication , which is also reflected in legislation and regulations as set out in the Mental Capacity (Deprivation of Liberty) Regulations (Northern Ireland) 2019. 5.7 of the Regulations note, "….every effort must be made to provide information in a way that is most appropriate to help the person to understand (e.g. via use of visual aids, or simple language)."

With the creation of the Patient Client Council and requirement of Personal and Public Involvement (PPI) and the RQIA Review (2016) there is also a need to introduce standards regarding advocacy. According to the Scottish Model, Keys to life, advocacy "supports people to understand information and choices and to make their voice heard." Different advocacy models should form part of any future Model to ensure that advocacy permeates throughout all areas of planning, practice and approaches; locally and regionally, providing a preventative and protective impact. The essence of the agreed Mental Capacity Act (Northern Ireland) 2016 provides this regulation in that it will promote service users rights; and challenge potential assumptions around choice and control.

The Mental Capacity Act (2016) means that everyone has the right to make choices about their own life and what they want. You can even make choices about your future now, so that everyone will know what you want later on in life. The government has made sure that there are certain safety measures in place under this new law. These are called Deprivations of Liberty Safeguards. A deprivation of Liberty is when all of the following occur:

- A person is in a place where care or treatment is being provided
- A person is not free to leave
- A person is under continuous supervision and control

Where an individual has the capacity to consent to family/carer involvement in any part of their contact with Learning Disability Services, they must give that consent prior to the service engaging with families and carers. With consent in place, Learning Disability Services should seek to fully involve families and carers in decision-making. Where an individual does not have the capacity to consent to family/carer involvement, Learning Disability Services will seek to fully involve families and carers in decision making as appropriate, and in the best interests of the individual." It would be reasonable to assume that the need for advocacy is likely to be effected by the implementation of the Mental Capacity (Deprivation of Liberty) Regulations (Northern Ireland).The Learning Disability Service Framework (2015) Standard 9 also called for independent advocacy, "independence means structurally independent from statutory department or agency providing the service

Carers have also called for standardised and universal day opportunities provision. During the engagement process they had mixed views on provision across HSC Trusts, and raised issues relating to access and cost differential. The Regional Learning Disabiity Day Opportunities Model Consultation Report (2014) recommended a new model for Day Opportunities to ensure a modern, sustainable and quality service for individuals, which should be delivered on a joint basis, requiring cross Departmental working, to put in place a network of services operating for individuals with learning disabilities. The Scottish Model, Keys to Life (2013) proposed that no individuals should go to a Day Centre full-time, and instead should use it as a base to identify and participate in activities in the wider community. It promoted that Day Centres or support services should become more community focused by helping individuals with learning disabilities to access continuing education and development, real jobs, achieve their desired outcomes and become more involved in their communities.

Many HSC Trusts since Bamford have been developing structured day activities, excluding work and volunteering, which provide a mix of day opportunities and day care based activities, this has afforded many service users a different experience in community based settings, whilst physical numbers have fallen slightly in daycare need has increased in terms of complexity, cost per head with service users with high dependency needs requiring higher staffing ratios, nursing interventions, service users with behaviours that challenge with bespoke arrangements and/or individual rooms and a range of high cost equipment. This has been a challenge to respond to within the constraints of existing: budgets, building stock and room sizes often not designed for these new needs.

It is recognised however that for individuals with more complex needs and those with profound and multiple learning disabilities, Day Centres will continue to be an important part of their overall support arrangements.

An excellent example of good practice can be found in South Lanarkshire and Renfrewshire Council Council areas in Scotland where they have invested in new Day Centres based entirely within their Council Leisure Centres. Not only has this resulted in more individuals with learning disabilities becoming part of the wider community, but has also achieved the positive outcome of easy access to healthy activities such as swimming and sports. In both Councils, there is the added benefit of encouraging the wider public to make use of the day services resources including sensory room, dance studio and music room, thus breaking down barriers traditionally associated with learning disabilities.

There are similar challenges around support in navigating and locating potential employment, volunteering and other meaningful activity. There are a range of projects run across Trusts provided by different organisations, offering educational or vocational training with supported employment, however programmes are time limited and there are no further supports or monitoring of work placements when the programme ends or resources to extend the programmes. A possible solution is to call Public Sector organisations to facilitate employment opportunities via positive

discrimination, and to consider reasonable adjustments like apprenticeships or job trialling as alternatives to minimum qualifications or job interviews.

As with employment opportunities, there are similar concerns expressed by individuals and carers that commencing volunteering can have a detrimental effect on respective social security benefits. There is obviously a role for the Department for communities (DfC) and/ or Department for Works and Pension (DWP) to ensure that the benefit system does not unfairly penalise service users or discourage individuals that access or seek to access employment or college.

The Norfolk County Council “My Life, My Ambition, My Future” strategy is an example of best practice in this area. The strategy was co-written by individuals with learning difficulties, their families and service providers. It says people with a learning disability want to “have the ambition, choice and opportunity to be equal members of the Norfolk community”. The new Life Opportunities model has three levels, known as pathways:

- Wellbeing – providing meaningful activity, social support and care for those with the most complex needs
- Promoting Independence – supporting individuals to develop life skills and access community provision and services
- Skills and Employment – supporting individuals to obtain paid work.

Self–directed support (SDS) also offers an opportunity for individuals and carers to make choices about how they receive domiciliary services. For those using and benefitting from direct payments, it is well received and spoken of warmly, however for others the process is lengthy and arduous. There are challenges around recruitment in rural locations or for someone with behaviours that challenge, as well as the system being described as difficult to navigate. Staff involved in Direct Payments asked if any future review of criteria could include provision for accessing health professional assessment e.g. occupational therapy or podiatry.

To enjoy a meaningful life individuals also need to be able to get out an about. Throughout the engagement process all stakeholders were unanimous that transport options and availability needs to improve, particularly outside of towns, allowing individuals access to educational, social, work, and volunteering opportunities. This area of work will require agreement across Government Departments to improve breadth of coverage, but it is outside the scope of this Model.

Individuals with learning disability and their carers also noted difficulties in accessing friends, connecting and even seeing old school friends. According to 'Preventing Loneliness and social isolation: interventions and outcomes', Windle et al (2014) noted that within the general population this is described as a risk factor in relation to premature deaths. Research has found that the impact of loneliness can cause earlier than planned admission to nursing or residential care. Potential remedies to loneliness include: befriending, navigating, mentoring, group services and wider community involvement.

Home

Ambition Statement 5*: I am supported to live in my home*

A good quality home and community life is at the centre of positive living and promoting independence for individuals with learning disability.

The DoH Systems, Not Structures Bengoa Report (2013) noted, "*when support becomes available and what should it look like, is the service able to support service users at home and their carers*." During the engagement process individuals expressed a desire to live as independently as possible. Home can mean different things to different people, however. The Office of the First Minister and Deputy First Minister (OFMDFM) (2013) stated that *"people with disabilities and their families have appropriate accommodation and adequate support to live independently."* It has already been noted that the vast majority, approximately 75% live with a carer as their home.

The Department for Communities (DfC) Facing the Future: Northern Ireland Housing Strategy Action Plan 2012-2017 recommended the introduction of “a new strategic, intelligence-led approach to needs assessment across all client groups to identify current future patterns of need”.

Led by the HSC NIHE Regional Housing Interface Group, the Health and Social Care Board Learning Disability Services carried out a pilot of the Strategic Needs Assessment (SNA) Template. 706 individuals with learning disabilty in Northern Ireland informed the SNA, 60% were male, 40% were female. 622 of 706 (88%) were assessed as requiring a move to specialist housing.

The preferred housing options was overwhelmingly for a move to supported housing (646 – 92%). The remaining 8% were assessed as either being able to remain in their current accommodation with or without support/adaptation. 361 (51%) were assessed as requiring a change in their accommodation needs between 2 years and 10 years and 141 (20%) were assessed as requirng a change in their accommodation needs in the next 6 months. 113 (16%) were predicted to require a change in accommodation within 6 months – 2 years.

More recently, Delegated Statutory Functions reports from HSC Trusts noted individuals were living with a family member, some lived alone with or without support, supported living, residential and nursing care, and a small minority reside temporarily in hospital for care and treatment. The vast majority of supported living, residential and nursing is group type or shared accommodation. Group living arrangements vary from a small shared accommodation from two to at least 20.

Whilst peripatetic support is not widespread in Trusts, it is an effective mechanism in some areas of one of our HSC Trusts, for allowing or maximising independence and should be considered throughout the Region. Additional housing options and levels of support could be extended from existing supported living priorities if floating support extended beyond core buildings to support individuals. When Equal Lives

was written in 2005 approximately 10% of service users lived alone in the community, a target which should be increased for the future.

Individuals with learning disability and carers requested better access and choice in their local areas, reducing dependence or reliance on others or services. They called for greater flexibility in terms of renting private accommodation with nursing support instead of nursing home provision. They also called for bespoke housing models. Carers have also called for a shift in the accommodation response, from reactive to preventative. Black and McKendrick's report entitled "Careful Plans' Report in (2010) in Northern Ireland identified that only a third of carers had a plan in place.

Due consideration should also be given to commission new technologies or assistive technologies. Research should be commissioned to identify the best products and approaches available or being used within learning disability or related fields.

Planning and/or anticipating future need can be challenging, however. The majority of carers supporting someone with severe cognitive and physical disability preferred to care for that person in their home in the long term. However those with lower levels of need were seeking independence and carers were supportive of this option. Carers noted during the consultation that preferred group accommodation should be focused and bespoke to the needs of individuals with learning disability and not mainstream residential or nursing care Funding of capital projects however, continues to be challenging. Cross Departmental partnerships and collaboration is key to meeting learning disability needs when planning, locating and expanding public housing stocks.

Commissioned services need to be responsive and flexible and this would suggest that the need for domiciliary support, SDS, short breaks and home adaptions will be necessary, to ensure homes are responsive to changes in health. An excellent example of this is the provision of a Disabled Facilities Grant which can improve accessibility for an individual with a disability and is used widely within Learning Disability Services. This provision is overseen by occupational therapist (OT) and paid from the Northern Ireland Housing Executive. This grant provision is applicable

to anyone with a learning disability, but staff and carers reported that eligibility and guidance are limiting accessibility. A broader definition which considers the physical needs of behaviours that challenge, dementia and those with autism would be beneficial.

Learning Disability Services continue to have a lack of control over development, funding and design of housing, which is compounded by the smaller population size comparative to other programmes of care or general housing needs. This could be changed by the creation of a Learning Disability Housing Project/ Lead that has funding control and design rights to anticipate future need and respond accordingly within general and bespoke learning disability housing throughout Northern Ireland.

More effective joint commissioning based on assessed need and timely transition across DoH and DfC is critical if transformational change is to be achieved.

Specialist Assessment and Treatment

Ambition Statement 6: *I will enjoy the highest attainable standard of physical and mental health possible and have access to high quality, compassionate, assessment and treatment services, when required*

Delayed discharges or delayed complex discharges occur within most health care systems and reflect as an issue in recent strategic and literary reviews within the UK.

An expedited regional Work Stream was convened in 2019 by the Department of Health to undertake an Independent Review of Learning Disability Acute (intensive community and inpatient) level care for adults. The key drivers for this expedited Review were:

- Findings from Draft Level 3 SAI Review report relating to Muckamore Abbey Hospital;
- Evaluation of the Bamford Action Plan 2015-2017 (report pending);
- Systems, Not Structures, DoH (2016)
- Service provision for people with learning disabilities and psychiatric disorders in Northern Ireland. Advances in Mental Health and Learning Disabilities, 1 (1), 18 – 21. Taggart, L. (2016);
- Transforming Care: A national response to Winterbourne View Hospital, DoH 2012;
- RQIA Review of Restraint and Seclusion 2018 (report pending);
- Delivering Together (2016);
- Learning Disability and Behaviour that Challenges: service design and delivery, NICE Guideline, March 2018.

The purpose of this workstream was to undertake a review of the current service model/provision and clinical pathways in order to recommend a future best practice model for Acute (inpatient and intensive community) care and support for adults with a learning disability, which is regionally consistent and focused on relevant clinical and patient related outcomes, and which would form part of this Model.
The key challenges set out in this Review will be explored by the new Regional Task and Finish Group, called the Community Based Assessment and Treatment for Adults with a Learning Disability and Complex Needs. It is represented by all key stakeholders, to co-produce specialist services for community and inpatient care, in line with legislative and policy direction, NICE guidance and best practice. The focus of this work will be for individuals with complex needs, including ASD, behaviours that challenge and forensic. The key recommendations of this work will feature in the Model's Strategic Delivery Plan, and will be published later in the year as an Annex to the Model itself.

A key recommendation which can be progressed in Year 1 of the SDP is Positive Behaviour Support (PBS). PBS is a person centred framework for providing long term support to people with a learning disability, and/or autism, including those with mental health conditions, who have, or may be at risk of developing behaviours that

challenge. PBS approaches are based on a set of overarching values. These values include the commitment to providing support that promotes inclusion, choice, participation and equality of opportunity.

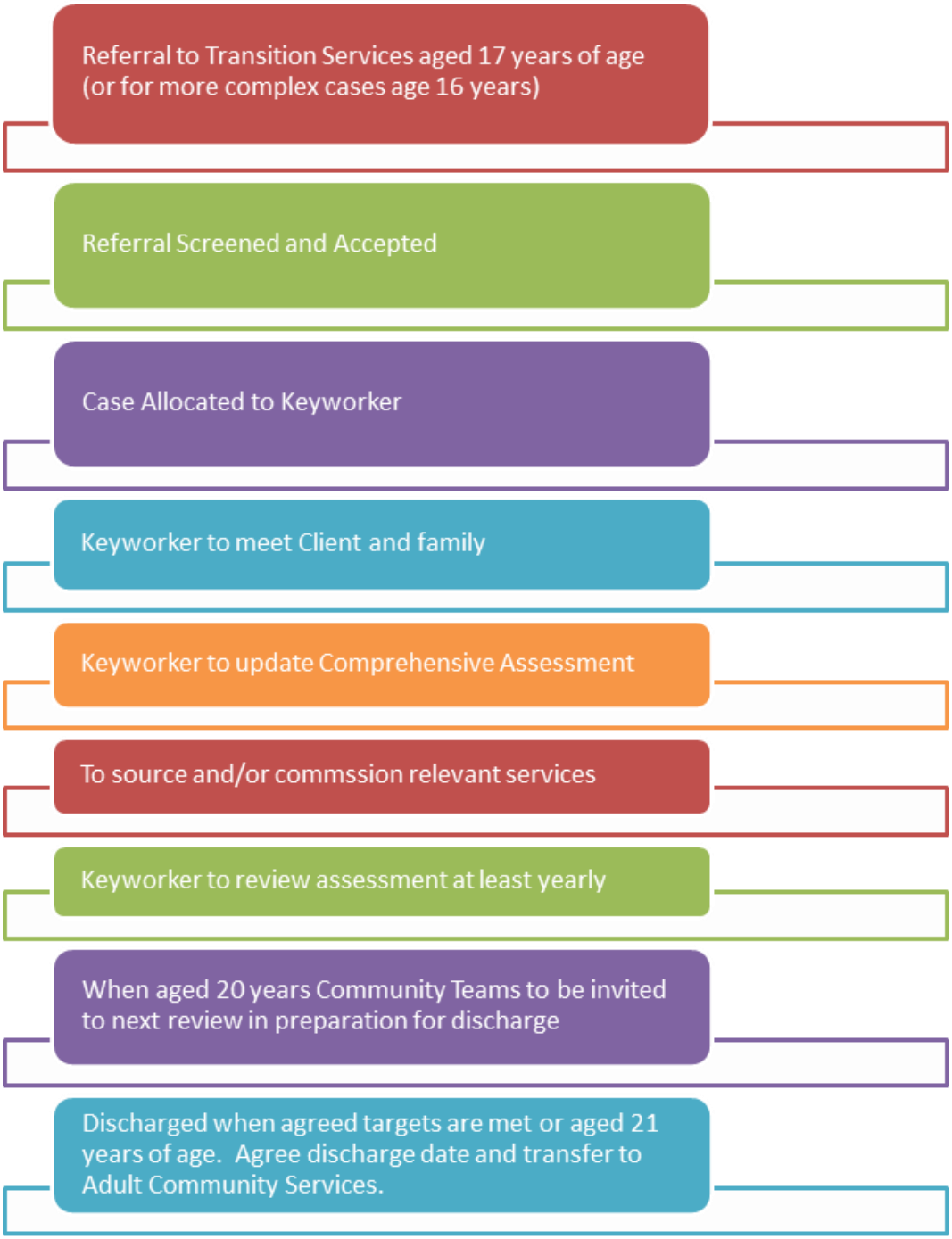
The overall aim of PBS is to improve the quality of a person's life and that of the people around them.

Over the past three decades, PBS has increasingly become the model of choice for supporting people whose behaviour poses a challenge to services. In order to ensure a regional PBS model for Northern Ireland, an Organisational and Workforce Development Framework should be developed as part of the overall LDSM Learning Development Framework. This will help support actions within all 6 Key Ambition Statements.

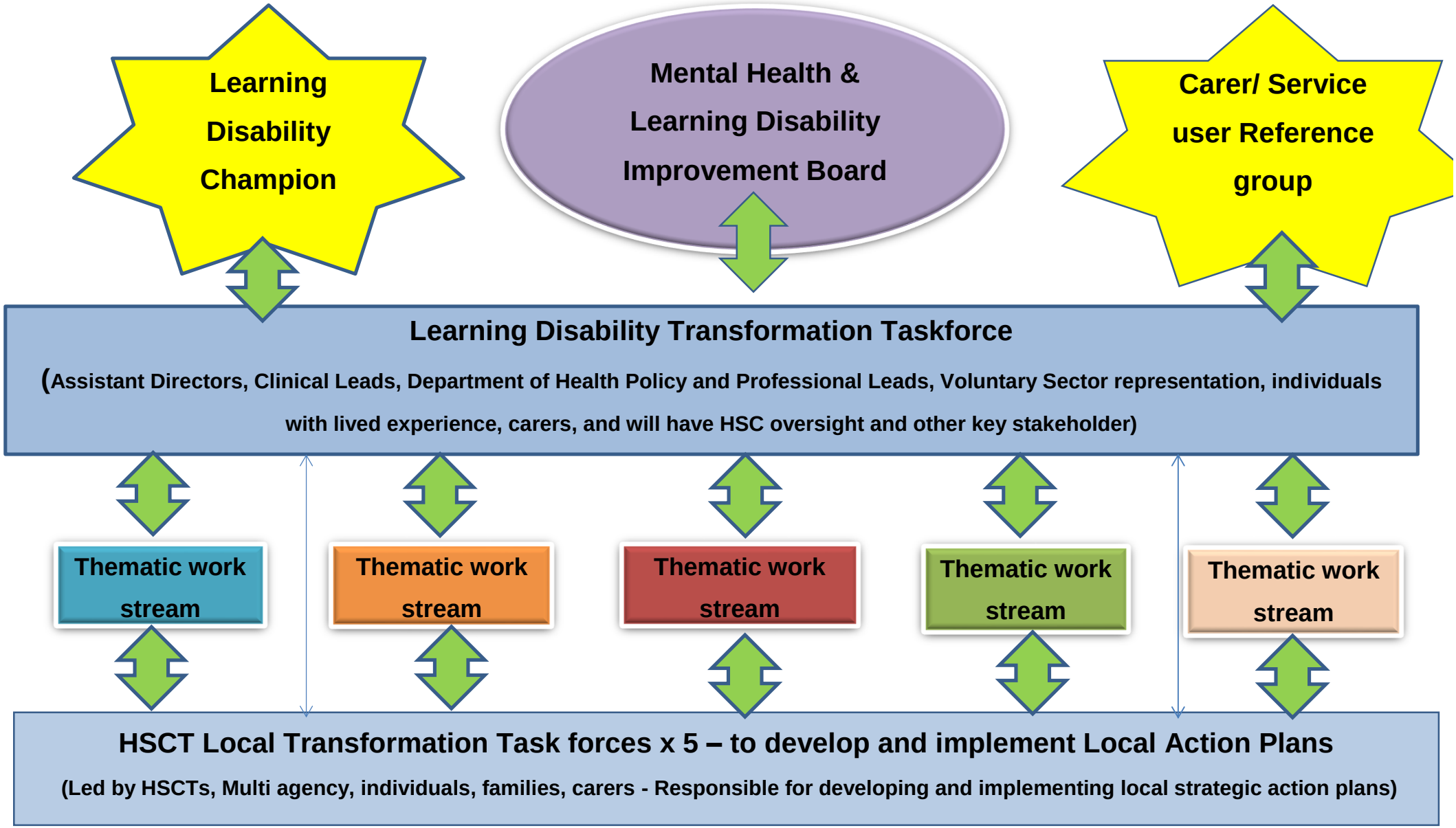
APPENDIX 7

Pathway of Care Example

Transitions from Children's Disability Services to Adult Learning Disability Services



APPENDIX 8 -Proposed Reporting Arrangements for "We Matter"



Health & Social Care Board

June 2021

"We Matter" Learning Disability Service Model for NI Executive Summary

SECTION 1

What is "We Matter"?

The NI Executive and leading organisations across Health & Social Care, Community & Voluntary Sectors and individuals with learning disabilities and carers, are committed to transforming care for individuals with learning disabilities.

Much progress has been made under Bamford and Equal Lives, but much more needs to be done.

The vision for "We Matter" is ***"as an individual with a learning disability I will be respected and empowered to lead a full and healthy life in my community. I will be supported to make choices and decisions in my life that enable me to develop, and live a safe, active and valued life".***

The Model has been developed in recognition that citizens live within a whole system sector and we need to involve other public sector organisations including for example, Department of Education (DE), Department of Communities (DfC), Department of the Economy (DOE). It is essential that DoH, other Government Departments, HSC organisations, voluntary and community sectors, private sector and carers work together providing support jointly to deliver the necessary change.

SECTION 2

Why "We Matter"?

The case for change for the Model is to address a number of on-going key challenges which have been identified by families, carers and staff working with individuals with learning disabilities, some of which include: -

- Reducing inequalities
- Increasing levels of complexity of needs
- Transitions
- Delayed discharges from hospital
- Lack of communication
- Provision of short breaks

A number of recent strategic developments, and more recent challenges have also highlighted a need to review Adult Learning Disability service provision, these include:

- Bamford Review of Mental Health and Learning Disability
- The Review of Learning Disability Community Services (Phase II) October 2016
- The draft Programme for Government (2016-2021)
- Health & Wellbeing 2026 Delivering Together (2016)
- The Mental Capacity Act (Northern Ireland) 2016
- Power to People: Proposals to reboot adult care and support in Northern Ireland (2017).

The Model outlines a road map for transforming learning disability services in NI over the next 3-5 years.

SECTION 3

Who is "We Matter" for?

The Model has been co-produced after engaging with over **3,600** service providers, carers and users of services. It is the result of an extensive programme of engagement, workshops, meetings and surveys between Feb 2019 – March 2020.

As the Vision states, we want individuals with a learning disability to be respected and empowered to lead a full and healthy life in their community. We want to support them make choices and decisions in their life that enable them to develop and to live a safe, active and valued life.

The Model is for all who access, develop and deliver services for individuals with learning disabilities and their families/carers. Whilst it specifically focuses on responsibilities for health and social care for Department of Health (DoH) and HSC providers, it also considers key actions for other Government Departments.

The Model will focus on the following key groups:

- Individuals diagnosed with a learning disability:
  - Who live in Northern Ireland
  - Who may have mild, moderate or severe learning disability and need support
  - Who may also have additional health conditions such as epilepsy, autism or dementia
  - Who may also have forensic learning disability needs
- Family and Carers
- Staff who provide care to individuals with a learning disability:
- Health and Social Care Trusts
- Local Communities
- Independent Community and Voluntary organisations

SECTION 4

How did we develop "We Matter"?

Over **190** engagement events were hosted across N. Ireland (March – December 2019) which 2860 individuals attended and/ or responded to.

A regional online survey was also rolled out and 3 regional workshops with local provider provisions were also facilitated, as well as visits to service providers were carried out.

In summary, **3,654** responses were received to identify the Key Ambitions, Outcome Measures and Key Actions for the Model. The feedback has been instrumental in developing key priorities for action for the next 3-5 years.

SECTION 5

What is the purpose of "We Matter"?

The purpose of the Model is to outline what individuals with learning disabilities expect of services, how services will achieve this and how they will be measured to ensure high quality, cost effective care.

The Model will provide more autonomy, choice and independence for individuals and support to their families and carers.

The Model describes a range of services and supports that should be in place for individuals with learning disability.

Depending upon their needs, individuals and their families will have services and support that is right for them and also be supported to navigate their way through the system, as their needs change.

SECTION 6

What will "We Matter" offer?

In order to achieve the vision set out in the Model, **6** Key Ambition Statements and **25** Outcome Measures have been developed. These will guide the transformation of services and be supported by ideas of transforming the way we work and Key Actions set out in the Delivery Plan (DP).

It is anticipated that the Key Actions set out will be implemented on a phased approach (3-5 years).This is set out in the Delivery Plan.

The 6 Key Ambitions are:

1. ***Life Changes***
2. ***Health and Wellbeing***
3. ***Carers and Families***
4. ***Meaningful Life and Citizenship***
5. ***Home***
6. ***Specialist Assessment and Treatment.***

These will be delivered across **25** Outcome Measures.

SECTION 7

What will "We Matter" offer individuals, families & carers?

"From my experience most family carers want services clearly signposted, access to these services in a timely way before crisis point, more education on the diagnosis and possibly training behavior that is challenging".- Carer

The Model outlines a roadmap for transforming learning disability services in Northern Ireland.

Most importantly the Model will place the individual at the centre and provide the right care in the right place at the right time. The Model will ensure that individuals with learning disabilities will have opportunities to make decisions that help maintain good health and wellbeing and HSC services will provide the tools to do this.

Services will be provided locally and will regard home as the hub. The Model offer a range of care based on the premise that individuals with learning disabilities can lead fulfilling lives in the community.

Where possible a mainstream service approach will be adopted, which entails facilitating access to generic/universal services for individuals with learning disability but with reasonable adjustments.

The Model will have standardised pathways to care in place.

In responding to changing need, crisis or circumstance, the Model will offer a swift response, with the flexibility to move between a range of supports available at each along the pathway of care.

Organisations will work together in a more integrated way to embed the pathways of care.

SECTION 8

"To make things better I'd like to go out in the evening and weekends so I'm not sitting in the house all the time". (Service User)

How will "We Matter" change the future?

The Model describes a number of transformational change ideas to help achieve the vision set out over the next 3-5 years and provide a road map to enable the dynamic change that will be required.

These include:

- **Learning Disability Systems Leader/Champion**
- **Learning Disability People's Parliament**
- **Learning Disability Network / Observatory**
- **Regional Website**
- **Regional Learning Disability Housing Lead**
- **Regional Informatics Framework and Register**
- **Learning** and **Development Framework**
- **An appropriately skilled multi-disciplinary work**

SECTION 9

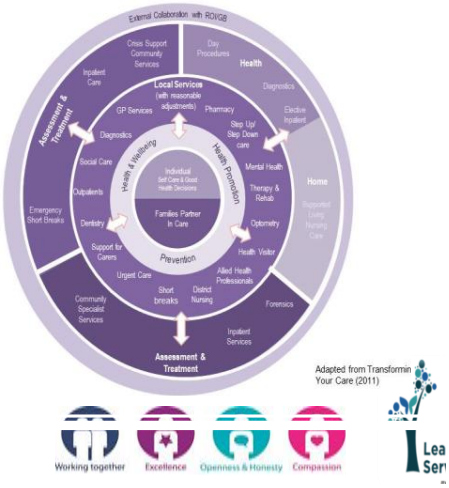
Who will take "We Matter" forward?

All Government Departments have a part to play in an individual's life, in terms of service provision. However, the Department of Health has primary responsibility for the delivery of this Model.

The existing Mental Health and Learning Disability Improvement Board will oversee the implementation of the Model against the Key Ambitions, Outcome Measures and Key Actions set out in the Strategic Delivery Plan (SDP).

A Learning Disability Transformational Taskforce (LDTT) will be established to oversee all developments relating to Learning Disability in general.

A Project Manager employed by the Health and Social Care Board will oversee the implementation of the Model in partnership with all the key stakeholders.



SECTION 10

How will we take "We Matter" forward?

"Family carers are presently providing the bedrock of social care; they know their family member better than anyone and need recognition as partners" (carer).

Publication of the Model is only the beginning of the process. There are a number of key things that now need to be put in place to ensure it is implemented. We call this the Strategic Delivery Plan (SDP).

The SDP will set out our Workplans, how we report progress, define**s** lead responsibility, identifies resource implications and sets timeframes. A **phased approach** to delivery will be described and developed.

Local Strategic Action Plans will be developed within each HSCT area specifically for learning disability and led by Local Transformation Taskforce(s). The composition of the groups should be "multi-agency multi spread" and have individuals, their families and their carers at the heart of the decision making process.

SECTION 11

Connecting "We Matter" to other Developments

The Model takes cognisance of Muckamore Abbey Action Plan and the SAI Report – A Way To Go and also draws on the views of HSC Trusts on the short, medium and long term approach to resettlement and provision of acute hospital care and specialist community and treatment services.

It is grounded in the following key Programme for Government outcomes:

- *We have a more equal society*
- *We enjoy long, healthy active lives*
- *We care for others and we help those in need*
- *We have high quality public services*
- *We give our children and young people the best start in life*