

Joint Commissioning Panel for Mental Health

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Guidance for commissioners of

mental health services for people with learning disabilities

Practical
mental health
commissioning

Joint Commissioning Panel for Mental Health

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Co-chaired by:



Royal College of
General Practitioners



Membership:



For better
mental health



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Ten key messages for commissioners

Many people with learning disabilities live full and rewarding lives as part of their local communities. In order to do this, they need support to have good mental health and wellbeing. Commissioners need to think about the following:

- 1 The prevalence of mental health problems in people with learning disabilities is considerably higher than the general population (see page 7)
 - commissioning for mental health problems must therefore be informed by a Joint Strategic Needs Assessment (JSNA) which takes into account the needs of people with learning disabilities (see page 13).
- 2 In addition to mental illness, people with learning disabilities often have coexisting autistic spectrum disorders, behaviours that challenge services, offending behaviour, or physical health conditions (see page 7). It is often hard to distinguish between these conditions especially when people have more severe intellectual impairments.
 - the JSNA must therefore provide detail about the number and needs of people with learning disabilities who have mental illnesses, as well as autism and behaviours that challenge services.
- 3 While there is no universally agreed commissioning model for mental health services supporting people with learning disabilities, the NHS Mandate¹ states that an NHS England objective is to:
 - ensure that Clinical Commissioning Groups (CCGs) work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities, and that a substantial reduction should occur in the reliance on inpatient care for these groups of people.
- 4 It is often difficult for people with learning disabilities to access generic and specialised mental health services. Consequently:
 - reasonable adjustments are a legal requirement and should be put in place to enable access to all mainstream services where appropriate
 - learning disability services should be provided alongside mainstream mental health services so that the skills and expertise from both services can be utilised in order to respond to individual need (see page 14)
 - there should be clarity with regard to commissioning arrangements between learning disability and mental health commissioners, with a presumption of accessing generic services wherever possible and there should be protocols setting out clear pathways between mainstream and specialist services.
- 5 The quality of mental health services should be measured from the perspective of the individual with learning disabilities and their family. Clinical effectiveness and outcomes, and patient safety, are also key (see page 18).
- 6 A positive experience for the individual with learning disabilities and their family is achieved by building a partnership through early involvement in service planning, delivery and evaluation as well as the provision of timely and seamless advice and support especially during periods of transition. Involving people with learning disabilities, their families and advocates in service planning, enables the provision of individualised services, one of the key characteristics of exemplary care or support².
- 7 Successful services provide individualised pathways of care, based on a thorough understanding of the individual and their experience. It should be person-centred and consist of a coordinated assessment of need, agreement of expected outcomes, provision of care and treatment, followed by a joint review of achieved outcomes with the people receiving services and their carers².
- 8 Commissioners should work in partnership with provider services in primary and acute care, and with local authorities including public health. This is a crucial first step to a better understanding of the needs of the population with learning disabilities and achieving an improvement in overall health and well being.
 - It is important to remember that NHS England should be promoting and facilitating joint and collaborative commissioning by local authorities and CCGs to support the development of better services.
- 9 Commissioning of mental health services should support the development of local, person-centred services, leading to the development of skilled local providers (see page 13).
- 10 Commissioners should evaluate the outcomes of the service models they are providing, checking for evidence of effectiveness, safety and user satisfaction. They should use this to agree priorities for investment as the commissioning landscape changes and personal budgets become more popular (see page 18).

Introduction

The Joint Commissioning Panel for Mental Health (JCP-MH) (www.jcpmh.info) is a new collaboration co-chaired by the Royal College of General Practitioners and the Royal College of Psychiatrists, which brings together leading organisations and individuals with an interest in commissioning for mental health and learning disabilities. These include:

- people with mental health problems and carers
- Department of Health
- Association of Directors of Adult Social Services
- NHS Confederation
- Mind
- Rethink Mental Illness
- National Survivor User Network
- National Involvement Partnership
- Royal College of Nursing
- Afiya Trust
- British Psychological Society
- Representatives of the English Strategic Health Authorities (prior to April 2013)
- Mental Health Providers Forum
- New Savoy Partnership
- Representation from Specialised Commissioning
- Healthcare Financial Management Association.

The JCP-MH is part of the implementation arm of the government mental health strategy *No Health without Mental Health*³.

The JCP-MH has two primary aims:

- to bring together people with mental health problems, carers, clinicians, commissioners, managers and others to work towards values-based commissioning
- to integrate scientific evidence, the experience of people with mental health problems and carers, and innovative service evaluations in order to produce the best possible advice on commissioning the design and delivery of high quality mental health, learning disabilities, and public mental health and wellbeing services.

The JCP-MH:

- has published *Practical Mental Health Commissioning*⁴, a briefing on the key values and principles for effective mental health commissioning
- provides practical guidance and a developing framework for mental health
- will support commissioners of public mental health to deliver the best possible outcomes for community health and wellbeing
- has so far published thirteen other guides on the commissioning of primary mental health care services⁵, dementia services⁶, liaison mental health services to acute hospitals⁷, transition services⁸, perinatal mental health services⁹, public mental health services¹⁰, rehabilitation services¹¹, forensic services¹², drug and alcohol services¹³, specialist community mental health services¹⁴, acute care (inpatient and crisis home treatment)¹⁵, older people's mental health services¹⁶, and child and adolescent mental health services¹⁷.

WHO IS THIS GUIDE FOR?

This guide is aimed at all commissioners responsible for mental health services for people with learning disabilities including young people in transition to adulthood. The guide will also be helpful for providers of mental health services and for family carers.

WHAT IS THIS GUIDE ABOUT?

This guide describes what we know about mental health services for adults with learning disabilities, and what effective and accessible services look like based on current policy, the law and best practice.

While this guide does make reference to autistic spectrum disorders and 'behaviours that challenge' (which people with learning disabilities who have mental health problems may also experience), the primary focus of this guide is on people with learning disabilities who have mental health problems.

Other guides on commissioning services for people with learning disabilities do exist (for example the publication *Improving the Health and Wellbeing of People with Learning Disabilities*¹⁸). It is also important to remember that all of the commissioning guides produced by the JCP (as outlined earlier) also equally apply to people with learning disabilities.

What are mental health services for people with learning disabilities?

WINTERBOURNE VIEW

Recent events at Winterbourne View Hospital have highlighted what we already know about the importance of robust CAMHS and transition services for young people with learning disabilities. People with learning disabilities are also more prone to develop dementia at an earlier age.

However, this guidance has been written because people with learning disabilities have particular needs that have not always been considered by commissioners of mental health services, and mental health and learning disability services do not always work well together to provide good support to people with learning disabilities and mental health problems.

HOW WILL THIS GUIDE HELP YOU?

This guide draws on current best practice and policy to describe what good mental health services for people with learning disabilities should look like.

By the end of this guide, readers should be more familiar with the needs of people with learning disabilities who have mental health problems, and should be better equipped to commission effective and accessible services for them. They should also be better equipped to work in partnership with social care commissioners in order to commission a full range of services that can support people to live in their own homes and live full and rewarding lives in the community.

The guide does not cover Child and Adolescent Mental Health Services (CAHMS). However, there is reference to good transition to adult mental health services. This guide also does not cover forensic services for people with learning disabilities.

WHAT IS A LEARNING DISABILITY?

Valuing People, the 2001 White Paper on the health and social care of people with learning disabilities, included the following definition of learning disabilities:

'Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development'¹⁹.

For a more detailed discussion of definitional issues, please see: www.improvinghealthandlives.org.uk/about/definition

WHAT IS A MENTAL HEALTH SERVICE FOR PEOPLE WITH LEARNING DISABILITIES?

A mental health service for people with learning disabilities provides specialist and personalised assessment, and care, treatment and support. The aim is to both (a) minimise the impact of mental illness and behavioural problems in order to (b) achieve an individual's maximum potential and a life that is fulfilling and integrated with the rest of society.

There is no one agreed model for mental health services for people with learning disabilities, and a wide variety of provision of both community and bed-based services. Due to an absence of a national policy, numerous service models have been developed locally. These include:

- jointly provided services where local mental health and learning disability services share facilities, teams and expertise and agree on outcomes to be achieved
- services where there is little joint working between mental health and learning disability services and little evidence of sharing resources
- poorly developed local services with a high reliance on out-of-area inpatient placements
- high reliance on mainstream mental health and older adult services, but sometimes without sufficient learning disability expertise to meet the mental health needs of this client group.

In an influential report for the Department of Health, Mansell (2007) recommended a model consisting of local services including small scale housing, work, education and day placements, with skilled staff backed up by specialist advice and support from multiprofessional teams and access to the full range of mental health and learning disability services². This also emphasised the need for practical support and training for family and other carers, including the availability of short breaks.

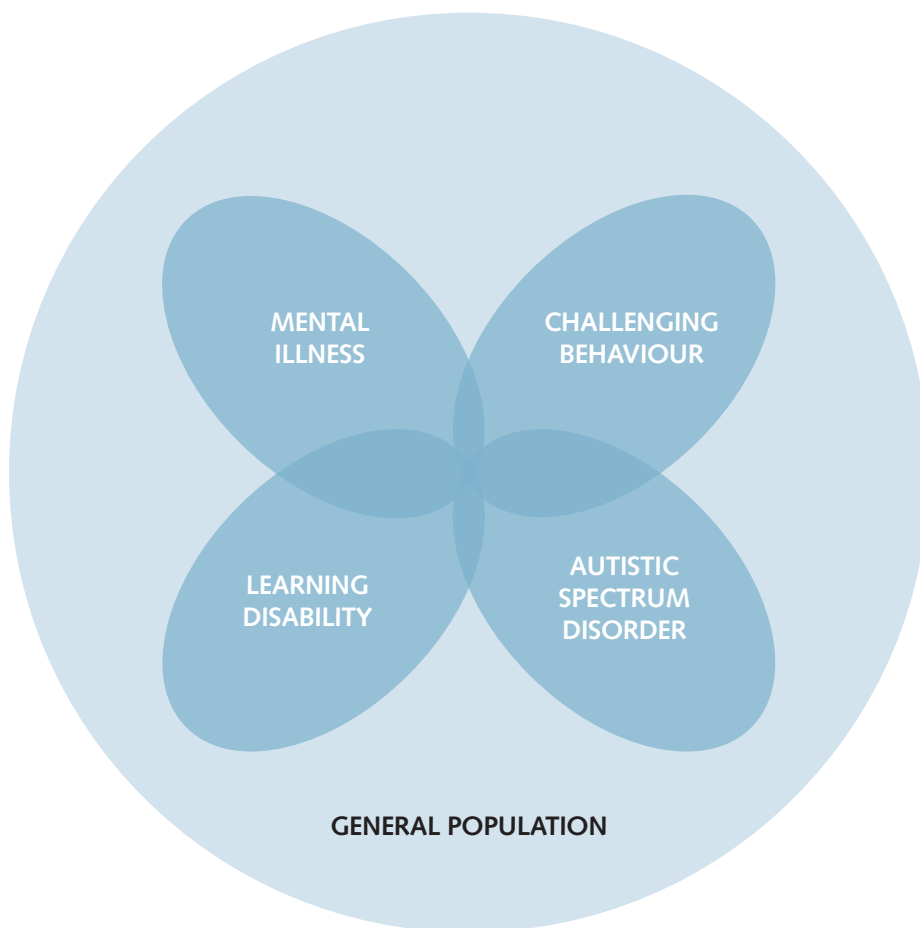
What are mental health services for people with learning disabilities? (continued)

WHAT ARE THE MENTAL HEALTH NEEDS OF PEOPLE WITH LEARNING DISABILITIES?

People with learning disabilities who have mental health needs, experience a wide range of problems and therefore require a wide range of services. They can have the full range of mental illnesses seen in the general population such as schizophrenia, bipolar disorder, depression, anxiety disorders, specific phobias, agoraphobia, obsessive compulsive disorder and dementia (see page 7).

A significant number of people with learning disabilities display behaviour problems that are described as challenging. These include aggressive behaviour directed towards others, self-injurious behaviour, and a range of socially unacceptable behaviours. Some of these behaviours may be sufficiently severe to lead to contact with the criminal justice system. Behaviour described as challenging should not be confused with mental health problems, although people may have both. There is also a high prevalence of autism spectrum disorders in people with learning disabilities who have mental health and behavioural problems. The overlap between mental illness, behaviour problems, offending behaviour and autism is shown in [Figure 1](#), and considered further on page 7.

Figure 1: Mental health needs of people with learning disabilities



Why are mental health services for people with learning disabilities important to commissioners?

There are four main reasons:

- 1 the increased prevalence of mental health problems among people with learning disabilities, compared to the general population
- 2 the large number of people with learning disabilities and mental health problems that have behaviours described as challenging, developmental disorders, or other conditions
- 3 the critical need for improvements in services for people with learning disabilities
- 4 cost considerations.

1 INCREASED PREVALENCE OF MENTAL HEALTH PROBLEMS

There are estimated to be about 1.2 million people with learning disabilities in England²⁰. Nine hundred thousand are over 18 and 189, 000 are known to services²⁰. The prevalence of mental health problems in adults with a learning disability is considerably higher than found in the general population. Estimates of prevalence range between 30% to 50%^{21,3}. Although this guide is about adults, commissioners will need to plan services for young people coming through transition. The prevalence of psychiatric disorders among children with learning disabilities is 36%, compared to 8% among children without learning disabilities²².

Based on the above estimates, this means that a General Practitioner (GP) caring for a population of 2000, would have 32 adults with learning disability on their register, of which 10-15 would have mental health problems.

Table 1: Estimated prevalence rates from population-based studies of adults with learning disability²¹

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%
Dementia at age 65 years and over	20%
Autism	7%
Severe problem behaviour	10–15%

Note: for further information on the local prevalence of people with learning disabilities please visit: www.ihal.org.uk/profiles/

2 COEXISTING PROBLEMS

Fifty percent of people with a learning disability referred to a community learning disability service had mental health needs in the same categories as people in the general population²³. The remaining proportion had a higher prevalence of challenging behaviours and autism. Common co-existing conditions include:

- people with learning disabilities have high levels of physical ill health. When combined with other factors such as poor access to services, this can result in a significant level of inequality of health status²⁰. The *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* found that 42% of the deaths they reviewed were premature. The most common reasons

for deaths being assessed as premature²⁴ were delays or problems with diagnosis and treatment; and problems with identifying needs and providing appropriate care in response to changing needs²⁵. Physical health problems can also trigger or worsen mental health and behaviour problems. Some physical problems can have a major impact on mental health and behaviour (e.g. pain, epilepsy, constipation, infections, and medication)²⁶.

- genetic syndromes such as Prader Willi, Cornelia de Lange and Down syndrome, which are associated with specific mental health and behaviour problems, and for which specialist skill is required²⁰.
- autistic spectrum conditions – the prevalence of autism has been reported to be as high as 20-30% in people with learning disabilities known to local authorities²⁰.
- behaviours that challenge (10-15% of people with learning disabilities): 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 exclusion²⁷.
- dementia: people with learning disabilities and Downs syndrome are at significant risk of developing Alzheimer's disease²⁰.
- attention deficit hyperactivity disorder (ADHD), which is known to co-exist in people with learning disabilities. Although most studies are in young populations ADHD it is well documented that ADHD can persist into adulthood^{28,29}.

What do we know about current acute care services? (continued)

3 CRITICAL NEED FOR IMPROVEMENT IN SERVICES

People with learning disabilities are a vulnerable population who have a significantly higher risk of developing mental health problems which can be overlooked or wrongly attributed to the learning disability itself. Undetected mental health problems cause considerable distress to the individual and to family carers, and can lead to expensive and unnecessary placements, when community placements break down. Recent events at Winterbourne View have reinforced the importance of good quality commissioning for people with learning disabilities who may also have mental health problems and behaviours that challenge services. Services for people with these overlapping set of conditions are expensive, and yet their quality and effectiveness is not always well monitored. Boundary disputes between learning disability services and mainstream mental health services can have adverse financial implications and produce poorer outcomes for the person.

4 COST CONSIDERATIONS

Delay in detection, assessment and treatment can lead to a progressive deterioration of mental health and behaviour. This can lead to the need for more intensive services for a longer period of time, often in a more restrictive and distant setting. As well as causing unnecessary suffering to the individual and their family, this can increase costs significantly. Therefore proactive and preventive approaches should always be employed. It should be recognised that initially, the cost of supporting an individual in the community may be more than the cost of a bed-based service. However, commissioners are strongly urged to consider 'invest to save' options, as the cost of services that meet people's needs and provide good outcomes is likely to reduce over time³⁰. These 'invest to save' options include:

- creating sufficiently skilled resources in community services such as intensive response teams
- supporting the development of skilled provider services
- agreeing the principle of seeking to reduce costs of individual services once they are firmly established – but in the context of demonstrable outcomes and safe practice, and not as a fixed or arbitrary figure per year (it should also be recognised that for some people the costs will not reduce, as it is the level of support provided which keeps the person stable, and which will vary depending on the outcome which can fluctuate)
- adopting flexible contracting systems that can rapidly respond to changes in the needs of people being supported.

Use of mainstream local services may reduce stigma and negative professional attitudes, as people are more likely to become part of their local community, and staff can see what may be achieved.

What do we know about the current provision of mental health services for people with learning disabilities?

This section is divided into two parts: (A) current service provision; and (B) wider policy frameworks.

A. CURRENT SERVICE PROVISION

People with learning disabilities and mental health problems can come into contact with a wide range of services including:

- 1 primary care
- 2 psychological therapies
- 3 community learning disability services
- 4 inpatient learning disability services
- 5 generic mental health services
- 6 services at the interface (transition services).

The level of coordination between different service elements can vary, and can also lead to delay and duplication as well as high costs.

1 PRIMARY CARE

The first point of contact with health services for many people is primary care. However, people with learning disabilities may not know that they are unwell, or may not be able to tell people that something is wrong. A reasonable adjustment that has been made to address this issue is the implementation of annual health checks as part of a Directed Enhanced Service (DES), as there is clear evidence that health checks identify unmet health needs. The DES specifies that the Cardiff Health Check or similar approach should be used for health checks. The Cardiff Health Check includes a section on 'the presence of behavioural disturbance'

which may help GPs identify mental health problems. There is also a section for the review of medication. However, only people with learning disabilities who are known to social services are eligible for an annual health check, which tends to exclude people with mild learning disabilities, and tightening of eligibility criteria will exclude more people. Only 53% of those eligible received a health check in 2012, although some areas did much better than others³¹.

See: www.improvinghealthandlives.org.uk/numbers

While we know about the number of people with learning disabilities known to GPs, and the number who have had health checks, we do not know how many were diagnosed with a mental health problem, or what happened to those that were. However, early detection and treatment, is important.

People with mild learning disabilities who are vulnerable to common mental health problems may not have access to the same support that might be available to people with more significant learning disabilities. This is because they may not fit easily into mainstream or specialist services.

2 PSYCHOLOGICAL THERAPIES

A range of psychological services are available from community learning disability and mental health services. It is government policy that the Increasing Access to Psychological Therapies (IAPT) programme should be accessible to people with learning disabilities³². However, there are anecdotal reports that some IAPT services may be excluding people with learning disabilities³³. If correct, this represents a breach of equalities legislation, and is not the intention of national policy.

The Department of Health (2009) has produced guidelines to improve access for learning disability populations³². These include strategies to improve understanding of the needs of people with learning disabilities, removing barriers to access, improved engagement with people with learning disabilities and better training and development of the workforce³⁴.

Recommendations

- reasonable adjustments should be made to local IAPT services to ensure that people with learning disabilities can access them
- clear pathways should exist between local IAPT services and community learning disability services (CLDTs) to ensure that no one who requires access to psychological therapies meets exclusion criteria for both services.

3 COMMUNITY LEARNING DISABILITY SERVICES

A significant part of existing mental health services for people with learning disabilities are provided by psychiatrists, psychologists, nurses and a range of therapists working in multidisciplinary teams. These teams often have close links with primary care teams through health facilitation nurses and other shared facilities. They should operate in an integrated manner with social work and local authority services as part of integrated or joint commissioning arrangements. They may also have links with local mental health services providing consultancy, advice and joint working. They may have professionals with special expertise in the management of people with behaviour problems, and may include intensive response, home treatment or crisis teams.

What do we know about the current provision of mental health services for people with learning disabilities? (continued)

A recent survey³⁵ highlighted the role of community learning disability services to involve:

- delivering direct specialist interventions and specialist advice
- reducing health inequalities
- supporting health professionals in general and mental health services
- reducing out-of-area placements
- supporting personalisation
- safeguarding
- supporting transition between teams (e.g. children and older people)
- working with the criminal justice system.

Recommendations include:

- ensuring that members of the community learning disability service are skilled in the assessment and support of people with learning disabilities who have additional mental health problems. This needs to include skills in risk management and the provision of community-based support to people who present additional needs.

4 INPATIENT LEARNING DISABILITY SERVICES

Inpatient services are used when the intensity and severity of mental illness and associated behaviour problems reaches a level when the individuals and people around them are at risk of harm and they can not be safely assessed and supported in community settings. The pattern of provision of these services has been reviewed³⁶. Provision varies, but the main aim of any inpatient service is to provide focused treatment and support with the aim of getting the individual back into the community as soon as possible. Discharge planning should start on admission or before. Weaknesses in commissioning can lead to prolongation of inpatient care as community-based placements are not readily available.

Recommendations include:

- appropriate inpatient and community services should be accessible to people with learning disabilities where possible
- care pathways should span community services and the different types of inpatient beds
- community services should work to reduce the numbers of people in inpatient beds and reduce stay to a minimum
- inpatient services should be subject to monitoring, inspection, audit of quality including effectiveness, safety and patient experience
- the skills of local provider services should be developed so that they can more effectively support people in the community, and do not need to rely on inpatient care as the only alternative.

5 GENERIC MENTAL HEALTH SERVICES

People with learning disabilities who have mental health problems may have needs that are better met in generic mental health services. However, in practice, generic services have often provided a service only for people with mild and borderline learning disability, although their role has been reviewed recently³⁶.

It is difficult to describe or recommend a universal interface between generic mental health services. This is because learning disability services as models of service vary across the country, and there has been a history of mental health and learning disability services working separately which has sometimes been exacerbated by disagreements about eligibility and funding. It is also difficult to tell how many people with learning disabilities access mainstream mental health services, as although all Foundation Trusts should have a flagging system in place, it is not clear how well they are used. Flagging systems should include the reasonable adjustments an individual needs, in order to provide appropriate care and support. In some areas, liaison nurses have been identified in mainstream mental health services to improve support for people with learning disabilities, with some success (see page 18). In-reach functions can also be provided by learning disability services.

A recent systematic review reported that there is no evidence that a comprehensive system of mental health care can be provided by hospital-based services or by services on their own³⁷. However, a balance is necessary which includes both hospital and community components (the 'balanced care' model). The relevance of this for people with learning disability needs to be explored.

6 TRANSITION SERVICES

In the absence of national guidelines in the form of National Service Frameworks there is no consistent model of integrated service provision between specialist areas of provision (services for young people, adults, older people, rehabilitation, forensic etc). However, the Integrated Care Network has summarised the strategies that services have used to improve joint working between services³⁸. Co-location structures could stimulate effective and efficient multidisciplinary working. The challenge and the opportunity is to find ways to work collaboratively, across agencies and departments, in a way that engages staff at all levels and works with them to develop structures and systems, rather than imposing them. The importance of JSNAs in understanding the future needs of the population is highlighted, as is effective engagement of people with learning disability. These principles would help bridge potential gaps at the interface of services. The Green Light for Mental Health team have also developed a toolkit for improving mental health support services for people with learning disabilities³⁹. These cover primary care services, mental health services, learning disability services as well as public and voluntary sector services. Evaluation of the toolkit flagged up obstacles to change which included a lack of local data; capacity issues and competing priorities; the need to change practices; engagement issues; the challenge of change; and a lack of agreements and pathways⁴⁰.

Due to the high number of children with learning disabilities who have mental health problems, a good CAMH service and mental health transition for young people with learning disabilities is vital, and health and social care commissioners should develop effective links with children's services to ensure early planning at transition and joint services⁴¹. The need to overcome existing

silos that lead to adult and child services being commissioned separately and the importance of a seamless transition have been highlighted recently by JCP-MH guidelines^{8,17}. Services for people with learning disability who show offending behaviour need to be effectively integrated with mental health services.

People from black and minority ethnic groups

Although robust data do not exist on the number of people with learning disabilities from black and minority ethnic groups who also have mental health problems, it is likely that they experience the same issues as other people from BME groups. In 2010, the National Mental Health Development Unit reported that:

- black ethnic groups are four times more likely to experience psychosis than white people
- black men are more likely to be admitted via the criminal justice system
- people from BME groups are over-represented in secure services
- fear is an ongoing barrier to accessing services
- BME communities feel that they are more likely to be prescribed higher doses of medication⁴².

They also reported that around 10% of people with mental health problems from a white ethnic background were hospitalised, compared to 11.5% from an asian or asian British group, 14% from a mixed ethnicity group, and 19% from a black or black British group⁴².

In 2009, Raghavan found that for ethnic minority communities additional barriers were knowledge and awareness of services, language difficulties, one size fits all (colour blind) services, religious beliefs and social stigma⁴³. Improving cultural sensitivity and cultural competence in staff will require the improved recognition of cultural beliefs and practices. A culturally

competent workforce is able to listen, understand and clarify the needs of people from ethnic minorities, and to examine their own beliefs and assumptions about other communities to develop inclusive thinking and behaviour.

B. WIDER POLICY FRAMEWORKS/INCENTIVES

These include:

- 1 Winterbourne View report
- 2 Winterbourne View – concordat
- 3 Nothing about us, without us
- 4 Valuing people now
- 5 Payment by Results

1 WINTERBOURNE VIEW REPORT

The DH report into Winterbourne View recommended that

- all current placements will be reviewed and everyone inappropriately in hospital will move to community-based support as quickly as possible
- each area will have a locally agreed joint plan to ensure high quality care and support services for all children, young people and adults with learning disabilities or autism and mental health conditions or behaviour described as challenging, in line with the models of good care; as a consequence, there will be a dramatic reduction in hospital placements for this group of people and the closure of large hospitals
- a new NHS and local government-led joint improvement team, with funding from the Department of Health, will be created to lead and support this transformation
- it would strengthen accountability of Boards of Directors and Managers for the safety and quality of care which their organisations provide, setting out proposals to close this gap

What would a good acute care service look like? (continued)

- the Care Quality Commission will strengthen inspections and regulation of hospitals and care homes for this group of people – this will include unannounced inspections involving people who use services and their families, and steps to ensure that services are in line with the agreed model of care
- the improvement team would monitor and report on progress nationally⁴⁴.

2 WINTERBOURNE VIEW REVIEW CONCORDAT

The Department of Health further committed itself to work with partners including the Association of Directors of Adult Social Services and providers to develop practical resources for commissioners, including:

- model service specifications
- new NHS contract schedules for specialist learning disability services
- models for rewarding best practice through the NHS Commissioning for Quality and Innovation (CQUIN) framework
- a joint health and social care self-assessment framework to support local agencies to measure and benchmark progress⁴⁵.

It also gave high priority to involving children, young people and adults with challenging behaviour and their families, carers and advocates in planning and commissioning services, and to seek and act on feedback about individual experience.

Safeguarding

Winterbourne View highlighted the need to strengthen adult safeguarding arrangements, as there was an absence of processes for commissioners to be told about safeguarding alerts, and a failure to follow-up concerns when commissioners were made aware of them. The government plans to put Safeguarding Adult Boards on a statutory footing, subject to parliamentary approval of the Care and Support Bill. Core membership will consist of the local authority, NHS and police organisations. Everyone involved in safeguarding should be clear about their roles and responsibilities.

3 NOTHING ABOUT US WITHOUT US

The Department of Health in collaboration with The Service Users Advisory Group published the above document in 2001 to emphasise the need “to include people with learning disabilities properly in everything that they do” including the planning, delivery and monitoring of services⁴⁶.

4 VALUING PEOPLE NOW

In 2009, Valuing People Now established cross-cutting themes that should underpin services for people with a learning disability: rights, independent living, control, and inclusion¹⁹. This document provided the following structure to commission better services:

- including everyone
- personalisation
- having a life (including health, housing, work, education, relationships and family)
- citizenship (including advocacy, transport, leisure and social activities, being safe and having access to justice)
- making it happen.

5 PAYMENT BY RESULTS (PbR)

The introduction of mental health PbR is a major organisational change for both providers and commissioners. For the first time, clinicians will have a direct impact on the funding that their organisation receives through their work to deliver high quality care and to achieve better outcomes. Commissioners will start to understand in detail how the services they are purchasing meet the needs of individual people, and how this directly affects the prospects for patient recovery⁴⁷.

While PbR has not yet been mandated for use in learning disability services, a review and possible modification of existing need clusters to improve applicability to this population will lead to greater integration and improve access to mental health services for people with learning disabilities⁴⁸.

A national pilot study has led to the drafting of additional mental health clusters which result in differing resource and skill requirements and resulting tariffs for commissioning mental health services for people with learning disabilities.

Recommendations

It is therefore recommended that (a) any additional need clusters should be used to develop costed pathways of care based on need; (b) there should be greater coordination and integration for commissioning mental health services for people with learning disabilities; and (c) need clusters should be used to profile the mental health needs of the population of people with ID.

What would good mental health services for people with learning disabilities look like?

Public sector agencies have a statutory duty, under the Equality Act 2010 and the NHS and Social Care Act 2008, to make reasonable adjustments to their services, so that they are accessible and effective for people with learning disabilities.

This legal duty is 'anticipatory', meaning that mental health agencies should consider, in advance, what adjustments people with learning disabilities need in order to access them. Reasonable adjustments include removing physical barriers to access, as well as making alterations to service delivery, policy, procedure and staff training to ensure that services work equally well for people with learning disabilities. The Equality Delivery System (EDS) is designed to help NHS organisations improve equality performance, embed equality into mainstream NHS business and meet their duties under the Equality Act.

For further information go to www.nhsemployers.org/EmploymentPolicyAndPractice/EqualityAndDiversity

Services for people with learning disability and mental health needs should be based on a clear understanding of the needs of the population served.

Assessment

Commissioners should ensure that the JSNA includes this information, including the needs of young people with learning disabilities who are in transition to adulthood. This forms the basis of collectively agreed priorities for action set out in the health and wellbeing strategy. However a recent analysis of JSNAs suggests that the information contained in JSNAs on people with learning disabilities currently is unlikely to be of use in planning services⁴⁹.

Nationally collected data on people with learning disabilities, along with research summaries and good practice guidance can be found on the IHaL website (www.ihal.org.uk). The IHaL website also hosts the Self-Assessment Framework (SAF) results. The SAF, which is now joint with social care, is a helpful tool as it involves specialist healthcare professionals as well as people with learning disabilities and family carers in assessing local services, and therefore provides good evidence of local involvement. The SAF brings together many standards for learning disability services that are in other documents. Details of the SAF and assessment results can be found at: www.ihal.org.uk/self_assessment/

Service development

Commissioners should work with their local authority colleagues to develop a range of responsive local services which can prevent admissions to hospital or other large institutional settings, and allow any existing patients to be moved to better settings, closer to home⁴⁴. This is an essential first step to avoid unnecessary and expensive admissions. Pooled budgets are an important way of developing shared ownership, and eliminating cost shunting.

Mansell (2007) classified senior managers and commissioners by their intentions in relation to services for people who challenge, which can also be applied to services for people with learning disabilities and mental health². It is recommended that local models should aim to be 'developers':

- **'removers'** seek to place people who cannot be served locally in out-of-area placements. They do not seek to develop local competence, maybe because they think that it is not worth the effort or too difficult.
- **'containers'** do provide local services but only provide low-cost, poorly staffed facilities that contain people.

- **'developers'** seek to provide services that meet individual needs, and give higher priority to funding these services, with more staff, training and management input.

Building on the Mansell report, *the Guide for commissioners of services for people with learning disabilities who challenge services* developed some practical advice for commissioners wanting to nurture a culture of development rather than containment or removal³⁰. Recommendations include:

- basing all decisions on a clear set of visions and values, with a commitment to 'ordinary life' principles
- working in partnership with individuals and families
- taking a medium to long-term approach to progress and not expecting unrealistic short-term gains
- all partners being willing to do 'whatever it takes' to achieve positive outcomes, even when the going gets difficult
- identifying and supporting innovators and risk takers
- strong clinical leadership that is committed to the vision and to partnership working
- commissioners (including care managers) and clinicians working together well, and using each others' expertise
- a trusting relationship between commissioners and providers rather than one based on arms-length contracting
- the NHS and local authority bring their resources together and agreeing clear boundaries based upon shared responsibility
- choosing providers who have a positive attitude to partnership, who are outward looking, who don't give up in difficult times

What would good mental health services for people with learning disabilities look like? (continued)

- staff being recruited on the basis of their attitude, in particular towards positive risk taking, at least as much as their formal skill base
- not using agency staff.

Mandate for NHS England

An NHS England objective is to: ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; and the Mandate contains an explicit expectation of a substantial reduction in reliance on inpatient care for these groups of people¹.

SPECIALIST TEAMS

In order to support community learning disability services and primary mental health care teams, commissioners should commission services that provide good mental health assessment, treatment and support with expertise in working with people with learning disabilities. This could be within an existing specialist learning disability team, as a specialist mental health team, or part of generic mental health services. This should include (but not necessarily be limited to):

- mental health and learning disability nurses
- clinical psychologists
- psychiatrists
- speech and language therapists.

Staff should have a strong commitment, and be skilled at working in a person-centred way to provide individualised services based on the person's aspirations. They should be skilled in mental health issues and be able to provide a range of interventions including psychological therapies. In addition, they should have skills in positive behaviour support approaches for those people that

require it (positive behaviour support is a framework for developing an understanding of an individual's behaviour, and for using this understanding to develop effective support).

Staff should also be able to work with a range of different agencies. There should be strong clinical leadership which promotes a 'no blame' culture, enabling staff to take appropriate risks so that people can live as independently as possible in their own homes. Their focus should be on providing expertise so that people can be supported at home in the local communities wherever possible.

There must be clarity with regard to commissioning arrangements between learning disability and mental health commissioners. There should be a presumption of accessing generic services wherever possible, and there should be protocols setting out clear pathways between mainstream and specialist services, including the support being provided by specialist practitioners to mainstream services.

The Green Light Toolkit (2004) provides standards for joint working in a number of areas an example of which is provided in box 1³⁹. This toolkit is currently being revised.

The service should also be commissioned in partnership with the local authority commissioners of learning disability services and the specialist mental health services operating as part of an integrated approach to service design and delivery. At the core of good practice lie the joint working arrangements between general adult mental health services and community learning disability services. This collaboration can ensure that care pathways for people who may need support for mental ill health are clearly delineated and that high-quality care, including reasonable adjustments where necessary, is delivered promptly³⁶. Adjusting mental health services to meet the needs of people with learning

BOX 1: JOINT WORKING Roles, responsibilities and cross-service support

- protocols for transfer or shared care between learning disability and generic mental health services exist and clearly specify consultant responsibility
- protocols for transfer or shared care between learning disability and mental health services exist and clearly specify the roles and responsibilities of inpatient and community teams in both mental health and learning disability services
- where a person with a learning disability is having services from both mental health and learning disability services there is joint care planning at an individual level
- where a person with a learning disability is having services from both mental health and learning disability services the written care plan specifies what support each service can expect from the other.

One or none of the features apply (red)

Two or three of the features apply (amber)

All of the features apply (green)

disabilities will not only enable services to meet their needs under equalities legislation, but is likely to improve the quality of services.

USEFUL RESOURCES

The Commissioning For Quality and Innovation payment framework (CQUIN) is a commissioning tool which makes a proportion of the providers income conditional on delivering quality and innovation. It has been used in mental health services to improve access for people with learning disabilities (see page 18).

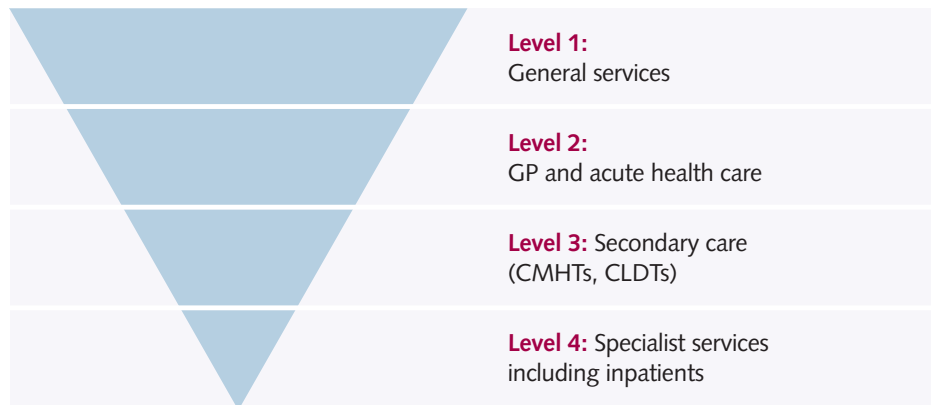
Personal Health Budgets in the NHS and Personal Budgets in social care are at the heart of personalisation, and should always consider facilitating recovery for people with mental health problems: *'People choosing Personal Budgets and a Personal Health Budget should have the right to an integrated assessment across the NHS and social care, an integrated support plan, a single individual budget and an integrated review, regardless of how they choose to hold the money.'*⁵⁰

Most areas still have Learning Disability Partnership Boards which were set up as a result of Valuing People and which bring together commissioners, service providers, people with learning disabilities and family carers amongst others, and provide helpful links to wider self-advocacy and family carer groups. They can be an excellent source of information about local needs.

KEY SERVICE COMPONENTS

People with learning disabilities will access a range of primary care and local authority services during their lives. A proportion will need additional secondary services, and a minority will receive the full range of services. To achieve this primary care teams led by GPs, secondary mental health services and learning disability services should be well integrated so that individual service users can receive coordinated care. Planning ahead is crucial. Advocacy services should be available, and individuals should have proper person-centred plans for the services they need now and in the coming years. Planning ahead also means building capacity into the system to cope with demand as it emerges, rather than waiting until crises occur². The relationships between these key components of the service are represented in Figure 2.

Figure 2: Service organisation for meeting mental health needs for people with learning disabilities



Level 1

These services are primarily focused on improving the health of the whole population of people with learning disabilities. Good access to housing, leisure, education, transport and employment are known to have a positive impact on mental health. Other priorities include neonatal screening, early detection and treatment for conditions such as congenital hypothyroidism and phenylketonuria.

Level 2

People with learning disabilities should have good access to mainstream health services. In primary care, this means regular health checks, advice and support on lifestyle factors such as diet, exercise, alcohol consumption and sexual health. Other services include health facilitation to improve access to primary care and health liaison to improve access to acute hospital-based care. Training and support for carers should be made available. Improving Access to Psychological Therapies is included at this level.

Level 3

Community mental health and learning disability teams which provide assessment, treatment and some on-going support for people with a **moderate degree of mental health need** (significant anxiety and depression, psychotic disorders, and cognitive impairment). These teams would need to have expertise in dealing with perceived behaviour problems associated with these conditions, as well as the whole range of learning disability and coexisting autism and ADHD.

Level 4

These services need to have expertise in dealing with people who are a severe risk to themselves and others, often with chronic severe treatment resistant mental illness, behaviour problems and offending behaviour. Services at this level include community-based assessment and treatment using a combination of crisis and home treatment teams, behaviour support services, forensic teams and experts in autism, ADHD, eating disorders, dementia and epilepsy. Inpatient services may also be required where 24 hour assessment and treatment would enable a safe return to well resourced community-based packages of care. The appropriate role for psychiatric hospital services for people with learning disabilities lies in short-term, highly-focused assessment and treatment of mental illness. This implies a small service offering very specifically, closely defined, time-limited services. The reason for admission must be clearly stated and families should be involved in decision making. Where an individual lacks capacity and does not have a family to support them, the procedures of the Mental Capacity Act 2005 should be followed to ensure that decisions made are in her/his best interest and, if appropriate, an Independent Mental Capacity Advocate appointed.

It is unlikely that one geographical area will provide all the specialist services that may be required from time to time (e.g. eating disorders for people with learning disabilities). Effective pathways and local protocols may be required with the specialist services.

What would good mental health services for people with learning disabilities look like? (continued)

COMMISSIONING A PERSONALISED PATHWAY OF CARE

To meet a variety of individualised needs consistently, effectively, safely and in partnership, commissioners will need to:

- understand the needs of the population
- plan intervention and treatment based on assessed need
- ensure/develop corresponding skills in providers
- use person-centred, outcome-focused treatment plans
- provide incentives to timely achievement of agreed outcomes
- develop a range of personalised pathways of care the core components of which are shown on figure 3.

This model of service provision relies on an integrated approach between mental health and learning disability services. There should be a single point of entry after which the assessment of need commences. This would clarify the range of skills best able to meet the assessed need and achieve mutually agreed outcomes. The agreed care plan is provided by professionals with the appropriate skills needed to support the individual to achieve agreed outcomes effectively and safely, regardless of which service or agency they work for. In some instances, the skills may be available wholly in the mental health service, or in the learning disability service. In other cases, there would be a need to share skills and work jointly across services. In complex care when several individuals provide care and treatment an agreed individual must coordinate the delivery of treatment.

Commissioners should “involve children, young people and adults with challenging behaviour and their families, carers and advocates in planning and commissioning services and seek and act on feedback about individual experience”⁴⁵.

People with learning disabilities must be able to access other specialist services such as eating disorder, substance misuse, personality disorder services as well as early intervention, crisis and home treatment and assertive outreach.

Table 2: Commissioning to improve integration of mental health and learning disability services

Protocols or practices in place to meet the mental health needs of adults with intellectual disability, jointly agreed between services for people with intellectual disability, adult mental health services and local authorities.

Patient care pathways through adult mental health services that include a wide range of expertise and skills such as recovery centres, crisis management, psychological therapies, rehabilitation, assertive outreach and home treatment teams.

Regular interface meetings between the two services to steer the strategic direction of service developments and resolve problems as they arise, as well as disseminate examples of good practice and shared care.

Integrated training across services.

OUTCOMES

Commissioning of all services should focus on outcomes. Outcomes for the NHS and Public Health Services are set out in The NHS Outcomes Framework 2012/13 and Improving Outcomes and Supporting Transparency 2013/16^{51,52}. The Adult Social Care Outcomes Framework 2013/14 sets out the outcomes for social care⁵³.

Although the outcome frameworks contain little that is specific to people with learning disabilities, all outcomes apply equally to people with learning disabilities (and mental health problems). The following outcomes frameworks specifically mention people with mental health problems and/or people with learning disabilities:

PUBLIC HEALTH OUTCOMES FRAMEWORK

Domain 1 – improving the wider determinants of health

Indicators

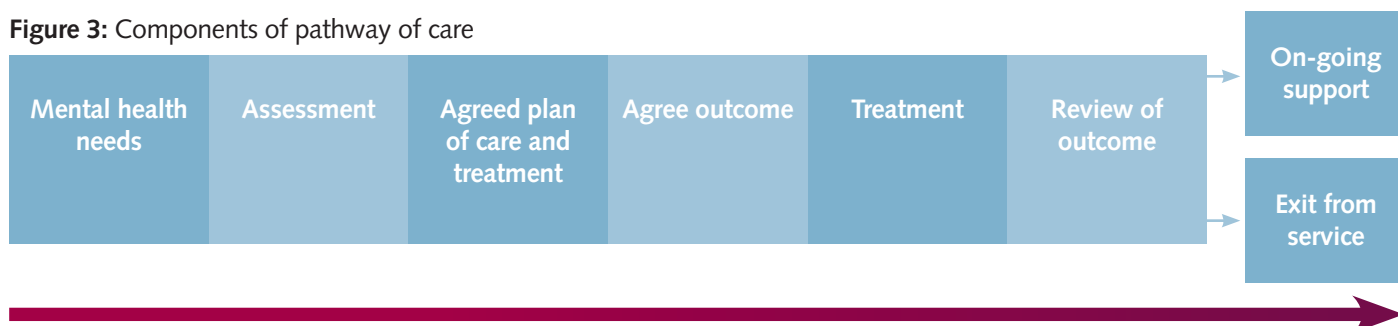
- people with a mental illness or disability in settled accommodation
- people in prison who have a mental illness or significant mental illness
- employment for those with a long-term health condition including those with a learning difficulty/disability or mental illness.

Domain 4 – healthcare, public health and preventing premature mortality

Indicators

- suicide
- dementia and its impacts.

Figure 3: Components of pathway of care



NHS OUTCOMES FRAMEWORK

Domain 1

- preventing people from dying prematurely
- reducing premature death in people with learning disabilities.

Domain 2

- enhancing quality of life of people with long-term conditions
- enhancing quality of life for people with mental illness.

2.5

- employment of people with mental illness
- enhancing quality of life for people with dementia.

2.6

indicator to be developed (but see http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info_home.cfm)

Domain 4

- ensuring people have a positive experience of care
- improving experience of healthcare for people with a mental illness.

4.7

- patient experience of community mental health services.

THE ADULT SOCIAL CARE OUTCOMES FRAMEWORK

Domain 1 – enhancing quality of life for people with care and support needs

- proportion of adults with a learning disability in paid employment
- proportion of adults in contact with secondary mental health services in paid employment
- proportion of adults with a learning disability living in their own homes or with their family
- proportion of adults in contact with secondary mental health services living independently, with or without support.

A recent review of health inequalities suggested five determinants of health inequalities experienced by people with learning disabilities²⁶. These are:

- social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness
- physical and mental health problems associated with specific genetic and biological conditions in learning disabilities
- communication difficulties and reduced health literacy
- personal health behaviour and lifestyle risks such as diet, sexual health and exercise
- deficiencies in access to and the quality of healthcare and other service provision.

The Health Equality Framework (HEF) works by monitoring the degree and impact of people with learning disabilities to these determinants⁵⁴. Attention is focused on the systems around the individual so that needs are identified and met. The outcome of service involvement would be a reduction in the adverse impact of exposure to such determinants and therefore a reduction in health inequality.

Health Inequality Indicators have been developed for each determinant. Each indicator has graded impact levels with associated adverse health consequences.

Commissioners should track outcomes for people with learning disabilities and mental health problems to ensure they are reducing health inequalities. See: www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1

A challenge to commissioners of services is the measurement of quality. Outcome frameworks for use in these services have been developed using the core quality measures⁵⁵. Possible outcomes that may be agreed at the outset are shown in Table 3.

Table 3: Possible outcomes of treatment

Improvement in degree of mental health need requiring reduced level of support
Improvement in degree of mental health need enabling the person to live in the least restrictive environment
Shortest length of time taken to return to optimum functioning by moving through a personalised pathway of care and treatment
Reduction in levels of harmful effects of treatment (e.g. medication, carer distress)
Maintenance of improved level of functioning
Long-term impact of residual behaviours and on-going treatment

OUTCOME MEASURES

The 18 item Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) provides clinicians with a measure of effectiveness of care focussing on behaviour and mental health, physical health and personal social functioning⁵⁶. The Health of the Nation Outcome Scale has been used in people with mild degrees of learning disability⁵⁷.

There are no agreed measures of safety across services though most trusts gather data with regard to adverse incidents, violence and aggression, and medication errors.

User experience measures are being developed and the 14 item Warwick–Edinburgh Mental Well-being Scale (WEMWBS) is being trialled in mental health services⁵⁸.

What would good mental health services for people with learning disabilities look like? (continued)

QUALITY ATTRIBUTES OF SERVICES – PERSPECTIVES OF PEOPLE WITH LEARNING DISABILITIES

When a group of people with learning disabilities were specifically consulted about improving commissioning services for people with mental health problems the following issues were highlighted⁵⁹.

- staff awareness of crowded environments in services and inappropriate mix of individuals
- acknowledging the views of people using services
- the importance of physical health care
- checking of service quality by independent agencies and by patients
- choice of services and avoidance of delays and waiting, and a strong preference for effective and safe services
- support for people to express their views and understand their rights
- understanding the need for individually tailored services
- have a pathway of care shared by patients and professionals
- have a treatment plan that is understood by patients and who can determine how to move forward and work towards discharge.

WORKFORCE DEVELOPMENT

There has been acknowledgement that the provision of high quality services depend on the availability of staff with appropriate skills to meet the mental health problems experienced by people with learning disabilities including autism and behaviours that challenge services⁴¹. Recruitment, training and supervision of staff are seen as key determinants of good outcomes. Skills for Health are developing a code of conduct and training standards for health care support workers.

INNOVATIVE PRACTICE EXAMPLES

There are a number of good practice examples (some about mental health) in the separate Good Practice document published alongside the DH Review of Winterbourne View⁶⁰.

Salford and Tower Hamlets services, for example, have been regarded as an example of notable practice in redesigning services.

Noteworthy practice in Salford

- influencing placing authorities about their choice of provider
- learning disability was "everybody's" concern in the local authority including housing, transport and leisure
- distributive model of leadership
- starting point was "ordinary" services that were adapted rather than "specialist" services that were created
- "one person at a time" strategy for planning
- positive behaviour support is the value-based framework for responding to clinical problems
- positive strategic partnerships to blur interfaces and professional silos.

Noteworthy practice in Tower Hamlets

- comprehensive JSNA focused on reducing health inequalities
- extensive use of local mental health services with very active support for people with learning disabilities to do so
- an agreed protocol with adult mental health services
- psychiatrists employed by the local mental health trust to enable local and strategic links
- pooled budget arrangements
- co-working between learning disability services and the mental health home treatment team.

Cumbria adapted their IAPT pathway to improve access for people with learning disabilities. They used easy read medication and self-help guides, allowed time for reading core questionnaires, and used a smaller set of techniques that were less cognitively demanding. They also encouraged supporters to attend therapy.

Avon and Wiltshire Partnership NHS Trust have a CQUIN agreement in place. The agreement includes the implementation of the MENCAP 'Getting it Right' charter in all inpatient wards⁶¹.

Hospital passports have also been implemented for all people with learning disabilities who are admitted to the service. There is also a learning disability link person on each ward, who can help advise on reasonable adjustments. A staff survey and focus groups helped identify the issues that needed tackling. Areas also did a benchmarking exercise before and after the implementation of training to measure progress, and have put resources on the Trust intranet.

Reasonably Adjusted? contains a number of examples of reasonable adjustments used in mental health services⁶². The Foundation for People with Learning Disabilities has in its Mental Health and Learning Disabilities programme given priority to informing and advising people with learning disabilities experiencing mental health problems and their families how to navigate the mental health system thereby empowering them to take control of their mental health care.

Supporting the delivery of the national strategy

NO HEALTH WITHOUT MENTAL HEALTH

Commissioning that leads to good services for people with learning disabilities who have mental health needs supports the delivery of the mental health strategy.

Shared objective 1: More people will have good mental health.

By commissioning a mental health service for people with learning disabilities which encourages primary care services to work closely with secondary mental health and learning disability services to enable better health checks and screening, joint assessments, treatments and greater mainstream opportunities with optimal support the mental health of this group would be expected to improve.

Shared objective 2: More people with mental health problems will recover.

Commissioning high quality services which take a holistic and personalised approach to care will enhance recovery and reduce long-term disability in people with learning disabilities who often have multiple complex mental health problems alongside with additional difficulties of stigma and social obstacles which have to be overcome.

Shared objective 3: More people with mental health problems will have good physical health.

Commissioning good services for people with learning disabilities who have mental health problems will ensure that frequently coexisting physical ill health is also dealt with in a timely and effective manner so as to improve outcomes for both physical and mental health.

Shared objective 4: More people will have a positive experience of care and support.

Commissioners of mental health services for people with learning disabilities can ensure that assessment, treatment and providing support to lead a full life will make progress in all domains of life including education, employment, accommodation and a rewarding social network.

Shared objective 5: Fewer people will suffer avoidable harm.

Commissioners of good quality mental health services for people with learning disabilities must expect that services heighten safety of this vulnerable group by prevention of avoidable harm from poor quality services where there is no effective timely and person-centred health care. Well coordinated, effective services provided in partnership with patients and carers can reduce avoidable harm.

Shared objective 6: Fewer people will experience stigma and discrimination.

Commissioners of high quality mental health services for people with learning disabilities will ensure that the double disadvantage that people with learning disabilities and mental ill health have is recognised and effectively overcome, so that there is a positive experience of the life and a greater likelihood of the maximising of individual potential.

A recent review of recovery in learning disability services has suggested that the term recovery needs to be redefined as it may not “fit naturally with the lived experience of a lifelong condition” (learning disability). This review calls for a review of existing services to assess the extent to which they are truly recovery orientated⁶³.

The Monitor Compliance Framework also requires NHS Foundation Trusts to put protocols in place to ensure pathways of care are reasonably adjusted. This includes putting a mechanism in place to identify and flag patients with learning disabilities, and protocols that ensure that pathways of care are reasonably adjusted to meet their needs.

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