

# Mental health problems with learning disabilities

## NICE quality standard

### Draft for consultation

August 2016

## Introduction

This quality standard covers the prevention, assessment and management of mental health problems<sup>1</sup> in people with learning disabilities in health, social care, educational, forensic and criminal justice settings. It will also cover family members, carers and care workers. For more information see the [topic overview](#).

Problem behaviours (challenging behaviour, aggressive behaviour, destructive behaviour, and/or self-injurious behaviour) are not addressed in this quality standard. They are covered by the NICE quality standard on [challenging behaviour and learning disabilities](#).

## Definitions

### Learning disabilities

The Department of Health report [Valuing people: a new strategy for learning disability for the 21st century](#) uses the term 'learning disabilities' when the following 3 core criteria are present:

- 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.

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<sup>1</sup> Mental disorders included in the ICD-10 classification system. See NICE's guideline on [mental health problems in people with learning disabilities](#) for more details of the mental health problems covered.

Some definitions of learning disabilities also require the person to have an IQ of less than 70, such as [The International Classification of Diseases \(ICD-10\) Classification of Mental and Behavioural Disorders](#) (World Health Organization). However, an IQ score does not give any information about a person's social, medical, educational and personal needs, or what help and support they might need.

### **Mental health problems**

NICE's guideline on [mental health problems in people with learning disabilities](#) and this quality standard use the term 'mental health problems' to cover mental health needs, mental ill-health, mental health conditions and mental disorders. The World Health Organization defines mental disorders as 'a broad range of problems, with different symptoms, [...] generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others' ([Mental health: a state of well-being](#)).

### ***Why this quality standard is needed***

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.

Around 1 in 4 people experience mental health problems in their lifetime (McManus et al. 2009). They contribute to 13% of the global disease burden – more than both cardiovascular disease and cancer (Collins et al. 2011; World Health Organization). Depression is the third largest contributor to the global disease burden, and every 7 seconds someone develops dementia (Ferri 2005). Mental health problems are more common in people with learning disabilities than in the rest of the population, with a point prevalence of about 30% (Cooper et al. 2007; Emerson and Hatton 2007). For people with learning disabilities, the most common mental health problems are depression, anxiety disorders, autism and (in adults) schizophrenia. They are also more likely to have bipolar disorder, dementia, ADHD and pica.

Despite the high prevalence, these mental health problems are often not recognised. This can be because behaviour and symptoms are attributed to the person's learning disabilities, or because changes in their presentation are not noticed by carers. This can result in prolonged distress for the person.

The quality standard is expected to contribute to improvements in the following outcomes:

- identifying mental health needs
- psychiatric hospital admissions
- patient experience of primary care and secondary care
- quality of life of people with learning disabilities and carers
- patient and carer satisfaction.

## ***How this quality standard supports delivery of outcome frameworks***

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – safety, experience and effectiveness of care – for a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 3 outcomes frameworks published by the Department of Health:

- [Adult Social Care Outcomes Framework 2015–16](#)
- [NHS Outcomes Framework 2016–17](#)
- [Public health outcomes framework for England 2016–19](#).

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1** [The Adult Social Care Outcomes Framework 2015–16](#)

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	<p><b>Overarching measure</b></p> <p>1A Social care-related quality of life**</p> <p><b>Outcome measures</b></p> <p><b>People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs</b></p> <p>1B Proportion of people who use services who have control over their daily life</p> <p>1C Proportion of people using social care who receive self-directed support, and those receiving direct payments</p> <p><b>Carers can balance their caring roles and maintain their desired quality of life</b></p> <p>1D Carer-reported quality of life**</p> <p><b>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation</b></p> <p>1E Proportion of adults with a learning disability in paid employment**</p> <p>1F Proportion of adults in contact with secondary mental health services in paid employment**</p> <p>1G Proportion of adults with a learning disability who live in their own home or with their family*</p>

	<p>1H Proportion of adults in contact with secondary mental health services living independently, with or without support*</p> <p>1I Proportion of people who use services and their carers, who reported that they had as much social contact as they would like</p>
<p>2 Delaying and reducing the need for care and support</p>	<p><b><i>Overarching measure</i></b></p> <p>2A Permanent admissions to residential and nursing care homes, per 100,000 population</p> <p><b><i>Outcome measures</i></b></p> <p><b>Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs</b></p> <p><b>Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services</b></p> <p>2B Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services*</p> <p><b>When people develop care needs, the support they receive takes place in the most appropriate setting and enables them to regain their independence</b></p> <p>2C Delayed transfers of care from hospital, and those which are attributable to adult social care</p> <p><i>Placeholder 2F Dementia – a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life**</i></p>

<p>3 Ensuring that people have a positive experience of care and support</p>	<p><b>Overarching measure</b>  <b>People who use social care and their carers are satisfied with their experience of care and support services</b></p> <p>3A Overall satisfaction of people who use services with their care and support</p> <p>3B Overall satisfaction of carers with social services</p> <p><i>Placeholder 3E The effectiveness of integrated care</i></p> <p><b>Outcome measures</b>  <b>Carers feel that they are respected as equal partners throughout the care process</b></p> <p>3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for</p> <p><b>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help</b></p> <p>3D The proportion of people who use services and carers who find it easy to find information about support</p> <p><b>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual</b></p> <p>This information can be taken from the Adult Social Care Survey and used for analysis at the local level.</p>
<p><b>Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework</b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

**Table 2 [NHS Outcomes Framework 2016–17](#)**

Domain	Overarching indicators and improvement areas
<p>1 Preventing people from dying prematurely</p>	<p><b>Reducing premature mortality in people with mental illness</b></p> <p>1.5 i Excess under 75 mortality rate in adults with serious mental illness*</p> <p><i>ii Excess under 75 mortality rate in adults with common mental illness*</i></p> <p><i>iii Suicide and mortality from injury of undetermined intent among people with recent contact from NHS services**</i></p> <p><b>Reducing premature death in people with a learning disability</b></p> <p><i>1.7 Excess under 60 mortality rate in adults with a learning disability</i></p>
<p>2 Enhancing quality of life for people with long-term</p>	<p><b>Overarching indicator</b></p> <p>2 Health-related quality of life for people with long-term</p>

conditions	<p>conditions**</p> <p><b>Improvement areas</b></p> <p><b>Ensuring people feel supported to manage their condition</b></p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p><b>Improving functional ability in people with long-term conditions</b></p> <p>2.2 Employment of people with long-term conditions*,**</p> <p><b>Enhancing quality of life for carers</b></p> <p>2.4 Health-related quality of life for carers**</p> <p><b>Enhancing quality of life for people with mental illness</b></p> <p>2.5 i Employment of people with mental illness**</p> <p>ii Health-related quality of life for people with mental illness**</p> <p><b>Enhancing quality of life for people with dementia</b></p> <p>2.6 i Estimated diagnosis rate for people with dementia*</p> <p>ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life*,**</p> <p><b>Improving quality of life for people with multiple long-term conditions</b></p> <p>2.7 Health-related quality of life for people with three or more long-term conditions**</p>
3 Helping people to recover from episodes of ill health or following injury	<p><b>Overarching indicators</b></p> <p><b>Improvement areas</b></p> <p><b>Improving outcomes from planned treatments</b></p> <p>3.1 Total health gain as assessed by patients for elective procedures</p> <p>ii Psychological therapies</p> <p>iii Recovery in quality of life for patients with mental illness</p>

4 Ensuring that people have a positive experience of care	<p><b>Overarching indicators</b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>ii GP Out-of-hours services</p> <p>4b Patient experience of hospital care</p> <p>4c <i>Friends and family test</i></p> <p>4d <i>Patient experience characterised as poor or worse</i></p> <p><i>I Primary care</i></p> <p><i>ii Hospital care</i></p> <p><b>Improvement areas</b></p> <p><b>Improving access to primary care services</b></p> <p>4.4 Access to i GP services</p> <p><b>Improving experience of healthcare for people with mental illness</b></p> <p><i>4.7 Patient experience of community mental health services</i></p> <p><b>Improving children and young people's experience of healthcare</b></p> <p><i>4.8 Children and young people's experience of inpatient services</i></p> <p><b>Improving people's experience of integrated care</b></p> <p><i>4.9 People's experience of integrated care**</i></p>
<p><b>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

**Table 3 [Public health outcomes framework for England 2016–19.](#)**

Domain	Objectives and indicators
1 Improving the wider determinants of health	<p><b>Objective</b></p> <p>Improvements against wider factors that affect health and wellbeing and health inequalities</p> <p><b>Indicators</b></p> <p>1.6 Adults with a learning disability/in contact with secondary mental health services who live in stable and appropriate accommodation*</p> <p>1.7 Proportion of people in prison aged 18 or over who have a mental illness</p> <p>1.8 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services*,**</p>
4 Healthcare public health and preventing premature mortality	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p>

	<p><b>Indicators</b></p> <p>4.9 Excess under 75 mortality rate in adults with serious mental illness*</p> <p>4.10 Suicide rate</p> <p>4.13 Health-related quality of life for older people</p>
<p><b><i>Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework</i></b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

## ***Safety and people's experience of care***

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to mental health problems in people with learning disabilities.

NICE has developed guidance and an associated quality standard on service user experience in adult mental health services (see the NICE pathway on [service user experience in adult mental health services](#)), which should be considered alongside this quality standard. They specify that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. They also cover the provision of information to people using services. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect people's experience of using services and are specific to the topic are considered during quality statement development.

## ***Coordinated services***

The quality standard for mental health problems in people with learning disabilities specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole mental health problems in people with learning disabilities care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with learning disabilities and mental health problems in health, social care, educational, forensic and criminal justice settings.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or

providing a high-quality service for mental health problems in people with learning disabilities are listed in [related NICE quality standards](#).

### **Resource impact considerations**

Quality standards should be achievable by local services given the resources required to implement them. Resource impact considerations are taken into account by the quality standards advisory committee, drawing on resource impact work associated with source guidelines. The resource impact products for the source guidelines provide more detailed resource impact information. Organisations are encouraged to use these tools to help estimate local costs.

Links will be available at the time of guidance publication (Sept 2016).

### **Training and competencies**

The quality standard should be read in the context of national and local guidelines on training and competencies. All health and social care practitioners involved in assessing, caring for and treating mental health problems in people with learning disabilities in health, social care, educational, forensic and criminal justice settings should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

### **Role of families and carers**

Quality standards recognise the important role families and carers have in supporting mental health problems in people with learning disabilities in health, social care, educational, forensic and criminal justice settings. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

## List of quality statements

[Statement 1](#). People with learning disabilities are offered an annual health check that includes a review of mental health problems.

[Statement 2](#). People with learning disabilities and identified mental health needs have a mental health assessment conducted by a professional with expertise in mental health problems in people with learning disabilities.

[Statement 3](#). People with learning disabilities and a serious mental illness have a key worker.

[Statement 4](#). People with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced or discontinued.

[Statement 5](#). Health and social care provider organisations provide parent training programmes for parents and carers of children with learning disabilities.

## Questions for consultation

### *Questions about the quality standard*

**Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?

**Question 2** Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

**Question 3** Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the [NICE local practice collection](#) on the NICE website. Examples of using NICE quality standards can also be submitted.

**Question 4** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them?

Please describe any resources that you think would be necessary for any statement.  
Please describe any potential cost savings or opportunities for disinvestment.

***Questions about the individual quality statements***

**Question 5** For draft quality statement 1: In line with quality statement 1 of [Learning disabilities: challenging behaviour Quality Standard \(QS101\)](#) - could we also call this annual health check a comprehensive health assessment? Please detail your answer.

**Question 6** For draft quality statement 3: What term would you use in your setting to describe this role? Key worker? Care or case coordinator? Please detail your answer.

**Question 7** For draft quality statement 4: Can you please define the timeframe of long-term antipsychotic drugs?

## Quality statement 1: Annual health check

### ***Quality statement***

People with learning disabilities are offered an annual health check that includes a review of mental health problems.

### ***Rationale***

Annual health checks for people with learning disabilities can improve the identification of mental health problems. People with learning disabilities and mental health needs may have difficulty explaining their physical health problems, so checking for health issues and regularly monitoring needs is important to ensure these are not missed.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that people with learning disabilities are offered an annual health check that includes a review of mental health problems.

***Data source:*** Local data collection.

#### **Process**

Proportion of people with learning disabilities who are offered an annual health check that includes a review of mental health problems in the past 12 months.

Numerator – the number in the denominator who receive an annual health check that includes a review of mental health problems in the past 12 months.

Denominator – the number of people with learning disabilities.

***Data source:*** Local data collection.

**Outcome**

a) Identification of mental health needs.

**Data source:** Local data collection.

b) Identification of physical health needs.

**Data source:** Local data collection.

***What the quality statement means for service providers, health and social care practitioners, and commissioners***

**Service providers** (primary and social care providers) ensure that people with learning disabilities are offered an annual health check that includes a review of mental health problems, and that a family member or carer (as appropriate) is involved.

**Healthcare professionals** (such as GPs and care workers) offer an annual health check that includes a review of mental health problems to people with learning disabilities, and involve a family member or carer (if appropriate).

**Commissioners** (NHS England) ensure they commission services for people with learning disabilities to be offered an annual health check that includes a review of the mental health problems, and that a family member or carer (as appropriate) is involved.

***What the quality statement means for people using services and carers***

**People with learning disabilities** are offered an annual health check that includes a review of their mental and physical health. This includes looking at all the treatments they are having, including the medications they are taking, whether they have had side effects, any difficulties taking medication or going to therapy sessions, or any other problems. At the check, the person and their healthcare professional agree a care plan for managing any physical 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](#) (2016) NICE guideline NGxx, recommendation 1.6.3.; and [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#) (2015) NICE guideline NG11, recommendation 1.2.1

## **Definition of terms used in this quality statement**

### **Annual health check**

This should be carried out with the involvement of a family member, carer, care worker, healthcare professional or social care practitioner who knows the person and includes:

- 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 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).

[Adapted from [Mental health problems in people with learning disabilities](#) (NICE guideline NGxx), 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, 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.

***Question for consultation***

**Question 5** In line with quality statement 1 of [Learning disabilities: challenging behaviour Quality Standard \(QS101\)](#) - could we refer to this annual health check as a comprehensive health assessment? Please detail your answer.

## **Quality statement 2: Assessment by a professional with relevant expertise**

### ***Quality statement***

People with learning disabilities and identified mental health needs have a mental health assessment conducted by a professional with expertise in mental health problems in people with learning disabilities.

### ***Rationale***

The lack of early recognition of mental health problems in people with learning difficulties leads to negative consequences for the person and their family. Lack of recognition can lead to no or ineffective treatment or inappropriate resource use. Poor recognition can be caused by a lack of knowledge in health and social care staff.

The mental health assessment needs to be coordinated and conducted by a professional with expertise in mental health problems in people with learning disabilities, so that the assessment and subsequent care is effective and tailored to the person's individual needs and circumstances.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that mental health assessments for people with learning disabilities and identified mental health needs are conducted by a professional with expertise in mental health problems in people with learning disabilities.

***Data source:*** Local data collection.

#### **Process**

Proportion of people with learning disabilities and identified mental health needs who are having a mental health assessment for whom this is conducted by a professional with expertise in learning disabilities and mental health problems.

Numerator – the number in the denominator who have a mental health assessment conducted by a professional with expertise in mental health problems in people with learning disabilities and identified mental health needs.

Denominator – the number of people with learning disabilities and identified mental health needs who have a mental health assessment.

**Data source:** Local data collection.

### **Outcome**

Identification of mental health problems.

**Data source:** Local data collection.

### ***What the quality statement means for service providers, healthcare professionals and commissioners***

**Service providers** (secondary care providers and specialist learning disabilities services) ensure that mental health assessments for people with learning disabilities and identified mental health needs are conducted by a professional with expertise in mental health problems in people with learning disabilities and identified mental health needs.

**Healthcare professionals or social care practitioners** with expertise in mental health problems in people with learning disabilities will conduct mental health assessments for people with learning disabilities and identified mental health needs, and complete a formal mental health assessment questionnaire as part of each assessment.

**Commissioners** (clinical commissioning groups, NHS England and local authorities) ensure they commission services that mental health assessments for people with learning disabilities are conducted by a professional with expertise in mental health problems in people with learning disabilities and identified mental health needs.

## ***What the quality statement means for people using services and carers***

**People with learning disabilities and identified mental health needs** have any mental health assessments they need carried out by a professional who specialises in caring 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. Staff should help the person with learning disabilities to prepare for the assessment, if needed.

### ***Source guidance***

[Mental health problems in people with learning disabilities](#) (2016) NICE guideline NGxx, recommendation 1.8.1.

### ***Definition of terms used in this quality statement***

#### **Mental health assessment**

This should be carried out in a place familiar to the person with the mental health problem, if possible, and staff should help them to prepare for it if needed. The person should be able to involve any family members, carers, care workers or others that they want in the assessment.

Before the assessment the professional needs to explain the process to the person with learning disabilities and identified mental health needs, and agree the goals of the assessment.

The assessment should include a review of the person's previous history (both physical and mental health) and personal circumstances. This is essential to assess the person's mental health problem and develop a mental health care plan. Complete a formal assessment questionnaire as part of the assessment.

[Adapted from [Mental health problems in people with learning disabilities](#) (NICE guideline NGxx), recommendations 1.8.1 and 1.8.6.

***Equality and diversity considerations***

Healthcare professionals should take into account the communication needs of people with a learning disability when coordinating a mental health assessment, 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 learning disabilities and a serious mental illness have a key worker.

### ***Rationale***

People with learning disabilities and a serious mental illness do not always have a designated key worker to coordinate their care. Appointing a key worker would improve care coordination and help services to communicate clearly with people with learning disabilities and their family members or carers.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements and written protocols to ensure that people with learning disabilities and a serious mental illness have a key worker.

***Data source:*** Local data collection.

#### **Process**

Proportion of people with learning disabilities and a serious mental illness who have a key worker.

Numerator – the number in the denominator who have a key worker.

Denominator – the number of people with learning disabilities and a serious mental illness.

***Data source:*** Local data collection.

#### **Outcomes**

a) Psychiatric hospital admissions (including length of stay or other outcomes related to admission).

***Data source:*** Local data collection.

b) Transition between and within services.

**Data source:** Local data collection.

c) Patient and carer satisfaction.

**Data source:** Local data collection.

### ***What the quality statement means for service providers, keyworkers, and commissioners***

**Service providers** (primary, secondary and social care providers) ensure that people with learning disabilities and a serious mental illness have a key worker.

**Keyworkers** ensure that they coordinate all aspects of care and communication, and monitor the implementation of the care plan and its outcomes for people with learning disabilities and a serious mental illness.

**Commissioners** (clinical commissioning groups, NHS England and local authorities) ensure that they commission services for people with learning disabilities and a serious mental illness to have a key worker who coordinates all aspects of care and communication, and monitors the implementation of the care plan and its outcomes.

### ***What the quality statement means for people using services and carers***

**People with learning disabilities and a serious mental illness** have a key worker who acts as their main contact. 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 learning disabilities.

### ***Source guidance***

- [Mental health problems in people with learning disabilities](#) (2016) NICE guideline NGxx, recommendation 1.2.8

## ***Definitions of terms used in this quality statement***

### **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.

[[Mental health problems in people with learning disabilities](#) (NICE guideline NGxx)]

### **Serious mental illness**

Severe and incapacitating depression or anxiety, psychosis, schizophrenia, bipolar disorder or schizoaffective disorder.

[[Mental health problems in people with learning disabilities](#) (NICE guideline NGxx)]

## ***Equality and diversity considerations***

Healthcare professionals should take into account the communication needs of people with a learning disability, 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.

### ***Question for consultation***

**Question 6:** What term would you use in your setting to describe this role? Key worker? Care or case coordinator? Please detail your answer.

## Quality statement 4: Reducing and discontinuing antipsychotic drugs

### ***Quality statement***

People with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced or discontinued.

### ***Rationale***

There have been significant concerns that antipsychotics are used inappropriately in people with learning disabilities. People with learning disabilities who are taking medication for a mental health problem would benefit from closer monitoring of adherence, side effects and potential polypharmacy. Effective use of medication to prevent and manage mental health problems is likely to improve the quality of life of people with learning disabilities and their families or carers, and reduce costs to secondary care.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that people with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced or discontinued.

**Data source:** Local data collection.

#### **Process**

a) Proportion of people with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced.

Numerator – the number in the denominator who have their prescriptions reduced.

Denominator – the number of people with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms.

**Data source:** Local data collection.

b) Proportion of people with learning disabilities who are taking antipsychotic drugs long-term and not experiencing psychotic symptoms who have their prescriptions discontinued.

Numerator – the number in the denominator who have their prescriptions of antipsychotic drugs discontinued.

Denominator – the number of people with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms.

**Data source:** Local data collection.

### **Outcome**

a) Use of long-term prescriptions of antipsychotic drugs.

**Data source:** Local data collection.

b) Quality of life

**Data source:** Local data collection.

### ***What the quality statement means for service providers, healthcare professionals, and commissioners***

**Service providers** (primary care providers) ensure that people with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced or discontinued.

**Healthcare professionals** (for example GPs) reduce or discontinue long-term prescriptions of antipsychotic drugs in people with learning disabilities who are not experiencing psychotic symptoms.

**Commissioners** (clinical commissioning groups and NHS England) ensure they commission services for people with learning disabilities who are taking antipsychotic drugs long-term and are not experiencing psychotic symptoms have their prescriptions reduced or discontinued.

## ***What the quality statement means for people using services and carers***

**People with learning disabilities who are taking antipsychotic drugs (medication to help with psychosis) long-term and not experiencing psychotic symptoms** switch to a lower dose of their medication, or stop taking it altogether.

### ***Source guidance***

- [Mental health problems in people with learning disabilities](#) (2016) NICE guideline NGxx, recommendation 1.10.8

### ***Equality and diversity considerations***

Prescribers should be aware that people with learning disabilities who are taking medication may have difficulties reporting the presence, magnitude and severity of side effects.

### ***Question for consultation***

**Question 7:** Can you please define the timeframe of taking long-term antipsychotic drugs?

## Quality statement 5: Parent training programmes

### ***Quality statement***

Health and social care provider organisations provide parent training programmes for parents and carers of children with learning disabilities.

### ***Rationale***

Parents and carers are likely to directly experience the impact of a child's mental health problem, and more likely to be able to identify mental health problems and help the child with them.

The training can help parents to better manage behaviour, avoiding long-term problems that cause a greater impact on the person, their family and the wider society. Parent training is likely to improve the health and wellbeing of parents and carers, and help them find out what support is available for them.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that parents and carers of children with learning disabilities can access parent training programmes.

***Data source:*** Local data collection.

#### **Process**

a) Proportion of parents of children with learning disabilities who have attended a parent training programme.

Numerator – the number in the denominator who have attended a parent training programme.

Denominator – the number of parents of children with learning disabilities.

***Data source:*** Local data collection.

b) Proportion of carers of children with learning disabilities who have attended a parent training programme.

Numerator – the number in the denominator who have attended a parent training programme.

Denominator – the number of carers of children with learning disabilities.

**Data source:** Local data collection.

### **Outcomes**

a) Parent and carer mental health (including rates of depression and anxiety) and quality of life.

**Data source:** Local data collection.

b) Quality of life for children with learning disabilities.

**Data source:** Local data collection.

c) Parent or carer satisfaction with parent training programmes.

**Data source:** Local data collection.

d) Quality of relationship between carer and person being cared for.

**Data source:** Local data collection.

### ***What the quality statement means for service providers, health and social care practitioners, and commissioners***

**Service providers** (secondary care and social care providers including specialist learning disabilities services) ensure that parents or carers of children with learning disabilities can have parent training programmes. Service providers should ensure that programmes are specifically designed and delivered in groups of parents or carers.

**Healthcare and social care practitioners** (in secondary care and social care including specialist learning disabilities services) ensure that they design and deliver

parent training programmes to groups of parents or carers of children with learning disabilities.

**Commissioners** (clinical commissioning groups and NHS England) ensure that they commission services that provide parent training programmes for parents and carers of children with learning disabilities.

### ***What the quality statement means for people using services and carers***

**Parents and carers of children with learning disabilities** have access to a parent training programme. This programme should help them to support their child's social and emotional growth, and teach them how to cope with problems.

### ***Source guidance***

[Mental health problems in people with learning disabilities](#) (2016) NICE guideline NGxx recommendations 1.9.9 and 1.9.8.

### ***Definitions of terms used in this quality statement***

#### **Children**

Aged 0–12 years.

[[Mental health problems in people with learning disabilities](#) (2016) (NICE guideline NGxx)]

#### **Parent training programmes**

Parent training programmes should:

- be specifically designed for parents or carers of children with learning disabilities
- 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.

[Adapted from [Mental health problems in people with learning disabilities](#) (NICE guideline NGxx), recommendation 1.9.9]

### ***Equality and diversity considerations***

Parent training programmes should be accessible to the parent or carer. For example, they could take place outside normal working hours or in community settings with childcare facilities.

Communication with the parent or carer carers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

## Status of this quality standard

This is the draft quality standard released for consultation from 5 August to 2 September 2016. It is not NICE's final quality standard on mental health problems with learning disabilities. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 2 September 2016. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the [NICE website](#) from January 2017.

## Using the quality standard

### *Quality measures*

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [What makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

### *Levels of achievement*

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, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

NICE's [quality standard service improvement template](#) helps providers to make an initial assessment of their service compared with a selection of quality statements. It includes assessing current practice, recording an action plan and monitoring quality improvement. This tool is updated monthly to include new quality standards.

### ***Using other national guidance and policy documents***

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in [development sources](#).

## **Diversity, equality and language**

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between health and social care practitioners for mental health problems in people with learning disabilities is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with learning disabilities and mental health problems should have access to an interpreter or advocate if needed.

Good communication between health and social care practitioners and children and young people with learning disabilities and mental health problems, and their parents or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people with learning disabilities and mental health problems and

their parents or carers (if appropriate) should have access to an interpreter or advocate if needed.

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.

## **Development sources**

Further explanation of the methodology used can be found in the [quality standards process guide](#).

### ***Evidence sources***

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the quality standards advisory committee to develop the quality standard statements and measures.

- [Mental health problems and learning disabilities](#) (2016) NICE guideline NGxx.

### ***Policy context***

It is important that the quality standard is considered alongside current policy documents, including:

- ACEVO (2016) [Time for change – the challenge ahead](#)
- Care Quality Commission (2015) [Monitoring the Mental Health Act in 2014/15](#)
- Care Quality Commission (2015) [Monitoring the deprivation of liberty safeguards 2014/15](#)
- Department of Health (2015) [Deprivation of Liberty Safeguards forms and guidance](#)
- Department of Health (2015) [Improving mental health services for young people](#)
- Department of Health (2015) [Mental Health Act 1983: Code of practice](#)
- Health and Social care Information Centre (2015) [Learning disability census report](#)

- National Audit Office (2015) [Care services for people with learning disabilities and challenging behaviour](#)
- NHS England (2015) [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 (2015) [Care and treatment review: policy and guidance](#)
- NHS England (2015) [The five year forward view mental health taskforce: public engagement findings](#)
- NHS England (2015) [Transforming care for people with learning disabilities - next steps](#)
- Public Health England (2015) [Public mental health leadership and workforce development framework](#)
- Royal College of Psychiatrists (2015) [Community-based services for people with intellectual disability and mental health problems: faculty report ID/06](#)
- Centre for Mental Health (2014) [The Bradley Report five years on](#)
- Criminal Justice Joint Inspection (2014) [A joint inspection of the treatment of offenders with learning disabilities within the criminal justice system - phase 1 from arrest to sentence](#)
- Department for Education (2014) [Special educational needs and disability code of practice: 0 to 25 years](#)
- Department of Health (2014) [Progress on improving nursing for people with learning disabilities](#)
- Department of Health (2014) [Progress on premature deaths of people with learning disabilities](#)
- Foundation for People with Learning Disabilities (2014) [Feeling down: improving the mental health of people with learning disabilities](#)
- Local Government Association (2014) [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 (2014) [Choice in mental health care: guidance on implementing patients' legal rights to choose the provider and team for their mental health care](#)

- Royal College of Psychiatrists (2014) [Report on the national audit of learning disabilities feasibility study \(NALD-FS\)](#)
- Department of Health (2013) [Winterbourne View: transforming care one year on](#)
- Joint Commissioning Panel for Mental Health (2013) [Guidance for commissioners of mental health services for people with learning disabilities](#)
- Royal College of Psychiatrists (2013) [People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services: faculty report ID/03](#)
- Care Quality Commission (2012) [Review of learning disability services](#)
- Department of Health (2012) [Transforming Care: a national response to Winterbourne View hospital](#)
- Foundation for People with Learning Disabilities (2012) [Reaching out to people with learning disabilities and their families from black and minority ethnic communities](#)
- National Development Team for Inclusion (2012) [Reasonably adjusted? Mental health services and support for people with autism and people with learning disabilities](#)
- Royal College of Psychiatrists (2012) [Enabling people with mild intellectual disability and mental health problems to access healthcare services](#)

## Related NICE quality standards

### Published

- [Learning disabilities: challenging behaviour](#) (2015) NICE quality standard 101
- [Patient experience in adult NHS services](#) (2012) NICE quality standard 15
- [Service user experience in adult mental health](#) (2011) NICE quality standard 14

### In development

- [Transition from children's to adults' services](#) Publication expected December 2016

### ***Future quality standards***

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Care and support of older people with learning disabilities
- Service model for people with learning disabilities and challenging behaviour

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.

## **Quality standards advisory committee and NICE project team**

### ***Quality standards advisory committee***

This quality standard has been developed by Quality Standards Advisory Committee 1. Membership of this committee is as follows:

**Dr Ivan Benett**

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GP/ CVD and Research lead, East Lancashire Clinical Commissioning Group

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## **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.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

This quality standard will be incorporated into the NICE pathway on mental health problems in people with learning disabilities.

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.

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