

Learning disabilities: identifying and managing mental health problems

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This standard is based on NG54 and NG11.

Quality statements

<u>Statement 1</u> Young people and adults with learning disabilities have an annual health check that includes a review of mental health problems.

<u>Statement 2</u> People with learning disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

<u>Statement 3</u> People with learning disabilities and a serious mental illness have a key worker to coordinate their care.

<u>Statement 4</u> People with learning and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

<u>Statement 5</u> People with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

NICE has developed guidance quality standards on patient experience in adult NHS services and service user experience in adult mental health services (see the NICE pathways on <u>patient</u> <u>experience in adult NHS services</u> and <u>service user experience in adult mental health services</u>) which should be considered alongside these quality statements.

A full list of NICE quality standards is available from the quality standards topic library.

Quality statement 1: Annual health check

Quality statement

Young people and adults with learning disabilities have an annual health check that includes a review of mental health problems.

Rationale

Annual health checks for young people and adults with learning disabilities can be used to identify and monitor mental health problems. Young people and adults with learning disabilities and mental health needs may have difficulty explaining their health problems, so checking for issues and regularly monitoring needs is important to ensure that these are not missed.

Quality measures

Structure

Evidence of local arrangements to ensure that young people and adults with learning disabilities have an annual health check that includes a review of mental health problems.

Data source: Local data collection.

Process

a) Proportion of young people with learning disabilities who have an annual health check that includes a review of mental health problems.

Numerator – the number in the denominator who have had an annual health check that includes a review of mental health problems.

Denominator - the number of young people with learning disabilities.

Data source: Local data collection.

b) Proportion of adults with learning disabilities who have an annual health check that includes a review of mental health problems.

Numerator – the number in the denominator who have had an annual health check that includes a review of mental health problems.

Denominator - the number of adults with learning disabilities.

Data source: Local data collection.

Outcome

a) Identification of mental health needs in young people and adults with learning disabilities.

Data source:Local data collection.

b) Identification of physical health needs in young people and adults with learning disabilities.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (enhanced GP services) ensure that young people and adults with learning disabilities have an annual health check that includes a review of mental health problems, and that a family member, carer or care worker is involved (as appropriate).

Healthcare professionals (such as GPs) conduct annual health checks that include reviews of mental health problems for young people and adults with learning disabilities, and involve a family member, carer or care worker (as appropriate).

Commissioners (clinical commissioning groups) ensure that general practices are signed up to provide annual health checks that prioritise a review of physical and mental health, for young people and adults with learning disabilities.

Young people and adults with learning disabilities have an annual health check that includes a review of their mental and physical health. This includes:

- identifying potential new problems
- looking at all the treatments they are having, to see if they are having any difficulties (for example with going to therapy sessions)

- reviewing the medications they are taking to see if they have had side effects, any difficulties taking medication or any other problems
- agreeing a care plan with the healthcare professional for managing any physical health and mental health problems.

If they want, the person may take a family member or carer with them.

Source guidance

- <u>Mental health problems in people with learning disabilities: prevention, assessment and</u> <u>management</u> (2016) NICE guideline NG54, recommendation 1.6.3
- <u>Challenging behaviour and learning disabilities: prevention and interventions for people with</u> <u>learning disabilities whose behaviour challenges</u> (2015) NICE guideline NG11, recommendation 1.2.1

Definitions of terms used in this quality statement

Young people

Aged 13–17 years.

[Mental health problems in people with learning disabilities (2016) NICE guideline NG54]

Annual health check

This should involve the person with learning disabilities and a family member, carer, care worker, GP or social care practitioner (as appropriate) who knows them. It should include:

- a review of any known or suspected mental health problems and how they may be linked to any physical health problems
- a physical health review, including assessment for the conditions and impairments that are common in people with learning disabilities
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence for both mental health and physical health conditions
- an agreed and shared care plan for managing any physical health and mental health problems (including pain).

[Adapted from <u>mental health problems in people with learning disabilities</u> (NICE guideline NG54), recommendation 1.6.3; and <u>challenging behaviour and learning disabilities</u> (NICE guideline NG11), recommendation 1.2.1]

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with learning disabilities. They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

Quality statement 2: Assessment by a professional with relevant expertise

Quality statement

People with learning disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Rationale

The mental health assessment should be conducted by a professional with expertise in mental health problems in people with learning disabilities. This ensures that the assessment and subsequent care is effective and tailored to the person's individual needs and circumstances, and makes reasonable adjustments to take account of their learning disabilities.

Quality measures

Structure

Evidence of local arrangements to ensure that people with learning disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Data source: Local data collection.

Process

a) Proportion of people with learning disabilities who need a mental health assessment and are referred to a professional with expertise in mental health problems in people with learning disabilities.

Numerator – the number in the denominator who are referred to a professional with expertise in mental health problems in people with learning disabilities.

Denominator – the number of people with learning disabilities who need a mental health assessment.

Data source: Local data collection.

b) Proportion of people with learning disabilities who are referred for a mental health assessment and are assessed by a professional with expertise in mental health problems in people with learning disabilities.

Numerator – the number in the denominator who are assessed by a professional with expertise in mental health problems in people with learning disabilities.

Denominator – the number of people with learning disabilities who are referred for a mental health assessment.

Data source: Local data collection.

Outcome

Identification of mental health problems in people with learning disabilities.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (secondary care providers, mental health services and specialist learning disabilities services) ensure that people with learning disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

Health and social care practitioners with expertise in mental health problems in people with learning disabilities conduct mental health assessments for people with learning disabilities. At the assessment, the professional completes a formal mental health assessment questionnaire.

Commissioners (clinical commissioning groups, NHS England and local authorities) commission services that ensure that people with learning disabilities who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities.

People with learning disabilities who need a mental health assessment are referred to a professional who has the skills to do this for people with learning disabilities and mental health problems. If possible, this should be carried out in a place familiar to the person, with any family

members, carers, care workers or others that they want to involve. If needed, staff should help the person with learning disabilities to prepare for the assessment.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.8.1

Definition of terms used in this quality statement

Mental health assessment

The assessment should include a review of the person's previous history (both physical and mental health) and personal circumstances. This is essential when assessing the person's mental health problem and developing a mental health care plan. A formal assessment questionnaire should be completed as part of the assessment.

[Adapted from <u>mental health problems in people with learning disabilities</u> (NICE guideline NG54), recommendations 1.8.1 and 1.8.6]

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with learning disabilities when conducting a mental health assessment. They should make reasonable adjustments for people accessing mental health services, and provide support if needed for people who have limited or no speech or who have difficulty with English.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

Quality statement 3: Key worker

Quality statement

People with learning disabilities and a serious mental illness have a key worker to coordinate their care.

Rationale

Appointing a key worker would improve care coordination and help services to communicate clearly with people with learning disabilities and their family members and 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 to coordinate their care.

Data source: Local data collection.

Process

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

Numerator - the number in the denominator who have a key worker to coordinate their care.

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

Data source: Local data collection.

Outcomes

Patient and carer satisfaction with their key worker's coordination of care.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (primary, secondary and social care services that provide care for people with learning disabilities and mental health problems) ensure that people with learning disabilities and a serious mental illness have a key worker to coordinate all aspects of care.

Key workers coordinate all aspects of care and communication for the person, their family members and carers, and the services that are involved. They should maintain regular contact with the person and their family members and carers and specify this in the care plan.

Commissioners (clinical commissioning groups, NHS England and local authorities) commission services that provide a key worker for each person with learning disabilities and a serious mental illness. The key worker should coordinate all aspects of care and communication.

People with learning disabilities and a serious mental illness have a key worker who acts as the main contact for them and their family members and carers. The key worker makes sure that all staff involved are working together, and that the care plan is being followed and is helping. They ensure that any assessments, care and treatments are explained clearly to the person with learning disabilities.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.2.8

Definitions of terms used in this quality statement

Serious mental illness

A diagnosis of:

- severe depression or anxiety that is impacting heavily on the person's functioning
- psychosis
- schizophrenia
- bipolar disorder
- an eating disorder

- personality disorder
- schizoaffective disorder.

[Mental health problems in people with learning disabilities (NICE guideline NG54) and expert consensus]

Key worker

A key worker (also known as a care or case coordinator, or a Care Programme Approach care coordinator) is the central point of contact for the person with learning disabilities, their family members and carers, and the services involved in their care. They are responsible for helping the person and their family members and carers to access services and for coordinating the involvement of different services. They ensure clear communication between all people and services and have an overall view of the person's needs and the requirements of their care plan. They ensure that services communicate regularly with the person and their family members and carers, in a suitable format.

[Adapted from mental health problems in people with learning disabilities (NICE guideline NG54)]

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with learning disabilities. They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

Quality statement 4: Tailoring psychological interventions

Quality statement

People with learning disabilities and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Rationale

Children, young people and adults with learning disabilities are at higher risk of mental health problems than the general population. Standard evidence-based psychological interventions are not designed to take account of the cognitive, communication or social impairments associated with learning disabilities. People with learning disabilities can have a broad range of difficulties, so the care setting and interventions need to be adapted and tailored to each person's preferences, level of understanding, and strengths and needs.

Quality measures

Structure

Evidence of local arrangements to ensure that people with learning disabilities and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Process

Proportion of people with learning disabilities and mental health problems who are receiving psychological interventions that are tailored to their preferences, level of understanding, and strengths and needs.

Numerator – the number in the denominator who receive psychological interventions that are tailored to their preferences, level of understanding, and strengths and needs.

Denominator – the number of people with learning disabilities and mental health problems who are receiving psychological interventions.

Data source: Local data collection.

Outcome

Quality of life of people with learning disabilities and mental health problems and their family members and carers.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (secondary care providers, mental health services and specialist learning disabilities services) ensure that people with learning disabilities and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs.

Health and social care practitioners tailor psychological interventions for people with learning disabilities and mental health problems, to match their preferences, level of understanding, and strengths and needs.

Commissioners (clinical commissioning groups, NHS England and local authorities) commission services that ensure that psychological interventions for people with learning disabilities and mental health problems are tailored to match their preferences, level of understanding, and strengths and needs.

People with learning disabilities and a mental health problem have access to psychological ('talking') therapies that are designed around their needs.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendations 1.9.1–1.9.4, 1.9.8 and 1.9.9

Quality statement 5: Annually documenting the reasons for continuing antipsychotic drugs

Quality statement

People with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Rationale

People with learning disabilities who are taking medication for a mental health problem would benefit from closer monitoring and a clear rationale for their treatment plan, such as an annual record of the reasons for continuing prescriptions. People with learning disabilities are often given long courses of medication. This is not always helpful, and regular review and agreed shared care protocols are necessary to avoid this.

Effective use of medication to prevent and manage mental health problems is likely to improve the quality of life of people with learning disabilities and their family members and carers, and reduce costs and inappropriate prescribing.

Quality measures

Structure

Evidence of local arrangements to ensure that people with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Data source: Local data collection.

Process

Proportion of people with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped and who have annual documentation on reasons for continuing this prescription.

Numerator – the number in the denominator who have annual documentation on reasons for continuing this prescription.

Denominator – the number of people with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped.

Data source: Local data collection.

Outcome

a) Antipsychotic medication prescribing rates for people with learning disabilities.

Data source:Local data collection.

b) Quality of life of people with learning disabilities and their family members and carers.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (secondary care providers) ensure that people with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

Healthcare professionals (clinicians) annually document the reasons for continuing prescriptions for people with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped.

Commissioners (NHS England) commission services that ensure that people with learning disabilities who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription.

People with learning disabilities who are taking antipsychotic drugs (medication to help with psychosis) that are not reduced or stopped have a review of their prescription and the reasons for continuing it recorded every year.

Source guidance

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54, recommendation 1.10.8

Equality and diversity considerations

Healthcare professionals should take into account the communication needs of people with learning disabilities. They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.

Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Information about how NICE quality standards are developed is available from the NICE website.

See <u>quality standard advisory committees</u> on the website for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the <u>quality standard's webpage</u>.

This quality standard has been incorporated into the NICE pathways on <u>challenging behaviour and</u> <u>learning disabilities</u> and <u>mental health problems in people with learning disabilities</u>.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

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

- identification of mental health needs in young people and adults with learning disabilities
- identification of physical health needs in young people and adults with learning disabilities
- experience of primary care and secondary care for people with learning disabilities

- experience of mental health services for people with learning disabilities
- quality of life of people with learning disabilities and their family members and carers.

It is also expected to support delivery of the Department of Health's outcome frameworks:

- Adult social care outcomes framework 2015-16
- NHS outcomes framework 2016–17
- Public health outcomes framework for England, 2016–19.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact products for the source guidance to help estimate local costs:

- <u>baseline assessment tool</u> for the NICE guideline on mental health problems in people with learning disabilities.
- <u>resource impact report and template</u> for the NICE guideline on mental health problems in people with learning disabilities.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and <u>equality</u> <u>assessments</u> are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- British Association of Art Therapists
- British Psychological Society
- College of Mental Health Pharmacy
- <u>Royal College of General Practitioners</u>