NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Care and support of people growing older with a learning disability

NICE quality standard

Draft for consultation

February 2019

This quality standard covers identifying, assessing and regularly reviewing the care and support needs of people with a learning disability as they grow older. It covers all settings where care and support is provided. This quality standard describes high-quality care in priority areas for improvement.

It is for commissioners, service providers, health, social care practitioners, and the public.

This is the draft quality standard for consultation (from 11 February to 11 March 2019). The final quality standard is expected to publish in July 2019.

Quality statements

Statement 1 People with a learning disability are actively involved when their care and support needs are being assessed.

Statement 2 People with a learning disability have a named lead practitioner responsible for coordinating their care and support.

Statement 3 People with a learning disability have a plan for the future that is reviewed at least annually.

Statement 4 People with a learning disability have their health action plan updated after every annual health check.

Statement 5 People with a learning disability meet with hospital staff before any planned hospital stay to agree reasonable adjustments which would make the stay easier for them.

NICE has developed guidance and a quality standard on patient experience in adult NHS services and service user experience in adult mental health services (see the NICE pathway on patient experience in adult NHS services and service user experience in adult mental health services, which should be considered alongside these quality statements.

Other quality standards that should be considered when commissioning or providing services for people growing older with learning disabilities include:

People's experience using adult social care services (QS TBC),

- Multimorbidity (2017) NICE quality standard 153
- Learning disabilities: challenging behaviour (2015) NICE quality standard 101
- End of life care for adults (2011, updated 2017) NICE quality standard 13.

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

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

Local practice case studies

Question 4 Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to NICE local practice case studies on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: Person-centred needs assessment

Quality statement

People with a learning disability are actively involved when their care and support needs are being assessed.

Rationale

Care and support needs change as people with a learning disability get older. Performing certain tasks, or doing things that used to be easy, may become more difficult. Care and support needs assessment is an ongoing process that can capture and reflect these changes. Supporting people with a learning disability to be actively involved in this assessment ensures that it recognises their strengths, aspirations and desires despite the increasing needs. To enable people with a learning disability to be actively involved in the process, the practitioner carrying out the assessment will already have a good relationship with the person and understand how to communicate with them effectively. They will also involve the family members and carers most engaged in the person's care and support to gather necessary context and information if that is the wish of the person with a learning disability.

Quality measures

Structure

a) Evidence of local arrangements to ensure that people with a learning disability are actively involved when their care and support needs are being assessed.

Data source: NHSI Learning Disability Improvement Standards organisational survey.

b) Evidence of local arrangements to ensure that practitioners carrying out assessments of the care and support needs of people with a learning disability have access to the person's full history (medical, social, psychological and the nature of their learning disability).

Data source: Local data collection, such as records from community learning disability teams or GP practices.

Process

Proportion of people with a learning disability who are actively involved when their care and support needs are assessed.

Numerator – the number in the denominator who were actively involved when their care and support needs were assessed.

Denominator – the number of people with a learning disability who had their care and support needs assessed.

Data source: NHSI Learning Disability Improvement Standards service user survey.

Outcome

Satisfaction with the assessment process among people with a learning disability.

Data source: NHSI Learning Disability Improvement Standards service user survey.

What the quality statement means for different audiences

Service providers (such as GP practices, community learning disability teams or adult social care services) ensure that care and support needs of people with a learning disability are reviewed as they grow older. They ensure that the practitioners have the skills and capacity to carry out person centred care and support needs assessments, actively involving the person with a learning disability and their family members and carers. They also ensure that practitioners carrying out these assessments know the person and have access to information about their communication needs, their full history (medical, social, psychological and the nature of their learning disability) and their usual behaviour.

Health and social care practitioners (such as GPs, learning disability nurses or social care workers) support the person with a learning disability who is growing older to lead on and be actively involved in their care and support needs assessment. They know the person and understand their communication needs, their full history (medical, social, psychological and the nature of their learning disability) and their usual behaviour. They ensure that this is an ongoing process that also involves the person's family members and carers most involved in supporting the person.

Commissioners (such as clinical commissioning groups or local authorities) ensure that they commission services that recognise that care and support needs change as people with a learning disability grow older. They monitor whether the services actively involve the person with a learning disability in the care and support needs assessment process and focus on their needs and also their strengths, aspirations and desires.

People with a learning disability who are growing older are supported to be involved in their care and support needs assessment, so that their views come first. They understand what the meeting is about and what to expect from it. They are encouraged to express what is really important to them and are given time and support to explain what they find difficult, what they may need help with and what they would like to do that they are not currently doing. They are also encouraged to explain what they enjoy doing, what they are good at and discuss how they could develop their interests further.

Family members and carers (family, friends and anyone else who provides informal support, for example spouses, friends or colleagues) are involved in assessing the care and support needs of the person with a learning disability who is growing older. Their role in existing caring arrangements is recognised and reviewed. Family members and carers also have a carer’s assessment to ensure that they receive any support they need. Mutual caring arrangements are also recognised as part of this process.

Source guidance

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96, recommendations 1.3.1, 1.3.4 and 1.3.5

Definitions of terms used in this quality statement

People with a learning disability

In this quality standard, a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

The severity of a person's learning disability may be classified as mild, moderate, severe or profound. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

A specific age limit is not used in this quality standard to define people growing older because adults with a learning disability typically experience age-related difficulties at different ages, and at a younger age than the general population.

[NICE’s guideline on care and support of people growing older with a learning disability, terms used in the guideline]

Actively involving people with a learning disability

People with a learning disability should lead the assessment and decide where and when they would like to meet, and who else should be involved. The assessment should be carried out by someone they feel comfortable with, who understands their communication needs and can encourage them to be engaged. The practitioner may need support from friends, family or carers to ensure that the person has a true opportunity to express their needs, aspirations and desires.

[Expert opinion]

Equality and diversity considerations

People with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with severe or profound learning disabilities may have particularly complex needs. Practitioners assessing the person's care and support needs may need additional support to engage with the person in a meaningful way. This may include involving speech and language therapists or working with family members on finding solutions to allow for effective communication. They may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and communication aids to help people communicate well.

Quality statement 2: Coordinated care and support

Quality statement

People with a learning disability have a named lead practitioner responsible for coordinating their care and support.

Rationale

Care and support needs change and become more complex as people with a learning disability grow older. A lead practitioner, who is the point of contact for people with a learning disability, their family members and carers, can support coordinating care between different health and social care providers as the person's needs change. A lead practitioner who has a good relationship with the person and can communicate with them well will help to ensure that the care and support needs of the person with a learning disability and their family members and carers’ are met across different services.

Quality measures

Structure

a) Evidence of local arrangements to ensure that named lead practitioners are responsible for coordinating care and support of people with a learning disability as they grow older.

Data source: Local data collection, such as records from community learning disability teams or GP practices.

b) Evidence of local arrangements to ensure that lead practitioners have access to all agencies involved in supporting people with a learning disability.

Data source: Local data collection, such as review of service level agreements.

Process

Proportion of people with a learning disability who have a named lead practitioner.

Numerator – the number in the denominator who have a named lead practitioner.

Denominator – the number of people with a learning disability.

Data source: Local data collection, such as records from community learning disability teams or GP practices.

Outcome

a) Satisfaction with care and support among people with a learning disability.

Data source: NHSI Learning Disability Improvement Standards service user survey.

b) Satisfaction with care and support among family members and carers.

Data source: NHSI Learning Disability Improvement Standards service user survey.

What the quality statement means for different audiences

Service providers (such as GP practices, community learning disability teams or adult social care services) ensure that systems are in place for people with a learning disability to have a named lead practitioner who is responsible for coordinating their care provided by different services as they grow older. They also ensure that lead practitioners have access to all agencies involved in supporting people with a learning disability and that they are informed and involved in decision making.

Health and social care practitioners (such as GPs, learning disability nurses or social care workers) work closely with the named lead practitioner and share any relevant information to ensure that the person with a learning disability has holistic care and support that meets their needs as they grow older.

Commissioners (such as clinical commissioning groups or local authorities) commission services in which people with a learning disability have a named lead practitioner who is responsible for coordinating their care and support as they grow older. They also put in place information sharing agreements and protocols to ensure that people with a learning disability receive holistic and responsive support.

People with a learning disability know who is coordinating their care and support as they grow older. They know that they can ask this person questions and get support from them when their needs change.

Family members and carers (family, friends and anyone else who provides informal support, for example spouses, friends or colleagues) have a named person who they can contact when they or the person with a learning disability they support need help or advice.

Source guidance

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96, recommendations 1.4.6 and 1.5.7

Definitions of terms used in this quality statement

People with a learning disability

In this quality standard, a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

The severity of a person's learning disability may be classified as mild, moderate, severe or profound. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

A specific age limit is not used in this quality standard to define people growing older because adults with a learning disability typically experience age-related difficulties at different ages, and at a younger age than the general population.

[NICE’s guideline on care and support of people growing older with a learning disability, terms used in the guideline]

Lead practitioner

A named contact for people with a learning disability and their family members, carers and advocates. This practitioner could be a member of the community learning disability team or a nurse with experience of learning disabilities. The lead practitioner should have a good relationship with the person, communicate well with them and have good knowledge of local resources.

[Adapted from NICE's guideline on care and support of people growing older with learning disabilities, recommendation 1.5.7]

Equality and diversity considerations

Lead practitioners may find it particularly difficult to communicate effectively with people who have severe or profound learning disability. They may have to identify support necessary to engage people with a learning disability in a meaningful way. This may include involving speech and language therapists or working with family members on finding solutions to allow for effective communication. They may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and aids to help people to communicate well.

Quality statement 3: Future planning and review

Quality statement

People with a learning disability have a plan for the future that is reviewed at least annually.

Rationale

People with a learning disability often start to experience age-related health conditions earlier than the general population. They may have to make changes because of these conditions, for example, it might become more difficult to live in their current home because of physical problems or reduced capacity to make decisions. In addition, people they rely on may grow older and not be able to continue providing support. Considering how circumstances may change and making plans for the future is important as people with a learning disability grow older. Proactive planning for the future helps to establish what is important for the person and what their preferences are before their circumstances change or a crisis point or life-changing event is reached. This means that the services and the person's support network will know how to best support the person in the future.

Quality measures

Structure

Evidence of local arrangements to ensure that health and social care practitioners who have a good relationship with people with a learning disability work with them, the family members and carers most involved in their care to agree a plan for the future.

Data source: Local data collection, for example service protocols

Process

a) Proportion of people with a learning disability who have a plan for the future.

Numerator – the number in the denominator who have a plan for the future.

Denominator – the number of people with a learning disability.

Data source: Local data collection, for example, local audit of individual care plans.

b) Proportion of people with a learning disability who had their plan for the future reviewed within the past 12 months.

Numerator – the number in the denominator who had their plan for the future reviewed within the past 12 months.

Denominator – the number of people with a learning disability who have a plan for the future.

Data source: Local data collection, for example, local audit of individual care plans.

Outcome

Satisfaction with plans for growing older among people with a learning disability.

Data source: Local data collection, such as service user survey.

What the quality statement means for different audiences

Service providers (such as community learning disability teams, adult social care services or GP practices) ensure that systems are in place for people growing older with a learning disability to have person-centred plans in place that consider possible changes to the needs and are reviewed at least once a year. The plans should be developed with practitioners who have a good relationship with the person with a learning disability and include future housing needs, financial and legal issues, any caring relationships and end of life care decisions, including where the person wants to be when they die.

Health and social care practitioners (such as learning disability nurses, social care workers or GPs) are proactive in carrying out person-centred planning with people with a learning disability as they grow older, to address their changing needs, wishes and capabilities and promote their independence. The plans should consider possible changes to housing needs, financial and legal issues, any caring relationships and end of life care decisions, including where the person wants to be when they die. Because people's needs and wishes change, the plan should be reviewed at least once a year.

Commissioners (such as clinical commissioning groups or local authorities) ensure that specifications for services for people with a learning disability include having a person-centred plan for the future. They also ensure that facilities and services are in place to support people with a learning disability as they grow older. This may include transport to help them get to services, appointments and activities or housing adaptations.

People with a learning disability are supported to think about their future and how things may change as they grow older. They have an opportunity to discuss what is important to them and what choices they would make in specific situations that may happen in future, and this in included in their plan for the future. This will include where they live and if they would like to stay there, their money and any financial decisions that they may need help with in future, any legal arrangements in case of death among family members and their choices when they get near to the end of their life. The plan is checked and updated at least every year.

Family members and carers (family, friends and anyone else who provides informal support, for example spouses, friends or colleagues) are involved in making plans for the future with the person with a learning disability as they grow older. Their caring responsibilities are recognised in these plans as well as the potential for those responsibilities and circumstances to change over time. Growing older, increasing needs and the potential for changes to living arrangements are some of the areas that they discuss with the practitioners.

Source guidance

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96, recommendations 1.4.1 and 1.4.5

Definitions of terms used in this quality statement

People with a learning disability

In this quality standard, a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning

- onset in childhood.

The severity of a person's learning disability may be classified as mild, moderate, severe or profound. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

A specific age limit is not used in this quality standard to define people growing older because adults with a learning disability typically experience age-related difficulties at different ages, and at a younger age than the general population.

[NICE’s guideline on care and support of people growing older with a learning disability, terms used in the guideline]

Plan for the future

A proactive plan led by the person with learning disabilities supported by family members and carers most involved in their care and involving a practitioner who has a good relationship with the person and communicates well with them. Key components of the plan for the future are listed in the section on planning for the future in the NICE guideline on care and support of people growing older with learning disabilities.

[NICE’s guideline on care and support of people growing older with learning disabilities, recommendation 1.4.7]

Equality and diversity considerations

People with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with severe or profound learning disability may have particularly complex needs. Practitioners working with people with a learning disability on plans for future may have to identify support necessary to engage with them in a meaningful way. This may include involving speech and language therapists or working with family members on finding solutions to allow for effective communication. They may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and communication aids to help people to communicate well.

Quality statement 4: Health action plan

Quality statement

People with a learning disability have their health action plan updated after every annual health check.

Rationale

People with a learning disability have poorer health and a lower life expectancy than the general population. All adults with a learning disability should have an annual health check at their GP practice. This ensures that any health issues are identified early and care is provided promptly, helping people stay well as they grow older. All people with a learning disability should also have a health action plan that has details of the help and support they need to look after their health. The results of their annual health check should inform an up-to-date health action plan, which is shared with the person with a learning disability in a format that reflects their communication needs.

Quality measures

Structure

a) Evidence of local arrangements to ensure that GP practices have an up-to-date register of people with a learning disability.

Data source: Quality and Outcomes Framework LD004

b) Evidence of local arrangements to ensure that the health action plan of the person with a learning disability is updated after each annual health check.

Data source: Local data collection, for example, review of GP records.

Process

a) Proportion of people with a learning disability who had a health check within the past 12 months.

Numerator – the number in the denominator who had a health check within the past 12 months.

Denominator – the number of people with a learning disability.

Data source: NHS England Learning Disabilities Health Check Scheme

b) Proportion of people with a learning disability who have a health action plan.

Numerator – the number in the denominator who have a health action plan.

Denominator – the number of people with a learning disability.

Data source: Local data collection, for example, review of GP records.

c) Proportion of people with a learning disability who had health action plans updated after an annual health check.

Numerator – the number in the denominator who had their health action plan updated after they had the health check.

Denominator – the number of people with a learning disability with a health action plan who had a health check within the past 12 months.

Data source: Local data collection, for example, review of GP records.

Outcome

a) Quality of life among people with a learning disability as they grow older.

Data source: Local data collection, for example a quality of life survey carried out with people with a learning disability.

a) Under 75 mortality rate among people with a learning disability.

Data source: Healthcare Quality Improvement Programme (HQIP) Learning disability mortality review programme and National Guidance on Learning from Deaths

What the quality statement means for different audiences

Service providers (such as GP practices or community learning disability teams) ensure that they have an up-to-date register of all people with a learning disability and invite them to an annual health check. They also ensure that the health checks are followed by prompt referral to specialist services if needed and that the health action plan is updated after each health check.

Healthcare practitioners (such as GPs or learning disability nurses) carry out annual health checks for people with a learning disability. They ensure they understand how to communicate with the person with a learning disability and what adjustments need to be made before the appointment. They also understand the potential for diagnostic overshadowing and carry out the health check without assuming that any new issues are linked to the learning disability. Healthcare practitioners should also investigate any concerns raised by people involved in care of the person with a learning disability and refer to specialist services whenever needed. Healthcare practitioners should record any actions identified by the annual health check in the person's health action plan.

Commissioners (such as clinical commissioning groups) ensure that they commission services which have an up-to-date register of all people with a learning disability and understand the needs of their local population. They also ensure that local GPs carry out annual health checks and record any actions identified in the person's health action plan.

People with a learning disability are invited every year to a health check. This health check is detailed and includes looking for health problems that are more common in people with a learning disability. The results of the checks are added to the person's health action plan.

Family members and carers (family, friends and anyone else who provides informal support, for example spouses, friends or colleagues) are involved in the annual health check for the person with a learning disability. They can raise any concerns about the health of the person and help the health professionals see the person and not just their disability. They can also find out how to support the person to stay healthy and look after themselves as they grow older.

Source guidance

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96, recommendation 1.5.12

Definitions of terms used in this quality statement

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- onset in childhood.

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A specific age limit is not used in this quality standard to define people growing older because adults with a learning disability typically experience age-related difficulties at different ages, and at a younger age than the general population.

[NICE’s guideline on care and support of people growing older with a learning disability, terms used in the guideline]

Annual health check

An NHS initiative for adults and young people aged 14 and over with learning disabilities to provide additional health support and help to identify health conditions that could otherwise go undetected.

The enhanced scheme for providing the Annual Health Checks for GPs specifies details of the checks required, including that they should be undertaken by an appropriately trained provider and based on a protocol that as a minimum covers:

- a collaborative review of physical and mental health with referral through the usual practice routes if health problems are identified. This includes conditions such as epilepsy and dysphagia
- a specific syndrome check
- a check on the accuracy of prescribed medications
- a review of whether vaccinations and immunisations are up to date, for instance seasonal influenza or hepatitis B

- a review of coordination arrangements with secondary care
- a review of transition arrangements if appropriate
- a discussion of likely reasonable adjustments should secondary care be needed
- a review of communication needs, including how the person might communicate pain or distress
- a review of family carer needs
- offering support to the person to manage their own health and make decisions about their health and healthcare, including through providing information in a format they can understand any support they need to communicate.

[NICE’s guideline on care and support of people growing older with learning disabilities, NHS England Learning Disability Annual Health Check electronic clinical template and Public Health England (2017) People with learning disabilities: health checks audit tool]

Health action plan

A personal plan for people with a learning disability about how to stay healthy. It should detail what help and support the person needs to look after their health. This might include support to manage physical or mental health conditions, or actions to improve lifestyle, such as diet and exercise.

[NICE’s guideline on care and support of people growing older with a learning disability, terms used in the guideline]

Quality statement 5: Planned hospital admissions

Quality statement

People with a learning disability meet with hospital staff before any planned hospital stay to agree reasonable adjustments which would make the stay easier for them.

Rationale

Hospital admissions can be distressing for people with a learning disability. Hospital staff may also find it difficult to provide good quality care if they do not understand the care and support needs of the person with a learning disability. A pre-admission meeting gives everyone involved the opportunity to discuss the level of support needed by the person, any reasonable adjustments to support them during their hospital stay, complete the pre-admission documentation, and share and discuss the person's hospital passport. Going through this process ensures that the person with a learning disability receives the support they need throughout their hospital stay.

Quality measures

Structure

a) Evidence of local arrangements to ensure that a learning disability is recorded in hospital case notes and electronic health records.

Data source: Local data collection, such as review of service level agreements.

b) Evidence of hospital protocols to ensure that reasonable adjustments are put in place for people with a learning disability before a planned hospital admission.

Data source: Local data collection, such as review of service level agreements.

c) Evidence of hospital structure including learning disability liaison nurse.

Data source: Local data collection, such as hospital audit.

Process

a) Proportion of planned hospital admissions in people with a learning disability who had a pre-admission planning meeting.

Numerator – the number in the denominator with a pre-admission planning meeting.

Denominator – the number of planned hospital admissions in people with a learning disability.

Data source: Local data collection, such as review of hospital admission records.

b) Proportion of planned hospital admissions in people with a learning disability with reasonable adjustments put in place for the hospital stay.

Numerator – the number in the denominator with reasonable adjustments put in place for the hospital stay.

Denominator – the number of planned hospital admission for people with a learning disability.

Data source: Local data collection, such as review of hospital admission records.

Outcome

Patient experience of hospital admission among people with a learning disability.

Data source: Local data collection, such as service user survey.

What the quality statement means for different audiences

Service providers (hospitals) ensure that they have processes in place to organise a pre-admission meeting for people with a learning disability who are having a planned admission. This meeting should include the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members or carers. The learning disability liaison nurse can support people with a learning disability before, during and after the admission, and ensure that their needs are being met and any reasonable adjustments are put in place for their hospital stay. Service providers also have arrangements in place for a family member or carer to stay overnight if that is the wish of the person with a learning disability.

Healthcare professionals (such as members of the hospital liaison team) ensure that they participate in the pre-admission meeting with the person with a learning disability and support them in a way that meets the person's needs. They put any reasonable adjustments in place before and during the admission to ensure that the person's experience of their hospital stay is as positive as possible. Healthcare professionals also ensure that all staff involved in care of the person with a learning disability are aware of their needs and have access to a hospital passport that includes information relevant to their care.

Commissioners put processes in place to ensure that planned admissions for people with a learning disability are highlighted to hospital staff in advance. They ensure that pre-admission planning meetings are arranged to discuss reasonable adjustments and complete pre-admission documentation. They also ensure that a sufficient level of support is available to people with a learning disability and arrangements are in place for family member or a carer to stay overnight if that is their wish.

People with a learning disability who need to stay in hospital for a planned treatment have a meeting with hospital staff before their hospital stay to talk about what will happen and what their needs and worries are. They can talk about what would make the hospital stay easier and better for them, and decide if they want someone to stay with them overnight.

Family members and carers (family, friends and anyone else who provides informal support, for example spouses, friends or colleagues) take part in a planning meeting with hospital staff before the person with a learning disability goes into hospital if that is the wish of the person with a learning disability. This is to ensure that the hospital has a full understanding of the needs of the person and to discuss the option of a family member or carer staying overnight in the hospital if the person they support wants them to.

Source guidance

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96, recommendation 1.5.26

Definitions of terms used in this quality statement

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In this quality standard, a learning disability is defined as meeting 3 core criteria:

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A specific age limit is not used in this quality standard to define people growing older because adults with a learning disability typically experience age-related difficulties at different ages, and at a younger age than the general population.

[NICE’s guideline on care and support of people growing older with a learning disability, terms used in the guideline]

Meeting with hospital staff

Participants should include the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person with a learning disability, and their family members, carers or advocate. At this meeting:

- the pre-admission documentation is completed, including information from the person's hospital passport
- any reasonable adjustments needed are discussed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.

[NICE’s guideline on care and support of people growing older with learning disabilities, recommendation 1.5.26]

Reasonable adjustments

Positive steps that the organisation must take to remove barriers a person may face because of their disability in line with the Equality Act 2010.

Equality and diversity considerations

Some people with a learning disability may find it difficult to communicate their needs, anxieties and concerns about being admitted to hospital. Hospital staff need to work with the person and the family members and carers most involved in their care to find ways to communicate effectively. Without mutual understanding, admission may be distressing for the person with a learning disability and for the hospital staff.

About this quality standard

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

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

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

See quality standard advisory committees on the website for details of standing committee 2 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the quality standard's webpage.

This quality standard has been included in the NICE Pathway on care and support of people growing older with learning disabilities, which brings together everything we have said on a topic in an interactive flowchart.

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:

- experience of people with a learning disability using adult social care services
- experience of people with a learning disability using healthcare services
- health- and social-care-related quality of life among people with a learning disability (including carer quality of life)
- sense of independence, choice and control over daily life among people with a learning disability.

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- Adult social care outcomes framework
- NHS outcomes framework
- Public health outcomes framework for England.

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 template and resource impact report on care and support of people growing older with learning disabilities

Diversity, equality and language

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

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

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