

# Learning disability: care and support of people growing older

Quality standard

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This standard is based on NG96.

This standard should be read in conjunction with QS101, QS153, QS137, QS136, QS123, QS50 and QS13.

## Quality statements

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

Statement 2 People growing older with a learning disability have a named lead practitioner.

Statement 3 People growing older with a learning disability are involved in developing a plan for the future and reviewing it at least annually.

Statement 4 People growing older with a learning disability have an annual health check, which is used to update their health action plan.

Statement 5 People growing older with a learning disability meet hospital staff before any planned hospital admission to agree arrangements that make the stay easier for them.

### *Information about this quality standard for people with a learning disability*

NICE has produced [information for the public](#) about this quality standard and its source guidance, and an [EasyRead version](#).

NICE has developed guidance and a quality standard on people's experiences using social care services, patient experience in adult NHS services and service user experience in adult mental health services (see the NICE Pathway on [people's experiences using social care service](#), [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 a learning disability include:

- [Multimorbidity \(2017\) NICE quality standard 153](#)
- [Mental wellbeing and independence for older people \(2016\) NICE quality standard 137](#)
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs \(2016\) NICE quality standard 136](#)
- [Home care for older people \(2016\) NICE quality standard 123](#)
- [Learning disabilities: challenging behaviour \(2015\) NICE quality standard 101](#)
- [Mental wellbeing of older people in care homes \(2013\) NICE quality standard 50](#)
- [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](#).

## Quality statement 1: Person-centred needs assessment

### *Quality statement*

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

### *Rationale*

Performing certain tasks, doing things that used to be easy or maintaining links with the community and other people may become more difficult as people with a learning disability grow older. Care and support needs assessment should be an ongoing process that captures these changes and influences the care and support people receive. People with a learning disability need to be actively involved in this process to ensure that the assessment builds on their strengths, aspirations and desires, and truly reflects what they want from their life as they age.

### *Quality measures*

A specific age limit is not used to define older people with a learning disability in this quality standard (see the [definitions section](#)). For measurement purposes, commissioners may wish to define a specific age group or range of age groups based on their local population.

### **Structure**

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

**Data source:** Local data collection, for example evidence of speech and language therapists or an advocacy service being used to support the assessment.

b) Evidence of local arrangements to ensure that practitioners carrying out assessments of the care and support needs of people growing older 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, for example, records from community learning disability teams or GP practices.

## Outcome

Proportion of people growing older with a learning disability who feel actively involved in shaping the care and support they receive.

Numerator – the number in the denominator who feel actively involved in shaping the care and support they receive.

Denominator – the number of people growing older with a learning disability who receive care and support from health and social care services.

**Data source:** Local data collection, for example, surveys for people with a learning disability on their experiences of care and support they receive.

## *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 continually 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 that reflect what the person with a learning disability wants from their life as they age. They should also ensure that practitioners carrying out care and support needs assessments have access to comprehensive information about communication needs, full history (medical, social, psychological and the nature of their learning disability) and usual behaviour of the person with a learning disability.

**Health and social care practitioners** (such as GPs, learning disability nurses or social care workers) support the person growing older with a learning disability to lead on and be actively involved in their care and support needs assessments. They encourage the person to consider not only their basic health and care needs, but also how they would like to spend their time and with whom, enabling them to explore personal and sexual relationships. They also encourage the person growing older with a learning disability to develop and maintain links with friends, family and community groups. The health and social care practitioners involved in the assessment should 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 should also allow the person time to prepare for the assessment and ensure that this is an ongoing process that also involves the person's support network (family, friends, carers, advocates or others who provide emotional and practical help to the person).

**Commissioners** (such as clinical commissioning groups or local authorities) have a good understanding of the care and support needs of people growing older with a learning disability in their area and what services should be available to promote health and wellbeing in this group. They commission and monitor services providing person-centred care that focuses on care and support needs of people with a learning disability, which also recognises their strengths, aspirations and desires as they grow older. They also commission services that may be necessary to actively involve the person with a learning disability in the care and support needs assessment, such as speech and language therapy, interpreters or independent advocacy.

**People growing older with a learning disability** are encouraged to say what is important to them and are given time and support to prepare for discussions about their care and support needs. They can talk about what they are good at, what they like doing and what they want to do in future.

**People from the person's support network** (family, friends, carers, advocates or others who provide emotional and practical help to the person) support the person growing older with a learning disability to be actively involved in the care and support needs assessment. Their needs are also understood – they can have carer's assessment and get support when they need it. Mutual caring arrangements are 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 growing older with a learning disability**

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 learning disabilities, terms used in this 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. They should also have enough time to prepare



for the assessment. 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 help from someone in the person's support network to ensure that the person has a true opportunity to express their needs, aspirations and desires.

[Expert opinion]

### *Equality and diversity considerations*

People growing older with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with a severe or a profound learning disability 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 people from the person's support network 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: Named lead practitioner

### *Quality statement*

People growing older with a learning disability have a named lead practitioner.

### *Rationale*

Care and support needs may change and become more complex as people with a learning disability grow older. A named lead practitioner is the point of contact for the person growing older with a learning disability and their support network (family, friends, carers, advocates or others who provide emotional and practical help to the person). They can help people access the right support at the right time and coordinate care between different health and social care providers.

### *Quality measures*

A specific age limit is not used to define older people with a learning disability in this quality standard (see the [definitions section](#)). For measurement purposes, commissioners may wish to define a specific age group or range of age groups based on their local population.

### **Structure**

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

**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 growing older with a learning disability.

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

### **Process**

Proportion of people growing older 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 growing older with a learning disability.

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

## Outcome

Proportion of people growing older with a learning disability who feel they can access the support they need when they need it.

Numerator – the number in the denominator who feel they can access the support they need when they need it.

Denominator – the number of people growing older with a learning disability who receive care and support from health and social care services.

**Data source:** Local data collection, for example, surveys on the experience of support among people growing older with a learning disability.

## *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 growing older with a learning disability to have a named lead practitioner who is responsible for coordinating their care across different services. They also ensure that lead practitioners have access to all agencies involved in supporting people growing older 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) with appropriate skills and knowledge act as the named lead practitioner for the person growing older with a learning disability. They get to know the person and coordinate support to meet their long-term needs. They work in partnership with the person, and their family or carers, to arrange regular meetings to discuss the person's care and support, and invite people in the person's support network to the meetings, if this is what the person wants or when decisions are made in a person's best interests. They identify gaps in support and service provision and report these to the lead commissioner. They develop and review the care and support plan with the person growing older with a learning disability, and their support network.

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

**People growing older with a learning disability** have a person who coordinates their care and support as they grow older. This means that they do not need to contact different services to get the support they need. They have a good relationship with this person and know that they can ask them questions or ask for help if they need it.

**People from the person's support network** (family, friends, carers, advocates or others who provide emotional and practical help to the person) have a person who they can contact when they or the person growing older with a learning disability need advice, information or support. They do not need to contact different services to get the support they need.

## *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 growing older with a learning disability**

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 learning disabilities, terms used in this guideline]

### **Named lead practitioner**

A named contact with appropriate skills and knowledge, such as a social worker or community learning disability team, or community learning disability nurse, who gets to know the person and coordinates support to meet their long-term needs. Their responsibilities include working in partnership with the person to:

- arrange regular meetings to discuss the person's care and support, and invite people in their support network, including the family, carers, independent advocates and practitioners from all services that support them
- recognise and use the expertise brought by all members of the person's support network (not only those who are paid)
- develop and review the person's care and support plans with community learning disability teams, social care services and other relevant providers.

[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 a severe or profound learning disability. They may have to identify support necessary to engage people growing older with a learning disability in a meaningful way. This may include involving speech and language therapists or working with people from the person's support network 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 growing older with a learning disability are involved in developing a plan for the future and reviewing it at least annually.

### *Rationale*

People with a learning disability often start to experience age-related health conditions earlier than the general population. Encouraging them to start planning for the future helps to establish what is important to them and what their preferences are before a crisis point or life-changing event is reached. These conversations should also involve the person's support network and recognise that the balance of caring relationships can change as carers (often parents) grow older and the person with a learning disability takes on a caring role. People growing older with a learning disability should have an opportunity to review these plans at least annually and every time their needs or circumstances change, to ensure that they continue to be supported according to their wishes and preferences.

### *Quality measures*

A specific age limit is not used to define older people with a learning disability in this quality standard (see the [definitions section](#)). For measurement purposes, commissioners may wish to define a specific age group or range of age groups based on their local population.

### **Structure**

Evidence of local arrangements to ensure that health and social care practitioners who have a good relationship with people growing older with a learning disability work with them and their support network to develop a plan for the future.

**Data source:** Local data collection, for example, service protocols.

### **Process**

a) Proportion of people growing older 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 growing older with a learning disability.

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

b) Proportion of people growing older with a learning disability who were involved in developing their plan for the future.

Numerator – the number in the denominator who were involved in developing their plan for the future.

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

**Data source:** Local data collection, for example, surveys on the experience of care and support services among people growing older with a learning disability.

c) Proportion of people growing older with a learning disability who had their plan for the future reviewed in the past 12 months.

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

Denominator – the number of people growing older 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

Proportion of people growing older with a learning disability who feel that their wishes are respected as their circumstances change.

Numerator – the number in the denominator who reported feeling that their wishes were respected as their circumstances changed.

Denominator – the number of people growing older with a learning disability who receive care and support from health and social care services.

**Data source:** Local data collection, such as surveys on the experience of support among people growing older with a learning disability.

## *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 health and social care practitioners have the skills and knowledge to support people growing older with a learning disability and people in their support network to develop plans for the future that address changing needs and circumstances before a crisis point or life-changing event takes place. They also ensure that systems are in place for these plans to be reviewed at least annually and every time the person's needs or circumstances change.

**Health and social care practitioners** (such as learning disability nurses, social care workers or GPs) encourage people growing older with a learning disability and people in their support network to make plans for the future that can address their changing needs, wishes and capabilities, and promote their independence and wellbeing. The plans should consider possible changes to housing needs, financial and legal issues, any caring relationships (including mutual caring) as well as end of life care decisions, including where the person wants to be at the end of their life. Because people's needs and wishes change, they should work with the person growing older with a learning disability to review the plan at least annually and every time the person's needs or circumstances change.

**Commissioners** (such as clinical commissioning groups or local authorities) ensure that specifications for services for people growing older with a learning disability include having a person-centred plan for the future that is reviewed at least annually. They also ensure that facilities and services are in place to provide people growing older with a learning disability and people in their support network with the care and support they need as their circumstances change. This may include transport to help them get to services, appointments and activities, or housing adaptations.

**People growing older with a learning disability** are supported to consider how things may change for them in future. They can talk about things like where they want to live in the future and what to do if a family member can no longer support them. They think about changes to their life, health, and the care they will need if they get ill or near the end of their life. The plan is checked and updated at least every year and every time their situation or needs change.

**People from the person's support network** (family, friends, carers, advocates or others who provide emotional and practical help to the person) are involved in making plans for the future with the person growing older with a learning disability. This may cover who will help with money and decisions if they are no longer able to. Their caring responsibilities are recognised in these plans as



well as the potential for those responsibilities and circumstances to change over time. They can also say how much longer they think they will be able to support the person with a learning disability.

## *Source guidance*

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96, recommendations 1.4.5 and 1.4.6

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

### **People growing older with a learning disability**

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 learning disabilities, terms used in this guideline]

### **Plan for the future**

A proactive plan led by the person with a learning disability 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 should include:

- Housing needs and potential solutions.
- Any home adaptations or technology that may address people's changing needs as they grow older.
- Members of the person's support network (both paid and unpaid).
- Any help the person gives to family members, whether this will continue as they age, and the impact this may have on their health and wellbeing.
- Planning for what will happen if someone who the person relies on dies or is no longer able to provide care and support.

- Financial and legal issues, for example whether someone has been appointed to have lasting power of attorney for the person.
- The provision of information on wills, trusts and benefits.
- Planning for unexpected changes or emergencies.
- Planning for a time when the person may lack capacity to make decisions themselves, in line with the Mental Capacity Act 2005.
- Consideration of deprivation of liberty safeguards, for instance if planned changes to care or the care environment are likely to increase restrictions on the person.
- End of life care decisions – including where the person wants to be when they die. These decisions should be reviewed at least once a year.

[NICE's guideline on [care and support of people growing older with learning disabilities](#), recommendations 1.4.5 and 1.4.7]

### *Equality and diversity considerations*

People with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with a 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: Annual health check

### *Quality statement*

People growing older with a learning disability have an annual health check, which is used to update their health action plan.

### *Rationale*

People with a learning disability have poorer health and a lower life expectancy than the general population. They may not recognise that they are unwell or may be unable to communicate how they feel. They may also develop conditions or face challenges that are associated with the learning disability. The annual health checks for people with a learning disability differ from NHS health checks and include a more specific and detailed examination of a person's physical and mental health. Carrying out these checks ensures that health issues are identified early, support can be provided promptly, and the person's health action plan is up to date.

### *Quality measures*

A specific age limit is not used to define older people with a learning disability in this quality standard (see the [definitions section](#)). For measurement purposes, commissioners may wish to define a specific age group or range of age groups based on their local population.

### **Structure**

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

**Data source:** [Quality and Outcomes Framework LD004](#).

b) Evidence of local arrangements to ensure that GP practices offer annual health checks for people growing older with a learning disability.

**Data source:** [NHS England Learning Disabilities Health Check Scheme](#).

c) Evidence of local processes to ensure that health action plans for people growing older with a learning disability are updated after the annual health checks are carried out.

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

## Process

a) Proportion of people growing older 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 growing older with a learning disability.

**Data source:** NHS England Learning Disabilities Health Check Scheme.

b) Proportion of people with a learning disability who had their health action plan updated after an annual health check.

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

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

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

## *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. Service providers have suitable arrangements in place to ensure that any communication about the appointments and the appointment itself meet the needs of the person growing older with a learning disability. They also have a process in place to share relevant information with the person's named lead practitioner and people in their support network if appropriate.

**Healthcare professionals** (such as GPs or learning disability nurses) carry out annual health checks in people growing older with a learning disability. They understand how to communicate with them and what arrangements 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 professionals should also investigate any concerns raised by people from the person's support network and refer to specialist services whenever needed. Healthcare professionals should record any actions identified by the annual health check in the person's health action plan and share the health action plan with the person.

**Commissioners** (such as clinical commissioning groups) ensure that they commission services that 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 in people growing older with a learning disability and record any actions identified in the person's health action plan.

**People growing older with a learning disability** have a detailed health check every year that 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, which helps them to understand how to stay healthy for longer. People growing older with a learning disability are involved in putting this plan together and they understand what it says.

**People from the person's support network** (family, friends, carers, advocates or others who provide emotional and practical help to the person) are involved in an annual health check for the person with a learning disability. They can talk to the doctor or nurse if they have any worries about the person they support 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*

### **People growing older with a learning disability**

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 learning disabilities, terms used

in this guideline]

## Annual health check for people with a learning disability

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

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

- A collaborative review of physical and mental health with referral through the usual practice routes if health problems are identified. This includes conditions such as epilepsy and dysphagia.
- A specific syndrome check.
- A check on the accuracy of prescribed medications.
- A review of whether vaccinations and immunisations are up to date, for instance seasonal influenza, pneumonia or hepatitis B.
- A review of coordination arrangements with secondary care.
- A review of transition arrangements if appropriate.
- A discussion of likely reasonable adjustments should secondary care be needed.
- A review of communication needs, including how the person might communicate pain or distress.
- A review of family carer needs.
- Offering support to the person to manage their own health and make decisions about their health and healthcare, including through providing information in a format they can understand and any support they need to communicate.

[NICE's guideline on [care and support of people growing older with learning disabilities](#), NHS England's [Learning Disability Annual Health Check electronic clinical template](#) and Public Health England's [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 their lifestyle, such as changes to diet and exercise.

[NICE's guideline on [care and support of people growing older with learning disabilities](#), terms used in this guideline]

## Quality statement 5: Hospital admissions

### *Quality statement*

People growing older with a learning disability meet hospital staff before any planned hospital admission to agree arrangements that make the stay easier for them.

### *Rationale*

Hospital admissions can be particularly 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*

A specific age limit is not used to define older people with a learning disability in this quality standard (see the [definitions section](#)). For measurement purposes, commissioners may wish to define a specific age group or range of age groups based on their local population.

### **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 growing older with a learning disability before a planned hospital admission.

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

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



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

## Process

Proportion of planned hospital admissions for people growing older with a learning disability that had a pre-admission planning meeting.

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

Denominator – the number of planned hospital admissions for people growing older with a learning disability.

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

## Outcome

Proportion of people growing older with a learning disability who felt satisfied with the support provided during their planned hospital stay.

Numerator – the number in the denominator who felt satisfied with the support provided during their planned hospital stay.

Denominator – the number of people growing older with a learning disability who had a planned hospital stay.

**Data source:** Local data collection, such as post-discharge patient survey.

## *What the quality statement means for different audiences*

**Service providers** (such as GP practices, community learning disability teams and hospitals) follow agreed protocols when people with a learning disability may need hospital admission. This includes organising a pre-admission meeting for planned admissions. This meeting should include the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and relevant people from their support network (family, friends, carers, advocates or others who provide emotional and practical help to the person). Services ensure that the learning disability liaison nurse has the skills and knowledge to support people growing older with a learning disability before, during and after the admission, and ensure that their needs are being met and any agreed arrangements 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 agreed with the person

with a learning disability.

**Healthcare professionals** (such as members of the hospital liaison team) participate in the pre-admission meeting with the person growing older with a learning disability and support them in a way that meets the person's needs. They put any agreed arrangements 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 growing older with a learning disability are aware of their needs and have access to a hospital passport that includes information relevant to their care.

**Commissioners** (such as clinical commissioning groups) put processes in place to ensure that GP practices, community learning disability teams and hospitals work together to agree protocols to be followed when people with a learning disability may need hospital admission. They monitor whether pre-admission planning meetings are undertaken to agree specific arrangements 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 a family member or a carer to stay overnight if agreed.

**People growing older with a learning disability** meet with hospital staff before they stay in hospital. They can ask about what will happen during their stay and talk about their needs and worries. Hospital staff can explain what will happen and explore how they can make the hospital stay easier for them, including if they want someone to stay with them overnight. People should also have an opportunity to talk about hospital admissions before the need for the admission arises.

**People from the person's support network** (family, friends, carers, advocates or others who provide emotional and practical help to the person) take part in a meeting with hospital staff and make sure the hospital staff understand the person's needs before the person with a learning disability stays in hospital. They can stay 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*

### **People growing older with a learning disability**

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 learning disabilities](#), terms used in this 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]

## *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 their family members and carers 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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## *Endorsing organisation*

This quality standard has been endorsed by The Department of Health and Social Care, as required by the Health and Social Care Act (2012)

## *Supporting organisations*

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

- [Care England](#)
- [Learning Disability England](#)
- [The Down's Syndrome Association](#)
- [National Development Team for Inclusion](#)
- [Royal College of General Practitioners \(RCGP\)](#)
- [Foundation for People with Learning Disabilities](#)
- [Voluntary Organisations Disability Group \(VODG\)](#)
- [British Geriatrics Society](#)
- [Skills for Care](#)
- [Royal College of Nursing \(RCN\)](#)