

Learning disability: behaviour that challenges

Quality standard

Published: 8 October 2015

Last updated: 24 July 2019

www.nice.org.uk/guidance/qs101

Contents

Quality statements	6
Information about this quality standard for people with a learning disability	7
Quality statement 1: Lead commissioner	9
Quality statement	9
Rationale	9
Quality measures.....	9
What the quality statement means for different audiences.....	10
Source guidance.....	10
Definitions of terms used in this quality statement	10
Quality statement 2: Annual health check	12
Quality statement.....	12
Rationale	12
Quality measures.....	12
What the quality statement means for different audiences.....	13
Source guidance.....	13
Definitions of terms used in this quality statement	13
Equality and diversity considerations	15
Quality statement 3: Initial assessment of behaviour that challenges	16
Quality statement.....	16
Rationale	16
Quality measures.....	16
What the quality statement means for different audiences.....	17
Source guidance.....	18
Definitions of terms used in this quality statement	18
Equality and diversity considerations	19
Quality statement 4: Named lead practitioner	20
Quality statement.....	20

Rationale	20
Quality measures.....	20
What the quality statement means for different audiences.....	22
Source guidance.....	23
Definitions of terms used in this quality statement	23
Equality and diversity considerations	24
Quality statement 5: Involving families and carers	25
Quality statement.....	25
Rationale	25
Quality measures.....	25
What the quality statement means for different audiences.....	27
Source guidance.....	27
Definitions of terms used in this quality statement	28
Quality statement 6: Parent-training programmes.....	30
Quality statement.....	30
Rationale	30
Quality measures.....	30
What the quality statement means for different audiences.....	31
Source guidance.....	31
Definitions of terms used in this quality statement	32
Quality statement 7: Personalised daily activities.....	33
Quality statement.....	33
Rationale	33
Quality measures.....	33
What the quality statement means for different audiences.....	34
Source guidance.....	35
Definitions of terms used in this quality statement	35
Equality and diversity considerations	36

Quality statement 8: Services in the community	37
Quality statement.....	37
Rationale	37
Quality measures.....	37
What the quality statement means for different audiences.....	39
Source guidance.....	40
Definitions of terms used in this quality statement	40
Equality and diversity considerations	41
Quality statement 9: Housing.....	42
Quality statement.....	42
Rationale	42
Quality measures.....	42
What the quality statement means for different audiences.....	43
Source guidance.....	44
Definitions of terms used in this quality statement	44
Equality and diversity considerations	46
Quality statement 10: Review of restrictive interventions.....	47
Quality statement.....	47
Rationale	47
Quality measures.....	47
What the quality statement means for different audiences.....	48
Source guidance.....	49
Definitions of terms used in this quality statement	49
Equality and diversity considerations	50
Quality statement 11: Use of medication.....	51
Quality statement.....	51
Rationale	51
Quality measures.....	51

What the quality statement means for different audiences.....	52
Source guidance.....	53
Definitions of terms used in this quality statement	53
Equality and diversity considerations	54
Quality statement 12: Review of medication	55
Quality statement.....	55
Rationale	55
Quality measures.....	55
What the quality statement means for different audiences.....	56
Source guidance.....	57
Definitions of terms used in this quality statement	57
Equality and diversity considerations	58
Update information	59
About this quality standard	60
Improving outcomes	61
Resource impact.....	61
Diversity, equality and language.....	62

This standard is based on NG11 and NG93.

This standard should be read in conjunction with QS59, QS51, QS14, QS154, QS187, QS142 and QS194.

Quality statements

Statement 1 Local authorities and clinical commissioning groups jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability. **[new 2019]**

Statement 2 People with a learning disability have an annual health check from their GP. **[2015, amended 2019]**

Statement 3 People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour. **[2015]**

Statement 4 People with a learning disability and behaviour that challenges have a named lead practitioner. **[2015, updated 2019]**

Statement 5 Families and carers of people with a learning disability and behaviour that challenges are involved by services in developing the person's care and support plan, which includes how to prevent or respond to a crisis. **[new 2019]**

Statement 6 Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme. **[2015]**

Statement 7 People with a learning disability and behaviour that challenges take part in personalised daily activities. **[2015]**

Statement 8 People with a learning disability and behaviour that challenges have access to specialist behavioural support in the community. **[new 2019]**

Statement 9 Adults with a learning disability and behaviour that challenges are supported to choose where and how they live. **[new 2019]**

Statement 10 People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used. **[2015]**

Statement 11 People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions. **[2015]**

Statement 12 People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months. **[2015]**

Information about this quality standard for people with a learning disability

NICE has produced information for the public and EasyRead versions about this quality standard and its source guidance. See:

- [information for the public](#) and the [EasyRead version](#) on support for people with a learning disability and behaviour that challenges
- [information for the public](#) and the [EasyRead version](#) on health and social care services for people with a learning disability and behaviour that challenges.

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

Other quality standards that should be considered when commissioning or providing services for people with a learning disability and behaviour that challenges include:

- [Learning disability: care and support of people growing older. NICE quality standard 187](#)
- [Learning disability: identifying and managing mental health problems. NICE quality standard 142](#)
- [Autism. NICE quality standard 51](#)

A full list of NICE quality standards is available from the [quality standards topic library](#).

Quality statement 1: Lead commissioner

Quality statement

Local authorities and clinical commissioning groups jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability. [new 2019]

Rationale

Having a lead commissioner who is experienced in working with children, young people and adults with a learning disability, including those with behaviour that challenges, will help to make sure that services meet their needs. In the longer term, the lead commissioner can bring together commissioning across health, social care and education for children, young people and adults. This will simplify the system, make better use of resources and clarify responsibilities. It might also improve the experience and outcomes of people with a learning disability, for example by reducing crises and the need for more intensive support.

Quality measures

Structure

a) Evidence of local arrangements for local authorities and clinical commissioning groups to jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability.

Data source: Local data collection, for example from joint working protocols.

b) Evidence that the lead commissioner role specifies that they have in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services.

Data source: Local data collection, for example job descriptions.

What the quality statement means for different audiences

Commissioners (local authorities and clinical commissioning groups) jointly choose a lead commissioner to oversee strategic commissioning of services for people with a learning disability. They choose a lead commissioner who has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services.

People of all ages with a learning disability use services for health, social care and education that are organised by one person who has worked with people with a learning disability and behaviour that challenges before, called the 'lead commissioner'. The lead commissioner is in charge of making sure that these different services work together to meet the needs of people with a learning disability.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.1.1

Definitions of terms used in this quality statement

Lead person to oversee strategic commissioning

A commissioner who plans and oversees joined-up commissioning arrangements for health, social care and education services for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges. They have in-depth knowledge and experience of working with people with a learning disability and behaviour that challenges, including knowledge of local services. They ensure that:

- resources are pooled across services and with neighbouring authorities to develop local and regional services
- service planning and delivery are based on assessments of current and future service needs

- services are planned and delivered in a way that is co-produced with people using services and their families, carers and independent advocates (see the definition of co-production in the [Think Local, Act Personal care and support jargon buster](#))
- organisations take joint responsibility for managing risk when developing and delivering care and support
- services liaise regularly with the named worker, keeping them informed and involved in decision making.

[[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), recommendations 1.1.1 to 1.1.3, 1.1.6, 1.1.7, 1.1.9 and 1.2.11]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from [NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Quality statement 2: Annual health check

Quality statement

People with a learning disability have an annual health check from their GP. **[2015, amended 2019]**

Rationale

Annual health checks in people with a learning disability are likely to lead to identification and management of underlying physical health problems at an early stage. Unrecognised physical illness in people with a learning disability may lead to pain and discomfort, which, in turn, may be an important factor in triggering and maintaining behaviour that challenges. Therefore, early identification of physical health problems in people with a learning disability may reduce behaviour that challenges, leading to a reduction in costs associated with assessing and managing such behaviour.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability have an annual health check from their GP.

Data source: Local data collection.

Process

Proportion of people with a learning disability who have an annual health check from their GP.

Numerator – the number in the denominator who had an annual health check from their GP in the past 12 months.

Denominator – the number of people with a learning disability in contact with a GP service.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (primary care providers) ensure that people with a learning disability have an annual health check from their GP.

Healthcare professionals (GPs) carry out an annual health check for people with a learning disability.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services in which GPs provide an annual health check for people with a learning disability.

People with a learning disability have a thorough health check from their GP every year. This should include checking their physical health and any medicines they are taking. The checks should help to plan the person's healthcare over the next year and make sure that any physical health problems are treated.

Source guidance

- [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 \(2015\), recommendation 1.2.1](#)
- [Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 \(2018\), recommendation 1.2.23](#)

Definitions of terms used in this quality statement

An annual health check

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 review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems.
- 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](#), terms used in this guideline, [NICE's guideline on challenging behaviour and learning disabilities](#), recommendation 1.2.1, [NHS England's Learning Disability Annual Health Check electronic clinical template](#) and [Public Health England's People with learning disabilities: health checks audit tool](#)]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 3: Initial assessment of behaviour that challenges

Quality statement

People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour. [2015]

Rationale

Early and timely assessment of behaviour that challenges can identify and seek to address the factors that lead to the behaviour and help to understand why the person is behaving in that way. In turn, this should help to reduce escalation of the behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Data source: Local data collection.

Process

Proportion of people with a learning disability and behaviour that challenges who have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Numerator – the number in the denominator who have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Denominator – the number of people with a learning disability presenting with behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (health and social care providers) ensure that systems are in place for people with a learning disability and behaviour that challenges to have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Health and social care practitioners ensure that people with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Commissioners (clinical commissioning groups, NHS England and local authorities) ensure that they commission services that provide initial assessments for people with a learning disability and behaviour that challenges to identify possible triggers, environmental factors and function of the behaviour.

People who have a learning disability have an assessment when there are signs of behaviour that challenges. The assessment includes the following:

- a description of the behaviour
- how often it occurs and for how long
- how it affects the person
- what events or situations make the behaviour happen
- what purpose the behaviour has for the person.

This helps to identify what may be causing the behaviour and any changes that might stop or reduce it.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.5.4

Definitions of terms used in this quality statement

Initial assessment

An initial assessment should include:

- a description of the behaviour and its function (including its severity, frequency, duration, purpose for the person and effect on the person and others); the description should be provided by the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- an explanation of the personal and environmental factors involved in triggering or maintaining the behaviour; the explanation should be provided by the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
- any involvement of the service, staff, family members or carers in triggering or maintaining the behaviour.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, recommendation 1.5.4]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 4: Named lead practitioner

Quality statement

People with a learning disability and behaviour that challenges have a named lead practitioner. **[2015, updated 2019]**

Rationale

Children, young people and adults with a learning disability, and their families and carers, can find it difficult to get support from the right services at the right time. Having a named lead practitioner to coordinate support can help with this and make sure that services work together. The person and their family or carer should be given a choice of lead practitioner that takes into account any personal needs, such as cultural or religious needs. The lead practitioner can also get to know the person and their family or carer, and involve them in decision making, which can improve understanding of the care and support the person needs. The lead practitioner can also improve outcomes for people with a learning disability by consistently making sure their care and support needs are met, and allowing them to feel empowered and involved in their care.

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 and behaviour that challenges.

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 and behaviour that

challenges.

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

Process

Proportion of people with a learning disability and behaviour that challenges 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 and behaviour that challenges.

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

Outcomes

a) Proportion of people with a learning disability and behaviour that challenges who feel satisfied with services.

Numerator – the number in the denominator who feel satisfied with services.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, using surveys, focus groups and other methods of gathering the views of people using services, such as those used in the Challenging Behaviour Foundation and Mencap's valuing the views of children with a learning disability.

b) Proportion of people with a learning disability and behaviour that challenges and their families and carers who feel satisfied with involvement in decision making.

Numerator – the number in the denominator who feel satisfied with services.

Denominator – the number of people with a learning disability and behaviour that

challenges and their families and carers.

Data source: Local data collection, for example, using surveys, focus groups and other methods of gathering the views of people using services and their families, such as those used in the Challenging Behaviour Foundation and Mencap's valuing the views of children with a learning disability.

What the quality statement means for different audiences

Service providers (such as social care providers, community mental health teams, community learning disability teams and disabled children's teams) ensure that there is a named lead practitioner for each child, young person and adult with a learning disability and behaviour that challenges. Service providers are in regular contact with the lead practitioner, keeping them informed and involved in decision making.

Health and social care practitioners (such as social workers in a disabled children's team or community learning disability team, community learning disability nurses or allied health professionals) with appropriate skills and knowledge act as the named lead practitioner for a child, young person or adult with a learning disability and behaviour that challenges. 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 (if the person is over 16, and in line with the Mental Capacity Act 2005). 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 with a learning disability and behaviour that challenges, and their family or carers.

Commissioners (such as local authorities, clinical commissioning groups and lead commissioners) ensure that services assign a named lead practitioner, for example, a social worker (in a disabled children's team or community learning disability team) or community learning disability nurse, for a child, young person or adult with a learning disability and behaviour that challenges. They are in regular contact with the lead practitioner, making sure that no decisions are made without involving them and the person with a learning disability and behaviour that challenges.

People of all ages with a learning disability and behaviour that challenges have one person, called the 'lead practitioner', who they can talk to about their support. The lead practitioner is a person who understands learning disability and behaviour that challenges. They might be a social worker or a nurse. The lead practitioner meets regularly with the person, gets to know them and makes sure they get the support they need.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.2.10

Definitions of terms used in this quality statement

Named lead practitioner

A named practitioner with appropriate skills and knowledge, such as a social worker in a disabled children's team 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 or relevant children's services (for example, disabled children's teams) and service providers.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendations 1.2.10, 1.2.12 to 1.2.14 and 1.2.16]

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from [NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Equality and diversity considerations

Lead practitioners may find it particularly difficult to communicate effectively with children, young people and adults who have severe or profound learning disability. They may need to call on additional support to help them communicate with the person. This could include involving speech and language therapists, or working with family members or social care providers who know the person well to find ways of improving communication. Lead practitioners may also use augmentative and alternative communication approaches such as manual signs, pictures, objects and aids to help people to communicate well.

Quality statement 5: Involving families and carers

Quality statement

Families and carers of people with a learning disability and behaviour that challenges are involved in developing the person's care and support plan, which includes how to prevent or respond to a crisis. **[new 2019]**

Rationale

Families and carers of children, young people and adults with a learning disability can find it hard to get information and support to help them understand behaviour that challenges, and to know the signs to look out for, what to do in a crisis and where to find services and support. Involving families in developing a care and support plan (if this is what the person wants), listening to their ideas, and providing information and support will increase their confidence and skills. This means that people with a learning disability are more likely to stay with their family, if they want to, and behaviour that challenges is less likely to occur or worsen.

Quality measures

Structure

Evidence of local arrangements to ensure that community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers work in partnership with the families and carers of people with a learning disability and behaviour that challenges to develop a care and support plan that includes how to prevent or respond to a crisis.

Data source: Local data collection, for example, from service level agreements and policy documents.

Process

Proportion of care and support plans for people with a learning disability and behaviour that challenges where families and carers were involved in developing them.

Numerator – the number in the denominator where families and carers were involved in developing them.

Denominator – the number of care and support plans for people with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, local audit of care and support plans or education, health and care plans.

Outcomes

a) Proportion of adults with a learning disability who live in their own home or with their family.

Numerator – the number in the denominator who live in their own home or with their family.

Denominator – the number of adults with a learning disability.

Data source: NHS Digital's data set 1G - Proportion of adults with a learning disability who live in their own home or with their family. This data set is part of Measures from the Adult Social Care Outcomes Framework, England.

b) Proportion of children and young people with a learning disability who live with their family.

Numerator – the number in the denominator who live with their family.

Denominator – the number of children and young people with a learning disability.

Data source: Local data collection, for example, from children's social care services data sets.

What the quality statement means for different audiences

Service providers (such as community learning disability teams or relevant children's services [for example, disabled children's teams or schools], community support providers, community mental health teams, social care providers, supported housing and residential care providers, and inpatient teams) ensure that staff have the time and resources to meet the families and carers of children, young people and adults with a learning disability and behaviour that challenges to discuss a care and support plan that sets out how to prevent or respond to a crisis.

Health, social care and education practitioners (such as social workers, care managers, advocates, community learning disability nurses, allied health professionals and education staff) meet the families and carers of children, young people and adults with a learning disability and behaviour that challenges, independent advocates and the named lead practitioner to discuss and develop a care and support plan together that sets out how to prevent or respond to a crisis.

Commissioners (such as NHS England, local authorities and lead commissioners) ensure that they monitor whether services meet and involve the families and carers of children, young people and adults with a learning disability and behaviour that challenges, independent advocates and the named lead practitioner in developing a care and support plan that sets out how to prevent or respond to a crisis.

Families and carers of people with a learning disability and behaviour that challenges are involved in developing a care and support plan. The plan includes tips on how to prevent a crisis and what families and carers should do if a crisis happens. The plan also includes practical information to help them in their role as carers.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendation 1.2.14

Definitions of terms used in this quality statement

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Care and support plan

A person-centred plan that:

- meets the person's needs and preferences
- works to support and maximise the person's mental capacity
- takes into account people's fluctuating mental capacity and needs
- adopts a 'whole life' approach that covers what they want to achieve in both the short and long term, and supports smooth transitions
- takes a positive approach to managing risk
- sets out what to do to prevent or respond to a crisis, including early intervention and management of a crisis. The plan includes key local emergency contact numbers and simple, practical interventions. It might also cover rapid involvement of additional services and provision of extra resources, such as short break services.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendation 1.2.14 and expert opinion]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Quality statement 6: Parent-training programmes

Quality statement

Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme. **[2015]**

Rationale

Early interventions for parents or carers support them to better understand and manage behaviour that challenges. This can help prevent the behaviour from developing into a long-term problem that is distressing for the person with a learning disability and leads to a greater burden of care for families and the wider service system. Parent-training programmes include training to promote the communication and social skills of children with a learning disability. They are designed to help parents and carers to understand, respond to and support children more effectively, with the aim of reducing and managing behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements to ensure that parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme for behaviour that challenges.

Data source: Local data collection.

Process

Proportion of parents or carers of children aged under 12 years with a learning disability and behaviour that challenges who are offered a parent-training programme for behaviour

that challenges.

Numerator – the number in the denominator whose parents or carers are offered a parent-training programme for behaviour that challenges.

Denominator – the number of children aged under 12 years with a learning disability and behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (secondary care and social care providers) ensure that parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme for behaviour that challenges.

Health and social care practitioners ensure that parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme for behaviour that challenges.

Commissioners (clinical commissioning groups, NHS England and local authorities) ensure that they commission services that offer parent-training programmes for behaviour that challenges to parents or carers of children aged under 12 years who have a learning disability and behaviour that challenges.

Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a training programme to help them better understand and support the child. They learn how to help children improve their communication and social skills, which can help to reduce behaviour that challenges.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendations 1.6.1 and 1.7.1

Definitions of terms used in this quality statement

Parent-training programme

Parent-training programmes:

- are delivered in groups of 10 to 15 parents or carers
- focus on developing communication and social functioning in the child with a learning disability
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow a treatment manual
- are accessible (for example, take place outside normal working hours or in community-based settings with childcare facilities)
- use practical materials to ensure consistent implementation of the programme.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, recommendation 1.7.2]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Quality statement 7: Personalised daily activities

Quality statement

People with a learning disability and behaviour that challenges take part in personalised daily activities. [2015]

Rationale

People with a learning disability and behaviour that challenges often have limited opportunity to engage in meaningful occupation or activity, or may take part in activities that are not meaningful to them. Very high rates of behaviour that challenges have been reported in institutions that typically offer relatively limited activities. Ensuring that people with a learning disability have planned, personalised daily activities will help to reduce rates of behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and behaviour that challenges take part in personalised daily activities.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges with a personalised daily activity schedule.

Numerator – the number in the denominator with a personalised daily activity schedule.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection.

b) Proportion of people taking part in personalised daily activities.

Numerator – the number in the denominator who take part in personalised daily activities.

Denominator – the number of people with a learning disability and behaviour that challenges with a personalised daily activity schedule.

Data source: Local data collection.

Outcome

Service user experience of personalised daily activities.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as health and social care providers, providers of residential care and providers in educational settings) ensure that systems are in place for people with a learning disability and behaviour that challenges to take part in personalised daily activities.

Health and social care practitioners (including staff in residential settings and educational settings) ensure that people with a learning disability and behaviour that challenges take part in personalised daily activities.

Commissioners (NHS England, clinical commissioning groups and local authorities) ensure that they commission services that plan personalised daily activities for people with a learning disability and behaviour that challenges.

People with a learning disability and behaviour that challenges take part in activities

planned for each day. The activities should be interesting for the person and should be recorded in a daily activity schedule. This should form part of the behaviour support plan that sets out how they will be supported. The activity schedule should be developed with the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.6.1

Definitions of terms used in this quality statement

Daily activity schedule

The daily activity schedule should be developed and agreed with the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers. The planned activities should be of interest to the person and be meaningful to them. The activities should be recorded in the daily activity schedule and form part of the behaviour support plan.

Behaviour support plan

A behaviour support plan should be developed and agreed with the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers. The behaviour support plan is based on a shared understanding about the function of the behaviour and should:

- identify proactive strategies designed to improve the person's quality of life and remove the conditions likely to promote behaviour that challenges
- identify adaptations to a person's environment and routine, and strategies to help them develop another behaviour that fulfils the same function by developing a new skill (for example, improved communication, emotional regulation or social interaction)
- identify preventive strategies to calm the person when they begin to show early signs

of distress

- identify reactive strategies to manage any behaviours that are not preventable
- incorporate risk management and take into account the effect of the behaviour support plan on the level of risk
- be compatible with the abilities and resources of the person's family members, carers or staff, including managing risk, and be able to be implemented within these resources
- identify training for family members, carers or staff to improve their understanding of behaviour that challenges shown by people with a learning disability.

[Adapted from [NICE's guideline on challenging behaviour and learning disabilities](#), recommendation 1.6.1]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from [NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 8: Services in the community

Quality statement

People with a learning disability and behaviour that challenges have access to specialist behavioural support in the community. **[new 2019]**

Rationale

A lack of specialist support in the community can affect quality of life for children, young people and adults with a learning disability and behaviour that challenges, and their families and carers. It can lead to problems after discharge from specialist inpatient care, such as assessment and treatment units or secure services. Insufficient community support can also delay or prevent discharges and transition from residential placements. Ensuring that specialist support is available locally for early intervention can help families and carers to look after the person at home, and reduce the incidence of crises and the need for intensive services and out-of-area and residential placements.

Quality measures

Structure

a) Evidence of local arrangements for specialist behavioural support to be available in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system).

Data source: Local data collection, for example from service specifications.

b) Evidence that local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support for people with a learning disability and behaviour that challenges, have been set.

Data source: Local data collection, for example from service specifications.

c) Evidence that professionals working in specialist behavioural support are trained in helping people with a learning disability and their families and carers to understand and change behaviour that challenges.

Data source: Local data collection, for example, local service specifications.

Process

Proportion of people with a learning disability and behaviour that challenges accessing specialist behavioural support who receive support in the community.

Numerator – the number in the denominator who receive support in the community.

Denominator – the number of people with a learning disability and behaviour that challenges accessing specialist behavioural support.

Data source: Local data collection, for example from patient records and surveys on the experience of people with a learning disability and behaviour that challenges accessing specialist behavioural support, and their families and carers.

Outcomes

a) Proportion of adults with a learning disability who live in their own home or with their family.

Numerator – the number in the denominator who live in their own home or with their family.

Denominator – the number of adults with a learning disability.

Data source: NHS Digital's data set 1G - Proportion of adults with a learning disability who live in their own home or with their family. This data set is part of Measures from the Adult Social Care Outcomes Framework, England.

b) Proportion of children and young people with a learning disability who live with their family.

Numerator – the number in the denominator who live with their family.

Denominator – the number of children and young people with a learning disability.

Data source: Local data collection, for example, from children's social care services data sets.

c) Rates of inpatient admissions for people with a learning disability.

Data source: NHS Digital's learning disability services statistics includes inpatient data on learning disabilities and autism from the assuring transformation and the mental health service data set.

d) Rates of restrictive intervention use for people with a learning disability.

Data source: Local data collection, for example audit of records from schools and inpatient settings.

What the quality statement means for different audiences

Service providers (such as community learning disability teams, specialist intensive support teams, schools, short break services, social care providers and community support providers) ensure that practitioners working in the community are trained to help children, young people and adults with a learning disability and behaviour that challenges and their families and carers understand why the behaviour occurs and how to prevent or change the behaviour if it is causing problems for them, before it gets worse. They ensure that services are available in the community. If a child, young person or adult develops, or is at risk of developing, offending behaviour, they should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible.

Health, social care and education practitioners (such as clinical psychologists, behaviour therapists, psychiatrists, learning disability nurses, community learning disability professionals, education staff, specialist intensive support workers and social workers) assess the needs and risk of children, young people and adults with a learning disability and behaviour that challenges in a community setting. They help the person and their family and carers, as well as other practitioners, to get support in line with this assessment. This support should help them to understand their behaviour, improve their quality of life, and reduce the behaviour that challenges before it gets worse, if it is

causing problems for them. If a child, young person or adult develops, or is at risk of developing, offending behaviour, they refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible.

Commissioners (such as local authorities and clinical commissioning groups) have a lead commissioner to act on their behalf to commission specialist behavioural support in the community for children, young people and adults with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system). The lead commissioner should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges.

People with a learning disability and behaviour that challenges can access specialist behavioural support in the community when they need it to help them understand their behaviour, if it is causing problems for them, and to stop it from getting worse. Families can have specialist learning disability support in the community instead of residential placements away from home, which will reduce the need for such placements.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendations 1.3.1 and 1.4.7

Definitions of terms used in this quality statement

Specialist behavioural support

Support provided by practitioners who have training in helping children, young people and adults with a learning disability and their families and carers to understand and change their behaviour if it is causing problems for them or other people. This includes assessing behaviour that challenges to understand why the behaviour occurs and the function of the behaviour, and developing a behaviour support plan that identifies strategies to prevent or change the behaviour and improve quality of life.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and

delivery, terms used in this guideline and [NICE's guideline on challenging behaviour and learning disabilities](#), recommendations 1.5.1, 1.5.6 and 1.6.1]

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from [NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Equality and diversity considerations

Children, young people and adults 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 may need to call on additional support to help them communicate with the person. This could include involving speech and language therapists or working with family members to find ways of improving communication. Practitioners 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 9: Housing

Quality statement

Adults with a learning disability and behaviour that challenges are supported to choose where and how they live. **[new 2019]**

Rationale

People with a learning disability and behaviour that challenges face barriers to choosing where they live and who they live with, such as lack of available support and housing arrangements to live independently. They may want to live alone with support, with a small number of people in shared housing or with their family. Supporting people with a learning disability to make decisions about how they want to live and to be part of their community will enable them to have more control and independence and improve their quality of life.

Quality measures

Structure

Evidence that a range of different housing and care options are available that meet the needs of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, from land registries and Care Quality Commission registrations.

Process

a) Proportion of adults with a learning disability and behaviour that challenges who are supported to communicate their housing preferences and any specific support needs or risks.

Numerator – the number in the denominator who are supported to communicate their housing preferences and any specific support needs or risks.

Denominator – the number of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example local audit of patient records.

b) Proportion of adults with a learning disability and behaviour that challenges who live somewhere that meets their needs.

Numerator – the number in the denominator who live somewhere that meets their needs.

Denominator – the number of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example local audit of patient records.

Outcome

Proportion of adults with a learning disability and behaviour that challenges who feel satisfied with the level of involvement in decision making about housing.

Numerator – the number in the denominator who feel satisfied with the level of involvement in decision making about housing.

Denominator – the number of adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example using surveys, focus groups and other methods of gathering the views of people using services, such as those used in the [Challenging Behaviour Foundation and Mencap's valuing the views of children with a learning disability](#).

What the quality statement means for different audiences

Service providers (such as social care providers, community mental health teams, community support providers, community learning disability teams, residential services, supported living services and housing providers) provide a range of different housing and

care options that meet the needs of adults with a learning disability and behaviour that challenges. They ensure that practitioners working with adults with a learning disability and behaviour that challenges have the time and resources to discuss individual housing preferences and support needs with the person, and their family or carers if needed. They ensure that practitioners have training in how to communicate with people with a learning disability, and support and include them in the discussion.

Health and social care practitioners (such as social workers, community learning disability nurses and lead practitioners) support adults with a learning disability and behaviour that challenges to communicate their individual housing preferences and support needs, with their families or carers if needed, and support them to live where they choose.

Commissioners (such as local authorities, clinical commissioning groups, NHS England and lead commissioners) ensure that they monitor whether services working with adults with a learning disability and behaviour that challenges support them to communicate their individual housing preferences and support needs. They discuss housing with housing providers to ensure that adults with a learning disability and behaviour that challenges are being considered in housing plans.

Adults with a learning disability and behaviour that challenges are helped to choose where and how they live, and given the support they need to live as they would like to.

Source guidance

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline NG93 (2018), recommendations 1.2.5 and 1.5.4

Definitions of terms used in this quality statement

Adults

People aged 18 years or older.

Supported to choose where and how they live

Support that takes into account their preferences, and any specific support needs or risks, including the effect of environmental factors, that:

- is person-centred, reflecting their individual needs and choices, and maximising their control
- helps them take an active part in all aspects of daily life that they choose, based on what they can do and what they want to do
- takes into account the severity of their learning disability, their developmental stage, any communication difficulties or physical or mental health problems, and their life history
- respects their cultural, religious and sexual identity
- helps them before problems occur or as soon as they emerge, not just when crisis has been reached
- encourages people to speak out if they have any worries
- promotes continuity of relationships.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, recommendations 1.2.5 and 1.5.4]

Carer

Someone who provides informal care and support to a child, young person or adult with a learning disability. It does not cover staff who are paid to provide care or support.

[NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

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 may need to call on additional support to help them communicate with the person. This could include involving speech and language therapists or working with family members to find ways of improving 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 10: Review of restrictive interventions

Quality statement

People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used. **[2015]**

Rationale

Restrictive interventions should be used as a last resort and decisions to use them should be based on the principle of using the least restrictive intervention necessary.

Documented risk assessment and review of restrictive interventions helps to ensure learning. This will reduce the use of future restrictive practices, identify and mitigate any risks associated with their use and ensure safety, dignity and respect for people with a learning disability and behaviour that challenges. A documented review will also help to ensure that people with a learning disability and behaviour that challenges and their families or carers understand why and when restrictive interventions could be used.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges who receive a restrictive intervention.

Numerator – the number in the denominator who receive a restrictive intervention.

Denominator – the number of people with a learning disability and behaviour that challenges.

Data source: Local data collection.

b) Proportion of people with a learning disability and behaviour that challenges who have a documented review every time a restrictive intervention is used.

Numerator – the number in the denominator who have a documented review every time a restrictive intervention is used.

Denominator – the number of people with a learning disability and behaviour that challenges who receive a restrictive intervention.

Data source: Local data collection.

Outcome

Rates of restrictive interventions.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as secondary care services, social care providers and providers of residential care) ensure that systems are in place for people with a learning disability and behaviour that challenges to have a documented review every time a restrictive intervention is used.

Health and social care practitioners (including staff in residential settings) ensure that people with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

Commissioners (such as clinical commissioning groups, NHS England and local

authorities) ensure that they commission services that carry out a documented review with people with a learning disability and behaviour that challenges every time a restrictive intervention is used.

People with a learning disability and behaviour that challenges who are stopped from moving around (for example, by being held or given an injection of medication) should have a review of how this was carried out and whether it was needed or could have been avoided. A review should help the person understand when and why this approach is used. A review should also make sure that the approach used restricts the person as little as possible.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendations 1.9.3 and 1.9.6

Definitions of terms used in this quality statement

Restrictive intervention

Interventions that may infringe a person's human rights and freedom of movement, including locking doors, preventing a person from entering certain areas of the living space, seclusion, manual and mechanical restraint, rapid tranquillisation and long-term sedation.

[NICE's guideline on challenging behaviour and learning disabilities]

Documented review of restrictive intervention

Use of a restrictive intervention should be accompanied by a documented review that includes the following:

- review of the delivery and outcome of the restrictive intervention, whether it was needed and how it could be avoided (and if so, what action will be taken)
- assessment of the safety, efficacy, frequency of use, duration and continued need for

reactive strategies

- involvement of everyone who cares for the person with a learning disability, including their family members and carers, and the person themselves, if possible.

[Adapted from [NICE's guideline on challenging behaviour and learning disabilities](#), recommendations 1.9.3 and 1.9.6]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from [NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#), terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 11: Use of medication

Quality statement

People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions. **[2015]**

Rationale

Antipsychotics are the most frequently used drugs for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. They should be used only if no or limited benefit has been derived from a psychosocial intervention, and treatment for any coexisting mental or physical health problem has not led to a reduction in behaviour that challenges. Psychosocial interventions are the most commonly reported forms of intervention used for people with a learning disability and behaviour that challenges and should be the first-line intervention to address any identified triggers for the behaviour.

Quality measures

Structure

Evidence of local arrangements to ensure that people with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges prescribed antipsychotic medication as part of treatment that includes psychosocial interventions.

Numerator – the number in the denominator who are receiving psychosocial interventions.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

Data source: Local data collection.

b) Proportion of people with a learning disability and behaviour that challenges prescribed antipsychotic medication with a recorded rationale for the prescribing decision.

Numerator – the number in the denominator with a recorded rationale for the prescribing decision.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

Data source: Local data collection.

Outcome

Prescribing rates of antipsychotics in people with a learning disability and behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (secondary care services) ensure that systems are in place for people with a learning disability and behaviour that challenges to only be prescribed antipsychotic medication as part of treatment that includes psychosocial interventions.

Healthcare professionals only prescribe antipsychotic medication for people with a learning disability and behaviour that challenges as part of treatment that includes psychosocial interventions.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that only prescribe antipsychotic medication for people with a learning disability and behaviour that challenges as part of treatment that includes

psychosocial interventions.

People with a learning disability and behaviour that challenges only have antipsychotic medication if they are also having psychological therapy or other therapies as part of their care. This should help to ensure that medication is only used if other therapies, or treatments for any physical health problems, have not changed or reduced the behaviour that challenges, or if there is a serious risk of the person harming themselves or others (for example, because of violence, aggression or self-harm).

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendation 1.8.2

Definitions of terms used in this quality statement

Psychosocial interventions

Psychosocial interventions include a broad range of therapeutic approaches designed to support the person. They are generally non-pharmacological and aim to identify underlying factors for behaviour, reduce the person's distress and increase their skills. Approaches include communication interventions, applied behaviour analysis, positive behaviour support and cognitive behavioural therapy.

[Adapted from NICE's full guideline on challenging behaviour and learning disabilities, section 11]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Quality statement 12: Review of medication

Quality statement

People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months. **[2015]**

Rationale

Antipsychotics are the most frequently used drugs for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. The use of antipsychotics should be limited and regular review should ensure that there is an appropriate rationale for prescribing. A full multidisciplinary review will also help to reduce prolonged use of antipsychotics and thereby potential side effects.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

Data source: Local data collection.

Process

a) Proportion of people with a learning disability and behaviour that challenges who have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment.

Numerator – the number in the denominator who have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

Data source: Local data collection.

b) Proportion of people with a learning disability and behaviour that challenges who have a multidisciplinary review of their antipsychotic medication at least every 6 months after the first 12 weeks of treatment.

Numerator – the number in the denominator who have a multidisciplinary review of their antipsychotic medication at least every 6 months after the first 12 weeks of treatment.

Denominator – the number of people with a learning disability and behaviour that challenges prescribed antipsychotic medication within the last 12 months.

Data source: Local data collection.

Outcome

Prescribing rates of antipsychotics in people with a learning disability and behaviour that challenges.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (secondary care services) ensure that systems are in place for people with a learning disability and behaviour that challenges to have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

Health and social care practitioners ensure that people with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication

12 weeks after starting treatment and then at least every 6 months.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that provide people with a learning disability and behaviour that challenges with a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

People with a learning disability and behaviour that challenges who take antipsychotic medication have their medication checked 12 weeks after they start taking it and then at least every 6 months. Their medication should be checked by a team that includes doctors, nurses and care staff. The check should include how well the medication is working (including whether it is causing any side effects) and whether the person should keep taking it. This should be explained to the person and their family or carers.

Source guidance

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 (2015), recommendations 1.8.4, 1.8.5 and 1.8.6

Definitions of terms used in this quality statement

Multidisciplinary review

A review of prescribed antipsychotic medication by a team that includes doctors, nurses and care staff that includes the following:

- a record of the extent of the response, how the behaviour has changed and any side effects or adverse events
- identification of any physical abnormalities
- the rationale for continuing the medication, if this is being done, and an explanation of this for the person with a learning disability and behaviour that challenges and everyone involved in their care, including their family members and carers.

[Adapted from NICE's guideline on challenging behaviour and learning disabilities, section 1.8]

Behaviour that challenges

Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person, or others around them. It also includes behaviour that is likely to severely limit, or result in the person being denied, access to and use of ordinary community facilities.

[Adapted from NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery, terms used in this guideline]

Equality and diversity considerations

The communication needs of people with a learning disability, particularly the needs of people who are unable to communicate through speech, should be taken into account in a health assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

Update information

July 2019: This quality standard was updated. Four new statements were added to the 2015 version, one statement from 2015 was updated and one was amended.

Statements are marked as:

- **[new 2019]** if the statement covers a new area for quality improvement
- **[2015, updated 2019]** if the statement covers an area for quality improvement included in the 2015 quality standard and has been updated
- **[2015, amended 2019]** if the statement has been amended
- **[2015]** if the statement remains unchanged.

Statement 2 (statement 1 in the 2015 version) has been amended to align with a statement on annual health checks in [NICE's quality standard on learning disability: care and support of people growing older](#). It is marked as **[2015, amended 2019]**.

Statement 4 (statement 3 in the 2015 version) has been updated and is marked as **[2015, updated 2019]**.

A definition of behaviour that challenges has been added to the 2015 statements, in line with [NICE's guideline on learning disabilities and behaviour that challenges: service design and delivery](#).

The [2015 quality standard for learning disabilities: challenging behaviour](#) is available as a pdf.

Minor changes since publication

June 2020: The source guidance for statement 6 was updated to include recommendation 1.6.1 from [NICE's guideline on challenging behaviour and learning disabilities](#).

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.

The statements in this quality standard have been developed with 2 different quality standards advisory committees. See [quality standard advisory committees](#) on the website for details of standing committee 3 members who advised on the 2019 statements in this quality standard. Information about the standing members who advised on the 2015 statements, along with 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 learning disabilities and behaviour that challenges](#), which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](#) 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:

- promotion of independence, choice and control over daily life
- experience of people with a learning disability and behaviour that challenges using social care services
- experience of people with a learning disability and behaviour that challenges using healthcare services
- experience of services working together
- use of restrictive practices
- health and social care-related quality of life for people with a learning disability and behaviour that challenges
- health and social care-related quality of life for carers of people with a learning disability and behaviour that challenges.

It is also expected to support delivery of the following national frameworks:

- [Adult social care outcomes framework](#)
- [NHS outcomes framework](#)
- [Public health outcomes framework for England](#)
- [Quality framework for public health](#).

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:

- [resource impact template and report for the NICE guideline on learning disabilities and behaviour that challenges: service design and delivery](#)
- [costing statement for the NICE guideline on challenging behaviour and 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.

ISBN: 978-1-4731-1467-8

Endorsing organisation

This quality standard has been endorsed by 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.

- [The Challenging Behaviour Foundation](#)
- [Royal College of Nursing \(RCN\)](#)

- Skills for Care
- Royal College of Paediatrics and Child Health
- Foundation for People with Learning Disabilities
- British Institute of Learning Disabilities
- British Psychological Society (BPS)