

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Service model for people with a learning disability and behaviour that challenges

NICE quality standard

Draft for consultation

February 2019

This quality standard covers the design, delivery and coordination of support and services for children, young people and adults with a learning disability (or a learning disability and autism) and behaviour that challenges, and their families and carers. It describes high-quality care in priority areas for improvement. It does not cover:

- preventing, assessing and managing mental health problems in people with learning disabilities
- additional care and support needs of people growing older with a learning disability.

These areas are covered by other published or referred quality standards.

'Behaviour that challenges' is not a diagnosis and is used in this quality standard to indicate that although such behaviour is a challenge to services, family members and carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and can include aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour. This quality standard uses the following definition of behaviour that challenges:

'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.' (Emerson, 1995)¹

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

This is the draft quality standard for consultation (from 18 February to 18 March 2019). The final quality standard is expected to publish in July 2019.

¹ Emerson E (1995) Challenging behaviour: analysis and intervention in people with learning disabilities. Cambridge University Press

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.

[Statement 2](#) People with a learning disability and behaviour that challenges have a named lead practitioner.

[Statement 3](#) 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.

[Statement 4](#) People with a learning disability and behaviour that challenges can have specialist behavioural support in the community.

[Statement 5](#) Adults with a learning disability and behaviour that challenges are supported to live where and how they want.

NICE has developed guidance and quality standards on patient experience in adult NHS services and service user experience in adult mental health services (see the NICE Pathway on [patient experience in adult NHS services](#) and [service user experience in adult mental health services](#)), which should be considered alongside these quality statements.

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

- [People's experience using adult social care services](#) Publication expected February 2019
- [Learning disabilities: identifying and managing mental health problems](#) (2017) NICE quality standard 142
- [Learning disabilities: challenging behaviour](#) (2015) NICE quality standard 101
- [Autism](#) (2014) NICE quality standard 51

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

Questions for consultation

Questions about the quality standard

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

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

Question 3 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Question 4 Do you have any comments on combining this quality standard with the existing quality standard on [learning disabilities: challenging behaviour](#), which covers care and support for adults, young people and children with a learning disability and behaviour that challenges?

Local practice case studies

Question 5 Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to [NICE local practice case studies](#) on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: 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.

Rationale

Having a lead commissioner who is experienced in working with people 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 and social care 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 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.

Outcomes

a) Self-reported level of satisfaction with services among people with a learning disability.

Data source: Local data collection, for example, surveys of people using services.

b) 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 collection and the mental health services data set.

What the quality statement means for different audiences

Commissioners (local authorities and clinical commissioning groups) ensure that they jointly choose a lead commissioner to oversee strategic commissioning of services for people with a learning disability. The lead commissioner 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 with a learning disability use services that are organised by 1 person who is in charge and who has worked with people with a learning disability and behaviour that challenges before.

Source guidance

[Learning disabilities and behaviour that challenges: service design and delivery](#)

(2018) NICE guideline NG93, recommendation 1.1.1

Definitions of terms used in this quality statement

Lead person to oversee strategic commissioning

The lead commissioner:

- 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
- 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

- plans services that take a 'whole life' approach from early childhood onwards and enable smooth transitions
- ensures that budgets and other resources are pooled across health, social care and education and with neighbouring authorities to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges
- ensures that service planning and delivery is based on an assessment of current and future service needs
- ensures that services are planned and delivered in a way that is co-produced with children, young people and adults using services and their families, carers and independent advocates
- ensures that local authorities and clinical commissioning groups take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges.

[NICE's guideline on [learning disabilities and behaviour that challenges: service design and delivery](#), recommendations 1.1.1, 1.1.2, 1.1.3, 1.1.6, 1.1.7 and 1.1.9]

Quality statement 2: Named lead practitioner

Quality statement

People with a learning disability and behaviour that challenges have a named lead practitioner.

Rationale

People with a learning disability and their families 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 lead practitioner can also get to know the person and their family 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, for example, local audit of patient records.

Outcomes

a) Self-reported level of satisfaction with services among people with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, surveys of people using services.

b) Self-reported and family-reported level of satisfaction with involvement in decision making among people with a learning disability and behaviour that challenges and their families and carers.

Data source: Local data collection, for example, surveys of people using services and their families.

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 person 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 for children or adult services and community learning disability nurses) act as the named lead practitioner for a person 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 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 and NHS England) 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 person 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 the named worker and the person with a learning disability and behaviour that challenges.

People with a learning disability and behaviour that challenges have 1 person who knows them, meets regularly with them and coordinates their support. People with a learning disability, and their families or carers, know how to contact this person.

Source guidance

[Learning disabilities and behaviour that challenges: service design and delivery](#)

(2018) NICE guideline NG93, 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, 1.2.13, 1.2.14 and 1.2.16]

Equality and diversity considerations

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

Quality statement 3: Support for families and carers

Quality statement

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.

Rationale

Families and carers of people with a learning disability can find it hard to get information and support to help them understand behaviour that challenges, the signs to look out for, and what to do in a crisis. Involving families in developing a care and support plan, 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 and behaviour that challenges is less likely to develop 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 sets out 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.

Outcome

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

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 - 2017-18.

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], 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 people 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 and social care practitioners (such as social workers, care managers, advocates, community learning disability nurses and allied health professionals) meet the families and carers of people 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 and local authorities) ensure that they monitor whether services meet and involve the families and carers of people 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, which includes how to prevent a crisis and what should happen in an emergency. They are also given support that helps them to manage their role as carers.

Source guidance

[Learning disabilities and behaviour that challenges: service design and delivery](#)

(2018) NICE guideline NG93, recommendation 1.2.14

Definitions of terms used in this quality statement

How to prevent or respond to a crisis

A person-centred plan of how to prevent or respond to a crisis, which includes key local emergency contact numbers and simple accessible interventions. The plan might include additional services becoming involved very quickly, or more resources being made available, such as short break services, and may involve a sudden change of placement. [Expert opinion]

Quality statement 4: Services in the community

Quality statement

People with a learning disability and behaviour that challenges can have specialist behavioural support in the community.

Rationale

A lack of specialist support in the community can affect the quality of life of people with a learning disability and behaviour that challenges, and their families and carers. It can lead to problems when people with a learning disability are discharged from specialist inpatient care, such as assessment and treatment units or secure services, and can delay or prevent discharges. Ensuring that specialist support is available locally can help families and carers look after the person at home, and prevent crises and the need to use intensive services and out-of-area and residential placements.

Quality measures

Structure

a) Evidence of local arrangements for specialist behavioural support to be available 7 days a week for people with a learning disability and behaviour that challenges.

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, 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 are offered support in the community.

Numerator – the number in the denominator offered 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.

Outcomes

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

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 - 2017-18.

b) Rates of hospital 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.

What the quality statement means for different audiences

Service providers (such as community learning disability teams, specialist intensive support teams, social care providers and community support providers) ensure that practitioners are trained to help people with a learning disability and behaviour that challenges and their families and carers understand and change their behaviour if it is causing problems for them. They ensure that services are available 7 days a week.

Health and social care practitioners (such as clinical psychologists, behaviour therapists, psychiatrists, learning disability nurses, community learning disability professionals, specialist intensive support workers and social workers) assess the needs and risk of people with a learning disability and behaviour that challenges in a

community setting. They help the person and their family and carers to get support in line with this assessment to help them understand their behaviour, improve their quality of life, and reduce the behaviour that challenges, if it is causing problems for them.

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 people with a learning disability and behaviour that challenges. 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 have specialist behavioural support in the community when they need it to help them understand their behaviour, if it is causing problems for them. 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](#) (2018) NICE guideline NG93, 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 people 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.

[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 to assess need and plan support 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 5: Housing

Quality statement

Adults with a learning disability and behaviour that challenges are supported to live where and how they want.

Rationale

People with a learning disability face barriers to choosing where they live and who they live with. They may want to live alone with support or with a small number of people in shared housing, perhaps outside their local community. Supporting people with a learning disability to make decisions about how they want to live 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.

Process

a) Proportion of adults with a learning disability and behaviour that challenges who have a discussion about their housing preferences and any specific support needs or risks.

Numerator – the number in the denominator who have a discussion about 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

Self-reported satisfaction with level of involvement in decision making about housing among adults with a learning disability and behaviour that challenges.

Data source: Local data collection, for example, surveys of people using services.

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) 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 and community learning disability nurses) discuss individual housing preferences and support needs with adults with a learning disability and behaviour that challenges, and their families or carers if needed, and support them to live where they want.

Commissioners (such as local authorities, clinical commissioning groups and NHS England) ensure that they monitor whether services working with adults with a learning disability and behaviour that challenges discuss individual housing preferences and support needs with them. 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 supported to talk about their housing preferences and support needs and choose where and how they want to live.

Source guidance

[Learning disabilities and behaviour that challenges: service design and delivery](#)

(2018) NICE guideline NG93, recommendations 1.2.5 and 1.5.4

Definitions of terms used in this quality statement

Supported to live where and how they want

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]

Equality and diversity considerations

People with a learning disability may have difficulties communicating because of disability or sensory impairment. Those with severe or profound learning disability may have particularly complex needs. Practitioners working with people with a learning disability on their housing preferences and support needs 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.

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 3 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 [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 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 report](#) for the NICE guideline on [learning disabilities and behaviour that challenges: service design and delivery](#) to help estimate local costs.

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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