NICE National Institute for Health and Care Excellence

NICE quality standard

Learning disabilities: challenging behaviour

Quality standard

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Contents

This standard is based on NG11.

This standard should be read in conjunction with QS59, QS51, QS27, QS26, QS14 and QS154.

Introduction

This quality standard covers the care of children, young people and adults with a learning disability and behaviour that challenges. For more information see the challenging behaviour and learning disabilities overview.

Why this quality standard is needed

Some people with a learning disability display behaviour that challenges. '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].

The Royal College of Psychiatrists' 2007 report Challenging behaviour: a unified approach defined 'challenging behaviour' very similarly as:

'Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'

Services for children, young people and adults with a learning disability and behaviour that challenges were described in Mencap's 2013 Out of sight report as fragmented and at times ineffective and unresponsive to family needs, sometimes to the point of being abusive. For children

and young people, services are generally provided within education (through their school and the educational psychology service), as well as through paediatric services and generic child and adolescent mental health services (CAMHS). Families report that they have to deal with a number of disconnected services and that many are unable to help. Moreover, very few early intervention services specific to behaviour that challenges are routinely available for children with a learning disability.

For adults, care is often managed through a community learning disabilities team (CLDT), which includes a range of professionals. In many areas, social workers are integrated into the CLDT. For adults with a learning disability and behaviour that challenges, day services, or the residential/ supported living service, may try to support them initially. Depending on the nature of the behaviour that challenges, there may be a referral to the CLDT and the adult's family or carers may also have access to the CLDT through the local GP or other agencies.

However, carers often receive insufficient support from professionals who do not have the required expertise and do not provide help early enough[2]. The failure of services, and families not being able to cope, are likely to lead to overmedication for people with a learning disability, disengagement by professionals, and eventually 'out-of-area' placements.

This quality standard is focused on ensuring that assessment leads to personalised care planning and access to meaningful activities. The statements aim to ensure that the approaches used by staff to support people with a learning disability follow the least restrictive practice and promote privacy and dignity.

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

- quality of life
- experience of care
- patient safety
- safeguarding
- control over daily life
- premature mortality
- physical and mental health and wellbeing
- personal dignity.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – patient safety, patient experience and clinical effectiveness – for a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 3 outcomes frameworks published by the Department of Health:

- Adult Social Care Outcomes Framework 2015–16
- NHS Outcomes Framework 2015–16
- Public Health Outcomes Framework 2013–16.

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 The Adult Social Care Outcomes Framework 2015–16

Domain	Overarching and outcome measures

1 Enhancing quality of life for people with care and support needs	*Overarching measure* 1A Social care-related quality of life* *Outcome measures* **People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs** 1B Proportion of people who use services who have control over their daily life 1C Proportion of people using social care who receive self-directed support, and those receiving direct payments **Carers can balance their caring roles and maintain their desired quality of life** 1D Carer-reported quality of life** **People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation** 1E Proportion of adults with a learning disability in paid employment 1G Proportion of adults with a learning disability who live in their own home or with their family 1I Proportion of people who use services and their carers who reported that they had as much social contact as they would like

3 Ensuring that people have a positive experience of care and support	*Overarching measure* **People who use social care and their carers are satisfied with their experience of care and support services** 3A Overall satisfaction of people who use services with their care and support 3B Overall satisfaction with social services of carers *Outcome measures* **Carers feel that they are respected as equal partners throughout the care process** 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D The proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual**

4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm	4A The proportion of people who use services who feel safe *Outcome measures* **Everyone enjoys physical safety and feels secure.** **People are free from physical and emotional abuse, harassment, and neglect and self-harm** **People are protected as far as possible from avoidable harm, disease and injuries** **People are supported to plan ahead and have the freedom to manage risks the way that they wish** 4B The proportion of people who use services who say that those services have made them feel safe and secure *Placeholder 4C Proportion of completed safeguarding referrals where people report they feel safe*
Alignment with NHS Outcomes Framework * Indicator is complementary ** Indicator is shared Indicators in italics in development	

Table 2 NHS Outcomes Framework 2015–16

Domain	Overarching indicators and improvement areas

1 Preventing people from dying prematurely	*Overarching indicator* 1a Potential years of life lost (PYLL) from causes considered amenable to healthcare i Adults ii Children and young people 1b Life expectancy at 75 i Males ii Females *Improvement areas* **Reducing premature death in people with a learning disability** 1.7 Excess under 60 mortality rate in adults with a learning disability
2 Enhancing quality of life for people with long-term conditions	*Overarching indicator* 2 Health-related quality of life for people with long-term conditions* *Improvement areas* **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition* **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers*
4 Ensuring that people have a positive experience of care	*Overarching indicator* 4b Patient experience of hospital care *Improvement areas* **Improving hospitals' responsiveness to personal needs** 4.2 Responsiveness to in-patients' personal needs **Improving children and young people's experience of healthcare** *4.8 Children and young people's experience of inpatient services*

5 Treating and caring for people in a safe environment and protecting them from avoidable harm	*Overarching indicators* *5b Severe harm attributable to problems in healthcare* *Improvement areas* 5.6 Patient safety incidents reported
Alignment with Adult Social Care Outcomes Framework * Indicator is complementary Indicators in italics in development	

Table 3 Public health outcomes framework for England, 2013–16

Domain	Objectives and indicators
4 Healthcare public health and preventing premature mortality	*Objective* Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities 4.3 Mortality rate from causes considered preventable** 4.4 Under 75 mortality rate from all cardiovascular diseases (including heart disease and stroke)* 4.5 Under 75 mortality rate from cancer* 4.6 Under 75 mortality rate from liver disease* 4.7 Under 75 mortality rate from respiratory diseases* 4.12 Preventable sight loss
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared ** Indicator is complementary	

Service user experience and safety issues

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to people with behaviour that challenges and a learning disability.

NICE has developed guidance and an associated quality standard on service user experience in

adult mental health services (see the NICE pathway on service user experience in adult mental health services), which should be considered alongside this quality standard. They specify that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. They also cover the provision of information to service users and their family members and carers. Quality statements on these aspects of service user experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect service user experience and are specific to the topic are considered during quality statement development.

Coordinated services

The quality standard for learning disabilities: challenging behaviour specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole care pathway for people with behaviour that challenges and a learning disability. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with a learning disability and behaviour that challenges.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality service for people with people with a learning disability and behaviour that challenges are listed in related quality standards.

Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All health and social care practitioners involved in assessing, caring for and treating people with a learning disability and behaviour that challenges should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with a learning disability and behaviour that challenges, in addition to the full involvement of the person themselves. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

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

[2] Griffith G, Hastings R (2013) 'He's hard work, but he's worth it.' The experience of caregivers of individuals with intellectual disabilities and challenging behaviour – a thematic synthesis of qualitative research. Journal of Applied Research in Intellectual Disabilities 27:401–19

List of quality statements

Statement 1. People with a learning disability have a comprehensive annual health assessment from their GP.

Statement 2. People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

Statement 3. People with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

Statement 4. People with a learning disability and behaviour that challenges take part in personalised daily activities.

Statement 5. People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

Statement 6. People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

Statement 7. 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.

Statement 8. Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent-training programme.

Quality statement 1: Comprehensive health assessment

Quality statement

People with a learning disability have a comprehensive annual health assessment from their GP.

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 a comprehensive annual health assessment from their GP.

Data source: Local data collection.

Process

Proportion of people with a learning disability who have a comprehensive annual health assessment from their GP.

Numerator – the number in the denominator who had a comprehensive annual health assessment 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 service providers, healthcare

professionals and commissioners

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

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

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

What the quality statement means for service users and carers

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 (2015) NICE guideline NG11, recommendation 1.2.1

Definitions of terms used in this quality statement

Comprehensive health assessment

A comprehensive health assessment should include:

- a review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems
- a review of physical health
- a review of all medicines and other types of treatment (for example psychological therapy)
- an agreed and shared care plan for managing any physical health problems (including pain)
- discussion with a family member, carer, healthcare professional or social care practitioner who

- knows the person.

[Adapted from challenging behaviour and learning disabilities (NICE guideline NG11), recommendation 1.2.1]

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 2: 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.

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

a) 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 service providers, health and social care practitioners, and commissioners

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.

What the quality statement means for service users and carers

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 (2015) NICE guideline NG11, 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 challenging behaviour and learning disabilities (NICE guideline NG11), recommendation 1.5.4]

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: Designated coordinator

Quality statement

People with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

Rationale

A designated person responsible for coordinating the behaviour support plan will ensure continuity of care both for the person with a learning disability and their family or carers. It will also reduce the need for families or carers to repeatedly give the same information to different staff. Having a designated person responsible for ensuring that plans are reviewed will help to make sure that plans are adjusted as treatment, behaviours and the person's preferences change. This will in turn promote the use of proactive strategies to ensure regular and effective support for people with a learning disability and behaviour that challenges.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

Data source: Local data collection.

Process

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

Numerator – the number of people in the denominator with a behaviour support plan.

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

designated person responsible for coordinating their behaviour support plan.

Numerator – the number of people in the denominator who have a designated person responsible for coordinating their behaviour support plan.

Denominator – the number of people with a learning disability and behaviour that challenges with an agreed behaviour support plan.

Data source: Local data collection.

c) Proportion of people with a learning disability and behaviour that challenges who have a designated person responsible for ensuring that their behaviour support plan is reviewed.

Numerator – the number of people in the denominator who have a designated person responsible for ensuring that their behaviour support plan is reviewed.

Denominator – the number of people with a learning disability and behaviour that challenges with an agreed behaviour support plan.

Data source: Local data collection.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers (secondary care services and social care providers) ensure that people with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

Health and social care practitioners ensure that people with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

Commissioners (clinical commissioning groups, NHS England and local authorities) ensure that they commission services that provide people with a learning disability and behaviour that challenges with a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

What the quality statement means for service users and carers

People with a learning disability and behaviour that challenges have one person who is responsible for coordinating the plan that sets out how they will be supported. The person with a learning disability, and their family or carers, knows who this person is and how they can contact them. This gives them a familiar single point of contact and reduces the number of times they have to repeat information to staff. This person will also be responsible for ensuring that the plan is reviewed. The aim of the review is to make sure that the plan is appropriate for the person with a learning disability and supports their daily living.

Source guidance

- Challenging behaviour and learning disabilities (2015) NICE guideline NG11, recommendation 1.6.1

Definitions of terms used in this quality statement

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 should be 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
- 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 challenging behaviour and learning disabilities (NICE guideline NG11), recommendation 1.6.1]

Review of behaviour support plan

The review should involve the person with a learning disability and behaviour that challenges and the people who support them, including their family or carers. The review should help to identify how the plan is helping to make improvements to the person's life and to reduce or stop behaviour that challenges. The behaviour support plan should be reviewed every other week for the first 2 months and then once a month.

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: Personalised daily activities

Quality statement

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

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 service providers, health and social care practitioners, and commissioners

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.

What the quality statement means for service users and carers

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 (2015) NICE guideline NG11, 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 challenging behaviour and learning disabilities (NICE guideline NG11), recommendation 1.6.1]

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 5: 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.

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 service providers, health and social care practitioners, and commissioners

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.

What the quality statement means for service users and carers

Peoplewith 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 (2015) NICE guideline NG11, 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.

[Challenging behaviour and learning disabilities (NICE guideline NG11)]

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 challenging behaviour and learning disabilities (NICE guideline NG11), recommendations 1.9.3 and 1.9.6]

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 6: 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.

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

a) 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 service providers, healthcare professionals and commissioners

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.

What the quality statement means for service users and carers

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 (2015) NICE guideline NG11, 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 challenging behaviour and learning disabilities (NICE guideline NG11), section 11 of the full 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 7: 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.

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 service providers, health and social care practitioners, and commissioners

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.

What the quality statement means for service users and carers

Peoplewith 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 (2015) NICE guideline NG11, 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 challenging behaviour and learning disabilities (NICE guideline NG11), section 1.8]

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: Family and carer support

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.

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

a) 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 service providers, health and social care practitioners, and commissioners

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.

What the quality statement means for service users and carers

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 (2015) NICE guideline NG11, recommendation 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 challenging behaviour and learning disabilities (NICE guideline NG11), recommendation 1.7.2]

Using the quality standard

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its Indicators for Quality Improvement Programme. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's what makes up a NICE quality standard? for further information, including advice on using quality measures.

Levels of achievement

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, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in development sources.

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments are available.

Good communication between health and social care practitioners and children, young people and adults with a learning disability and behaviour that challenges, and their families or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with a learning disability and behaviour that challenges and their families or carers (if appropriate) should have access to an interpreter or advocate if needed.

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.

Development sources

Further explanation of the methodology used can be found in the quality standards process guide.

Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- Challenging behaviour and learning disabilities (2015) NICE guideline NG11

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- NHS England (2015) Transforming care for people with learning disabilities – next steps
- Department of Health (2014) Positive and proactive care: reducing the need for restrictive interventions
- Local Government Association (2014) Ensuring quality services: core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges
- NHS England (2014) Winterbourne View – time for change: transforming the commissioning of services for people with learning disabilities and/or autism
- Royal College of Psychiatrists (2014) Executive summary and recommendations: national audit of learning disabilities feasibility study
- United Response (2014) Transforming care: supporting people with learning disabilities, autism and challenging behaviour to live happily in their local community
- Joint Commissioning Panel for Mental Health (2013) Guidance for commissioners of mental health services for people with learning disabilities
- Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability (2013) People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services

- Care Quality Commission (2012) Review of learning disability services
- Department of Health (2012) Transforming care: a national response to Winterbourne View hospital
- HM Government (2005) Mental Capacity Act

Definitions and data sources for the quality measures

- Health and Social Care Information Centre (2014) Learning disabilities census

Related NICE quality standards

Published

- Antisocial behaviour and conduct disorders in children and young people (2014) NICE quality standard 59
- Autism (2014) NICE quality standard 51
- Attention deficit hyperactivity disorder (2013) NICE quality standard 39
- The epilepsies in children and young people (2013) NICE quality standard 27
- The epilepsies in adults (2013) NICE quality standard 26
- Service user experience in adult mental health (2011) NICE quality standard 14

In development

- None identified.

Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Care and support of older people with learning disabilities. Status: referred.
- Mental health problems in people with learning disabilities. Status: referred.
- Service model: challenging behaviour and learning disabilities. Status: referred.
- Service user and carer experience: service users and carer experience of social care. Status: referred.
- Transition between social care and healthcare services. Status: referred.
- Transition from children's to adult services. Status: referred.

The full list of quality standard topics referred to NICE is available from the quality standards topic library on the NICE website.

Quality Standards Advisory Committee and NICE project team

Quality Standards Advisory Committee

This quality standard has been developed by Quality Standards Advisory Committee 2. Membership of this committee is as follows:

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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.

The methods and processes for developing NICE quality standards are described in the quality standards process guide.

This quality standard has been incorporated into the NICE pathway on challenging behaviour and learning disabilities.

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.

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Endorsing organisation

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

Supporting organisations

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

- British Psychological Society
- Royal College of General Practitioners
- Royal College of Nursing
- Association for Real Change