Challenging behaviour in people with learning disabilities: prevention and management

NICE quality standard

Draft for consultation

May 2015

# Introduction

This quality standard covers the care of adults, children and young people with learning disabilities and behaviour that challenges. For more information see the [Challenging behaviour and learning disabilities overview](http://www.nice.org.uk/guidance/indevelopment/gid-qsd101/documents).

## Why this quality standard is needed

Some people with learning disabilities 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 or 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 includes aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour.

Services for children, young people and adults with learning disabilities and behaviour that challenges have been described in Mencap’s 2013 [out of sight report](https://www.mencap.org.uk/outofsight-report) as fragmented and at times ineffective and unresponsive to family needs, to the point sometimes 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 unrelated services and that many will offer no help. Moreover, there are very few early intervention services routinely available for children with learning disabilities and behaviour that challenges.

For adults, care is often managed through a community learning disabilities team (CLDT), which includes a range of professionals. Social workers are also integrated into the CLDT in many areas. However, in some areas they are located at separate social services offices. For adults with learning disabilities and behaviour that challenges, day services, or the residential/supported living service, may try to support them initially. If the behaviour that challenges continues, they may refer people to the CLDT and their families may also access the CLDT through the local GP or other agencies.

However, carers often experience insufficient support from professionals who do not have the required expertise and who do not provide help early enough[[1]](#footnote-1). The failure of services and families not being able to cope is likely to lead to over-medication of people with learning disabilities, disengagement by professionals, and eventually ‘out of area’ placements. These are often located away from families, and some have restrictive practices and very high costs. The NICE guideline on challenging behaviour and learning disabilities estimates that many ‘assessment and treatment’ units cost in the region of £250,000 per person per year.

The failure of services at Winterbourne View demonstrated the dislocation and poor quality of services experienced by children, young people and adults with learning disabilities and behaviour challenges, and highlighted the restrictive practices used and lack of positive assessment or intervention.

This quality standard is focused on ensuring that positive assessment leads to personalised care planning and access to meaningful activities. Statements aim to ensure that the approaches used by staff to support people with learning disabilities 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](https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016)
* [NHS Outcomes Framework 2015–16](https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016)
* [Public Health Outcomes Framework 2013–2016](https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency).

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](https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016)

|  |  |
| --- | --- |
| **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, 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 complementary  \*\* Indicator shared | |

### Table 2 [NHS Outcomes Framework 2015–16](https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016)

|  |  |
| --- | --- |
| **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 shared  \*\* Indicator is complementary | |

### Table 3 [Public health outcomes framework for England, 2013–2016](https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency)

|  |  |
| --- | --- |
| **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 |

## 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 behavior that challenges and learning disabilities.

Throughout this quality standard it is expected that assessment, care planning and decision-making is conducted with a family member, carer or healthcare professional or social care practitioner who knows the person.

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](http://pathways.nice.org.uk/pathways/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, 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 impact on service user experience and are specific to the topic are considered during quality statement development.

## Coordinated services

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

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 behaviour that challenges and learning disabilities are listed in Related quality standards. [Link to section in web version]

### 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 behaviour that challenges and learning disabilities 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 learning disabilities and behaviour that challenges. 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.

# List of quality statements

[Statement 1](http://publications.nice.org.uk/QSXX/quality-statement-1-referral). (placeholder) Early (0-5 years) support with behaviour that challenges for children with learning disabilities

[Statement 2](http://publications.nice.org.uk/QSXX/quality-statement-1-referral). People with learning disabilities and behaviour that challenges have an initial assessment to identify possible triggers for the behaviour.

Statement 3. People with learning disabilities and behaviour that challenges have a comprehensive annual health assessment from their GP.

Statement 4. People with learning disabilities and behaviour that challenges have a designated coordinator who is responsible for their behaviour support plan.

Statement 5. People with learning disabilities and behaviour that challenges have personalised daily activities planned and documented in their behaviour support plan.

Statement 6. People with learning disabilities and behaviour that challenges have their behaviour support plan reviewed every other week for the first 2 months and then every month.

Statement 7. People with learning disabilities and behaviour that challenges have a documented review every time a restrictive intervention is used.

Statement 8. People with learning disabilities and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

Statement 9. People with learning disabilities 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 10. Parents or carers of children aged under 12 years with learning disabilities and at risk of developing behaviour that challenges are referred to a parent training programme for challenging behaviour.

# 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** If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

**Question 3** For each quality statement what do you think could be done to support improvement and help overcome barriers?

**Question 4** What are the 6 most important quality improvement areas from the 10 statements in this quality standard?

## Questions about the individual quality statements

**Question 5** For draft placeholder statement 1: Do you know of any relevant evidence-based guidance that could be used to develop this placeholder statement? If so, please provide details. If not, would new evidence-based guidance relating to early support and training for families and those who support children with learning disabilities have the potential to improve practice? If so, please provide details.

**Question 6** For draft quality statement 3: How far is a comprehensive annual health assessment for people with learning disabilities who display behaviour that challenges already happening in practice?

**Question 7** For draft quality statement 3: An annual health assessment for adults is commissioned as part of a Directed Enhanced Service. Therefore, should this statement be targeted at under 14s only?

**Question 8** For draft quality statement 4: Is the identification of a designated coordinator who is responsible for the behaviour support plan currently happening in practice?

**Question 9** For draft quality statement 4: Who would be the designated coordinator responsible for this?

**Question 10** For draft quality statement 6: Are there any tools or methods for assessing the quality of the behaviour support plan in a review that could be referenced?

**Question 11** For draft quality statement 7: Who is responsible for carrying out the review? How soon should it take place after the intervention?

# Quality statement 1 (placeholder): Early (0–5 years) support with behaviour that challenges for children with learning disabilities

## What is a placeholder statement?

A placeholder statement is an area of care that has been prioritised by the Quality Standards Advisory Committee but for which no source guidance is currently available. A placeholder statement indicates the need for evidence-based guidance to be developed in this area.

## Rationale

Early intervention can reduce the likelihood of behaviour that challenges arising or persisting. There are very few early intervention services routinely available for children with learning disabilities. Current services can appear to have a bias to crisis management, with fewer resources being made available for early intervention or prevention. Without early intervention support problems may escalate.

## Question for consultation

Do you know of any relevant evidence-based guidance that could be used to develop this placeholder statement? If so, please provide details. If not, would new evidence-based guidance relating to early (0–5 years) support and training for families and those who support children with learning disabilities have the potential to improve practice? If so, please provide details.

# Quality statement 2: Initial assessment of behaviour that challenges

## Quality statement

People with learning disabilities and behaviour that challenges have an initial assessment to identify possible triggers for the behaviour.

## Rationale

Early and timely assessment of behaviour that challenges can identify and seek to address the factors that generate the behaviour and thereby help to reduce its escalation.

## Quality measures

### Structure

Evidence of local arrangements to ensure that people with learning disabilities and behaviour that challenges have an initial assessment to identify the possible triggers for the behaviour.

***Data source:*** Local data collection.

### Process

a) Proportion of people with learning disabilities and behaviour that challenges who have an initial assessment to identify the possible triggers for the behaviour.

Numerator – the number in the denominator who have an initial assessment to identify the possible triggers for the behaviour.

Denominator – the number of people with learning disabilities 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 learning disabilities and behaviour that challenges to have an initial assessment to identify possible triggers for the behaviour.

**Health and social care practitioners** ensure that people with learning disabilities and behaviour that challenges have an initial assessment to identify possible triggers for the behaviour.

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

## What the quality statement means for service users and carers

**People who have learning disabilities** have an assessment as soon as 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.

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

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.5.4

## Definitions of terms used in this quality statement

### Initial assessment

An initial assessment should include:

* a description of the behaviour (including its severity, frequency, duration 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 NGX), recommendation 1.5.4]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, should be taken into account in an initial assessment. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

# Quality statement 3: Comprehensive health assessment

## Quality statement

People with learning disabilities and behaviour that challenges have a comprehensive annual health assessment from their GP.

## Rationale

Annual health checks in people with learning disabilities are likely to lead to identification and management of underlying physical health problems at an early stage. Unrecognised physical illness in people with learning disabilities may lead to pain and discomfort, which, in turn, may be an important factor in initiating and maintaining behaviour that challenges. Therefore, early identification of health problems in people with learning disabilities 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 learning disabilities and behaviour that challenges have a comprehensive annual health assessment from their GP.

***Data source:*** Local data collection.

### Process

a) Proportion of people with learning disabilities and behaviour that challenges 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 learning disabilities 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** (primary care providers) ensure that people with learning disabilities and behaviour that challenges have a comprehensive annual health assessment from their GP.

**GPs** give a comprehensive annual health assessment to people with learning disabilities and behaviour that challenges.

**Commissioners** (clinical commissioning groups and NHS England) ensure that they commission services in which GPs provide a comprehensive annual health assessment to people with learning disabilities and behaviour that challenges.

## What the quality statement means for service users and carers

**People with learning disabilities and behaviour that challenges** have a thorough health check from their GP every year. This should include a check of their physical health and a review of any medicines they are taking. The check should lead to a plan for how healthcare will be delivered in the next year. The health check should help to identify and deal with any physical health problems that may be causing the behaviour.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, 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 or healthcare professional or social care practitioner who knows the person. [Adapted from Challenging behaviour and learning disabilities (NICE guideline NGXX), recommendation 1.2.1]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, 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.

## Question for consultation

How far is a comprehensive annual health assessment for people with learning disabilities who display behaviour that challenges already happening in practice?

An annual health assessment for adults is commissioned as part of a Directed Enhanced Service. Therefore, should this statement be targeted at under 14s only?

# Quality statement 4: Designated coordinator

## Quality statement

People with learning disabilities and behaviour that challenges have a designated coordinator who is responsible for their behaviour support plan.

## Rationale

A designated coordinator will ensure continuity of care both for the person with a learning disability and their family or carers and reduce the need for transition to other services. A designated coordinator will also reduce the need for families or carers to repeatedly give the same information to different staff.

## Quality measures

### Structure

Evidence of local arrangements and written protocols to ensure that people with learning disabilities and behaviour that challenges have a designated coordinator who is responsible for their behaviour support plan.

***Data source:*** Local data collection.

### Process

a) Proportion of people with learning disabilities 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 learning disabilities and behaviour that challenges.

Data source: Local data collection.

b) Proportion of people with learning disabilities and behaviour that challenges who have a designated coordinator responsible for their behaviour support plan.

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

Denominator – the number of people with learning disabilities 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 and social care providers) ensure that people with learning disabilities and behaviour that challenges have a designated coordinator who is responsible for their behaviour support plan.

**Health and social care practitioners** ensure that people with learning disabilities and behaviour that challenges have a designated coordinator who is responsible for their behaviour support plan.

**Commissioners** (clinical commissioning groups, NHS England and local authorities) ensure that they commission services that provide people with learning disabilities and behaviour that challenges a designated coordinator who is responsible for their behaviour support plan.

## What the quality statement means for service users and carers

**People with learning disabilities 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.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.6.1

## Definitions of terms used in this quality statement

### Behaviour support plan

A behaviour support plan should be developed by the person with learning disabilities and behaviour that challenges and the people who support them, including their families. 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 learning disabilities. [Adapted from Challenging behaviour and learning disabilities (NICE guideline NGXX), recommendation 1.6.1]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, should be taken into account. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

## Question for consultation

Is the identification of a designated coordinator who is responsible for the behaviour support plan currently happening in practice?

Who would be the designated coordinator responsible for this?

# Quality statement 5: Personalised daily activities

## Quality statement

People with learning disabilities and behaviour that challenges have personalised daily activities planned and documented in their behaviour support plan.

## Rationale

People with learning disabilities 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 learning disabilities have planned personalised daily activities should reduce rates of behaviour that challenges.

## Quality measures

### Structure

Evidence of local arrangements to ensure that people with learning disabilities and behaviour that challenges have personalised daily activities planned and documented in their behaviour support plan.

***Data source:*** Local data collection.

### Process

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

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

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

***Data source:*** Local data collection.

b) Proportion of people with personalised daily activities planned and documented in their behaviour support plan.

Numerator – the number in the denominator who have personalised daily activities planned and documented in their behaviour support plan.

Denominator – the number of people with learning disabilities and behaviour that challenges with a written behaviour support plan.

***Data source:*** Local data collection.

### Outcome

Service user experience of personalised daily activities and behaviour support plans.

***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 learning disabilities and behaviour that challenges to have personalised daily activities planned and documented in their behaviour support plan.

**Health and social care practitioners** (including staff in residential settings and educational settings) ensure that people with learning disabilities and behaviour that challenges have personalised daily activities planned and documented in their behaviour support plan.

**Commissioners** (NHS England, clinical commissioning groups and local authorities) ensure that they commission services that plan personalised daily activities for people with learning disabilities and behaviour that challenges and document these in their behaviour support plan.

## What the quality statement means for service users and carers

**People with learning disabilities and behaviour that challenges** have activities planned for each day. The activities should meet the person’s interests and should be written in the plan that sets out how their behaviour will be supported. The plan should be developed by the person with learning disabilities and behaviour that challenges and the people who support them, including their family. The plan should note what makes the behaviour happen and what can be done to reduce or stop it.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.6.1

## Definitions of terms used in this quality statement

### Behaviour support plan

A behaviour support plan should be developed by the person with learning disabilities and behaviour that challenges and the people who support them, including their families. 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 learning disabilities. [Adapted from Challenging behaviour and learning disabilities (NICE guideline NGXX), recommendation 1.6.1]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, should be taken into account when planning support. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

# Quality statement 6: Reviewing behaviour support plans

## Quality statement

People with learning disabilities and behaviour that challenges have their behaviour support plan reviewed every other week for the first 2 months and then every month.

## Rationale

Interventions for behaviour that challenges in people with learning disabilities are often reactive. Regular and timely review of behaviour support plans should ensure that these remain current and are adjusted as treatment, behaviours and the person’s personal preferences change. This will promote the use of proactive strategies to ensure regular and effective support for people with learning disabilities and behaviour that challenges.

## Quality measures

### Structure

Evidence of local arrangements to ensure that people with learning disabilities and behaviour that challenges have their behaviour support plan reviewed every other week for the first 2 months and then every month.

***Data source:*** Local data collection.

### Process

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

Numerator – the number in the denominator who have a behaviour support plan.

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

***Data source:***Local data collection.

b) Proportion of people with learning disabilities and behaviour that challenges who have their behaviour support plan reviewed every other week for the first 2 months.

Numerator – the number in the denominator who have their behaviour support plan reviewed every other week for the first 2 months.

Denominator – the number of people with learning disabilities and behaviour that challenges with a written behaviour support plan.

c) Proportion of people who have their behaviour support plan reviewed once a month from 2 months.

Numerator – the number in the denominator who have their behaviour support plan reviewed once a month from 2 months.

Denominator – the number of people with learning disabilities and behaviour that challenges with a written 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** (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 learning disabilities and behaviour that challenges to have their behaviour support plan reviewed every other week for the first 2 months and then once a month.

**Health and social care practitioners** (including staff in residential settings and educational settings) ensure that behaviour support plans for people with learning disabilities and behaviour that challenges are reviewed every other week for the first 2 months and then once a month.

**Commissioners** (NHS England, clinical commissioning groups and local authorities) ensure that they commission services that review behaviour support plans for people with learning disabilities and behaviour that challenges every other week for the first 2 months and then once a month.

## What the quality statement means for service users and carers

**People with learning disabilities and behaviour that challenges** have regular reviews of the plan that sets out how their behaviour will be supported. The review should be every other week for the first 2 months and then once a month. The review should involve the person with learning disabilities and behaviour that challenges and the people who support them, including their family. 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.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.6.1

## Definitions of terms used in this quality statement

**Behaviour support plan**

A behaviour support plan should be developed by the person with learning disabilities and behaviour that challenges and the people who support them, including their families. 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 learning disabilities. [Adapted from Challenging behaviour and learning disabilities (NICE guideline NGXX), recommendation 1.6.1]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, should be taken into account in planning support. Practitioners may need to provide support for those who have limited speech and for those who have difficulty with English.

## Questions for consultation

Are there any tools or methods for assessing the quality of the behaviour support plan in a review that could be referenced?

# Quality statement 7: Review of restrictive interventions

## Quality statement

People with learning disabilities 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 principles of least-restrictive alternatives. Documented risk assessment and review of restrictive interventions helps to ensure learning. This will prevent future restrictive practices, identify and mitigate any risks associated with their use and ensure the safety, dignity and respect for people with learning disabilities and behaviour that challenges. A documented review should also help to ensure that people with learning disabilities and behaviour that challenges and their families or carers understand why or when restrictive interventions may be used.

## Quality measures

### Structure

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

***Data source:*** Local audit

### Process

a) Proportion of people with learning disabilities 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 learning disabilities and behaviour that challenges.

**Data source**: Local data collection.

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

## What the quality statement means for service users and carers

**People** **with learning disabilities and behaviour that challenges** who are stopped from moving around (for example, by being restrained, isolated or being given medication to calm them down) 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 works with the minimum restriction for the person with a learning disability.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, 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. [From Challenging behaviour and learning disabilities (NICE guideline NGXX)]

### 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 NGXX), recommendations 1.8.3 and 1.8.6]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, should be taken into account when conducting a review. Practitioners may need to provide support for those who have limited speech and those who have difficulty with English.

## Questions for consultation

Who is responsible for carrying out the review? How soon should it take place after the intervention?

# Quality statement 8: Use of medication

## Quality statement

People with learning disabilities and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

## Rationale

Medication is mainly used to reduce excitation and overt aggression despite the limited evidence in the area of learning disability. Antipsychotics are the most frequently used drugs for people with learning disabilities and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. The use of antipsychotics should be limited and they should only be used when 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 behaviour that challenges in people with a learning disability and should be the first-line intervention to address any identified triggers for that behaviour. Medication may be used initially when there is an immediate need to prevent self-harm or harm to others from severe behaviour that challenges, but will usually follow psychological, sensory, communication or other interventions designed to support the person with learning disabilities and behaviour that challenges.

## Quality measures

### Structure

a) Evidence of local arrangements to ensure that people with learning disabilities 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 learning disabilities 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 learning disabilities and behaviour that challenges prescribed antipsychotic medication within the past 12 months.

***Data source:*** Local data collection.

b) Proportion of people with learning disabilities 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 learning disabilities 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 learning disabilities and behaviour that challenges.

***Data source:***Local data collection.

## What the quality statement means for service providers, healthcare professionals and commissioners

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

**Healthcare professionals** only prescribe antipsychotic medication to people with learning disabilities 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 people with learning disabilities and behaviour that challenges antipsychotic medication as part of treatment that includes psychosocial interventions.

## What the quality statement means for service users and carers

**People with learning disabilities and behaviour that challenges** only receive antipsychotic medicine alongside psychological therapy or other therapies as part of their care. This should help to ensure that medication is only used when all other approaches have not reduced or changed the behaviour that challenges or when the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.7.1

## Definitions of terms used in this quality statement

### Psychosocial interventions

Psychosocial interventions include a broad range of therapeutic approaches designed to support the individual. They are generally non pharmacological and aim to identifying underlying factors for behaviour, reduce the distress of the individual and increase skills. Approaches include communication interventions, applied behaviour analysis, positive behaviour support and cognitive behavioural therapy. [Adapted from Challenging behaviour and learning disabilities (NICE clinical guideline NGXX), section 11.2]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, should be taken into account. Practitioners may need to provide support for both those who have limited speech and those who have difficulty with English.

# Quality statement 9: Review of medication

## Quality statement

People with learning disabilities 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 learning disabilities, 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 reduce prolonged use and thereby potential excess morbidity caused by side effects.

## Quality measures

### Structure

Evidence of local arrangements and written protocols to ensure that people with learning disabilities 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 learning disabilities 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 learning disabilities and behaviour that challenges prescribed antipsychotics medication within the past 12 months.

***Data source:*** Local data collection.

b) Proportion of people with learning disabilities 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 learning disabilities 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 learning disabilities 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 services) ensure that systems are in place for people with learning disabilities 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 learning disabilities 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 learning disabilities 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

**People** **with learning disabilities and behaviour that challenges** have a review of their antipsychotic medicine 3 months after their treatment started and then a review every 6 months. This should be done by a team of staff that includes doctors, nurses and care staff. The review should find out how the medicine is affecting the person (including side effects) and why the medicine is being taken, and should make sure that this is explained to the person and their family or carers. This should help people to understand why they are having medicine and ensure that they are taking medicine for the right reasons and for the right amount of time.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.7.5

## Definitions of terms used in this quality statement

### Multidisciplinary review

A review of prescribed antipsychotic medication should include the following:

* a record of the extent of the response, how the behaviour has changed and any side effects or adverse events
* the rationale for continuing the medication, if this is being done, and an explanation of this for the person with learning disabilities 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 NGXX), section 1.7]

## Equality and diversity considerations

The communication needs of people with profound or severe disabilities, particularly the needs of people who do not speak, need to be taken into account when conducting a review. Practitioners may need to provide support for those who have limited speech and those who have difficulty with English.

# Quality statement 10: Family and carer support

## Quality statement

Parents or carers of children aged under 12 years with learning disabilities and behaviour that challenges are referred to a parent training programme for challenging behaviour.

## Rationale

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

## Quality measures

### Structure

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

***Data source:*** Local data collection.

### Process

a) Proportion of parents or carers of children aged under 12 years with learning disabilities and behaviour that challenges who are referred to a parent training programme for challenging behaviour.

Numerator – the number in the denominator whose parents or carers are referred to a parent training programme for challenging behaviour.

Denominator – the number of children aged under 12 years with learning disabilities 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 learning disabilities and behaviour that challenges are referred to a parent training programme for challenging behaviour.

**Health and social care practitioners** ensure that parents or carers of children aged under 12 years with learning disabilities and behaviour that challenges are referred to a parent training programme for challenging behaviour.

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

## What the quality statement means for service users and carers

**Parents or carers of children aged under 12 years with learning disabilities and at risk of developing behaviour that challenges** are referred to a training programme to help them to support their child or the child they care for to develop their communication and social skills. This should help the parent or carer to understand how to better support the child.

## Source guidance

* Challenging behaviour and learning disabilities (in development) NICE guideline, recommendation 1.8.6

## Definitions of terms used in this quality statement

### Parent training programme

Parent training programmes have the following components:

* are delivered in groups of 10 to 15 parents or carers
* focus on developing communication and social functioning in the child with learning disabilities
* 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 NGXX), recommendation 1.6.2]

# Status of this quality standard

This is the draft quality standard released for consultation from 29 May to 26 June 2015. It is not NICE’s final quality standard on behaviour that challenges and learning disabilities. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 26 June 2015. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee’s considerations. The final quality standard will be available on the [NICE website](http://www.nice.org.uk/standards-and-indicators) from October 2015.

# 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](http://www.hscic.gov.uk/iqi). 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?](http://www.nice.org.uk/Standards-and-Indicators/Developing-NICE-quality-standards-/NICE-quality-standards-FAQs) 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 [Link to section in web version]

# Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](http://www.nice.org.uk/guidance/indevelopment/gid-qsd101/documents) are available.

Good communication between health and social care practitioners and adults, children and young people with learning disabilities 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. Adults, children and young people with learning disabilities 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](http://www.nice.org.uk/Standards-and-Indicators/Developing-NICE-quality-standards).

## 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 (in development) NICE guideline NGXX

## 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](http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/transform-care/)
* Department of Health (2014) [Positive and proactive care: reducing the need for restrictive interventions](https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-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](http://www.local.gov.uk/place-i-call-home/-/journal_content/56/10180/5971490?_56_INSTANCE_0000_templateId=ARTICLE)
* NHS England (2014) [Winterbourne View – Time for change: transforming the commissioning of services for people with learning disabilities and/or autism](http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/transform-care/)
* Royal College of Psychiatrists (2014) [Executive summary and recommendations: national audit of learning disabilities feasibility study](http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/auditoflearningdisabilities/learningdisabilities.aspx)
* United Response (2014) [Transforming care: supporting people with learning disabilities, autism and challenging behaviour to live happily in their local community](http://www.scie-socialcareonline.org.uk/transforming-care-supporting-people-with-learning-disabilites-autism-and-challenging-behaviour-to-live-happily-in-their-local-community/r/a11G0000004qU5yIAE)
* Joint Commissioning Panel for Mental Health (2013) [Guidance for commissioners of mental health services for people with learning disabilities](http://www.jcpmh.info/resource/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](http://www.rcpsych.ac.uk/workinpsychiatry/faculties/intellectualdisability/professional.aspx)
* Care Quality Commission (2012) [Review of learning disability services](http://www.cqc.org.uk/content/review-learning-disability-services-1)
* Department of Health (2012) [Transforming care: a national response to Winterbourne View hospital](https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response)

## Definitions and data sources for the quality measures

* Health and Social Care Information Centre (2014) [Learning disabilities census](http://www.hscic.gov.uk/ldcensus)

# Related NICE quality standards

## Published

* [Antisocial behaviour and conduct disorders in children and young people](http://www.nice.org.uk/guidance/qs59) (2014) NICE quality standard 59
* [Autism](http://www.nice.org.uk/guidance/qs51) (2014) NICE quality standard 51
* [Attention deficit hyperactivity disorder](http://www.nice.org.uk/Guidance/QS39) (2013) NICE quality standard 39
* [The epilepsies in adults](http://www.nice.org.uk/guidance/qs26) (2013) NICE quality standard 26
* [The epilepsies in children and young people](http://www.nice.org.uk/guidance/qs27) (2013) NICE quality standard 27
* [Service user experience in adult mental health](http://www.nice.org.uk/guidance/qs14) (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.
* Service model: challenging behaviour and learning disabilities. Status: referred.
* Mental health problems in people with 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](http://www.nice.org.uk/Standards-and-Indicators/Developing-NICE-quality-standards-/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:

**Mr Ben Anderson**Consultant in Public Health, Public Health England

**Mr Barry Attwood**Lay member

**Professor Gillian Baird**Consultant Developmental Paediatrician, Guy’s and St Thomas’ NHS Foundation Trust, London

**Mrs Belinda Black**Chief Executive Officer, Sheffcare, Sheffield

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Deputy Director of Quality, NHS Gloucestershire Clinical Commissioning Group

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**Mr David Minto**Adult Social Care Operations Manager, Northumbria Healthcare Foundation Trust

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The following specialist members joined the committee to develop this quality standard:

**Vivien Cooper**Chief Executive, The Challenging Behaviour Foundation

**Joanna Dwyer**Clinical Specialist Occupational Therapist, Community Services for Adults with Learning Disabilities, Guy’s and St Thomas’ NHS Foundation Trust

**Angela Hassiotis**Professor in Psychiatry of Intellectual Disabilities, UCL Division of Psychiatry

**Simon Jones**Head of Behavioural Support, Care UK

**Glynis Murphy**Professor of Clinical Psychology and Disability, Tizard Centre, University of Kent

**Philippa Scott**Operations Director, Agincare Homes Holdings

## NICE project team

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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](http://www.nice.org.uk/Standards-and-Indicators/Developing-NICE-quality-standards).

This quality standard has been incorporated into the NICE pathway on Challenging behaviour and learning disabilities, which is currently in development.

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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1. Griffith G and 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, 5, p. 401-419. [↑](#footnote-ref-1)