

# Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

NICE guideline

Published: 29 May 2015

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# Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations wherever possible](#).

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This guideline is the basis of QS101 and QS142.

This guideline should be read in conjunction with NG93.

## Overview

This guideline covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges. It highlights the importance of understanding the cause of behaviour that challenges, and performing thorough assessments so that steps can be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers.

NICE has produced an easy read version for people with a learning disability.

## Who is it for?

- Healthcare professionals, commissioners and providers in health and social care
- Parents, family members or carers of children, young people and adults with a learning disability and behaviour that challenges

## Context

A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. Although the term 'intellectual disability' is becoming accepted internationally, 'learning disability' is the most widely used and accepted term in the UK and is therefore used in this guideline. The amount of everyday support a person with a learning disability needs will depend mostly on the severity of the disability. It is important to treat each person as an individual, with specific strengths and abilities as well as needs, and a broad and detailed assessment may be needed.

Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this guideline 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. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system.

It is relatively common for people with a learning disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around 5–15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings). People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

The behaviour may appear in only certain environments, and the same behaviour may be considered challenging in some settings or cultures but not in others. It may be used by the person for reasons such as creating sensory stimulation, getting help or avoiding demands. Some care environments increase the likelihood of behaviour that challenges. This includes those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care

environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed.

Multiple factors are likely to underlie behaviour that challenges. To identify these, thorough assessments of the person, their environment and any biological predisposition are needed, together with a functional assessment. Interventions depend on the specific triggers for each person and may need to be delivered at multiple levels (including the environmental level). The aim should always be to improve the person's overall quality of life.

This guideline will cover the care and shared care provided or commissioned by health and social care, in whatever care setting the person lives.

## Safeguarding children

Remember that child maltreatment:

- is common
- can present anywhere, such as emergency departments and primary care or on home visits.

Be aware of or suspect abuse as a contributory factor to or cause of behaviour that challenges shown by children with a learning disability. Abuse may also coexist with behaviour that challenges. See the [NICE guideline on child maltreatment](#) for clinical features that may be associated with maltreatment.

This section has been agreed with the Royal College of Paediatrics and Child Health.

## Safeguarding adults

Adults with a learning disability are vulnerable to maltreatment and exploitation. This can occur in both community and residential settings. A referral (in line with local safeguarding procedures) may be needed if there are concerns regarding maltreatment or exploitation, or if the person is in contact with the criminal justice system.

# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

## 1.1 General principles of care

### Working with people with a learning disability and behaviour that challenges, and their families and carers

- 1.1.1 Work in partnership with children, young people and adults who have a learning disability and behaviour that challenges, and their family members or carers, and:
- involve them in decisions about care
  - support self-management and encourage the person to be independent
  - build and maintain a continuing, trusting and non-judgemental relationship
  - provide information:
    - about the nature of the person's needs, and the range of interventions (for example, environmental, psychological and pharmacological interventions) and services available to them
    - in a format and language appropriate to the person's cognitive and developmental level (including spoken and picture formats, and written versions in Easy Read style and different colours and fonts)
  - develop a shared understanding about the function of the behaviour

- help family members and carers to provide the level of support they feel able to.
- 1.1.2 When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers:
- take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
  - aim to provide support and interventions:
    - in the least restrictive setting, such as the person's home, or as close to their home as possible, and
    - in other places where the person regularly spends time (for example, school or residential care)
  - aim to prevent, reduce or stop the development of future episodes of behaviour that challenges
  - aim to improve quality of life
  - offer support and interventions respectfully
  - ensure that the focus is on improving the person's support and increasing their skills rather than changing the person
  - ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion
  - offer independent advocacy to the person and to their family members or carers.

## **Understanding learning disabilities and behaviour that challenges**

- 1.1.3 Everyone involved in commissioning or delivering support and interventions for people with a learning disability and behaviour that challenges (including family members and carers) should understand:

- the nature and development of learning disabilities
- personal and environmental factors related to the development and maintenance of behaviour that challenges
- that behaviour that challenges often indicates an unmet need
- the effect of learning disabilities and behaviour that challenges on the person's personal, social, educational and occupational functioning
- the effect of the social and physical environment on learning disabilities and behaviour that challenges (and vice versa), including how staff and carer responses to the behaviour may maintain it.

## Delivering effective care

- 1.1.4 Health and social care provider organisations should ensure that teams carrying out assessments and delivering interventions recommended in this guideline have the training and supervision needed to ensure that they have the necessary skills and competencies.
- 1.1.5 If initial assessment (see section 1.5) and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support and intervention services. These services should provide advice, supervision and training from a range of staff to support the implementation of any care or intervention, including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians, paediatricians and pharmacists.

## Staff training, supervision and support

- 1.1.6 Health and social care provider organisations should ensure that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of behaviour that challenges, including:

- developing personalised daily activities
- adapting a person's environment and routine
- strategies to help the person develop an alternative behaviour to achieve the same purpose by developing a new skill (for example, improved communication, emotional regulation or social interaction)
- the importance of including people, and their family members or carers, in planning support and interventions
- strategies designed to calm and divert the person if they show early signs of distress
- delivering reactive strategies.

1.1.7 Health and social care provider organisations should ensure that all staff get personal and emotional support to:

- enable them to deliver interventions effectively for people with a learning disability and behaviour that challenges
- feel able to seek help for difficulties arising from working with people with a learning disability and behaviour that challenges
- recognise and manage their own stress.

1.1.8 Health and social care provider organisations should ensure that all interventions for behaviour that challenges are delivered by competent staff. Staff should:

- receive regular high-quality supervision that takes into account the impact of individual, social and environmental factors
- deliver interventions based on the relevant treatment manuals
- consider using routine outcome measures at each contact (for example, the Adaptive Behavior Scale and the Aberrant Behavior Checklist)
- take part in monitoring (for example, by using Periodic Service Review methods)

- evaluate adherence to interventions and practitioner competence (for example, by using video and audio recording, and external audit and scrutiny).

## Organising effective care

The recommendations in this section are adapted from the NICE guideline on common mental health disorders.

- 1.1.9 A designated leadership team of healthcare professionals, educational staff, social care practitioners, managers and health and local authority commissioners should develop care pathways for people with a learning disability and behaviour that challenges for the effective delivery of care and the transition between and within services that are:
- negotiable, workable and understandable for people with a learning disability and behaviour that challenges, their family members or carers, and staff
  - accessible and acceptable to people using the services, and responsive to their needs
  - integrated (to avoid barriers to movement between different parts of the care pathways)
  - focused on outcomes (including measures of quality, service-user experience and harm).
- 1.1.10 The designated leadership team should be responsible for developing, managing and evaluating care pathways, including:
- developing clear policies and protocols for care pathway operation
  - providing training and support on care pathway operation
  - auditing and reviewing care pathway performance.
- 1.1.11 The designated leadership team should work together to design care pathways that promote a range of evidence-based interventions and support people in their choice of interventions.
- 1.1.12 The designated leadership team should work together to design care

pathways that respond promptly and effectively to the changing needs of the people they serve and have:

- clear and agreed goals for the services offered
- robust and effective ways to measure and evaluate the outcomes associated with the agreed goals.

- 1.1.13 The designated leadership team should work together to design care pathways that provide an integrated programme of care across all care services and:
- minimise the need for transition between different services or providers
  - provide the least restrictive alternatives for people with behaviour that challenges
  - allow services to be built around the care pathway (and not the other way around)
  - establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs)
  - have designated staff who are responsible for coordinating people's engagement with a care pathway and transition between services within and between care pathways.
- 1.1.14 The designated leadership team should work together to ensure effective communication about the functioning of care pathways. There should be protocols for sharing information:
- with people with a learning disability and behaviour that challenges, and their family members or carers (if appropriate), about their care
  - about a person's care with other staff (including GPs)
  - with all the services provided in the care pathway
  - with services outside the care pathway.

## 1.2 Physical healthcare

- 1.2.1 GPs should offer an annual physical health check to children, young people and adults with a learning disability in all settings, using a standardised template (such as the Cardiff health check template). This should be carried out together with a family member, carer or healthcare professional or social care practitioner who knows the person and include:
- a review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems
  - a physical health review
  - a review of all current health interventions, including medication and related side effects, adverse events, drug interactions and adherence
  - an agreed and shared care plan for managing any physical health problems (including pain).

See the Royal College of General Practitioners' guide for GP practices on annual health checks for people with a learning disability for further information.

## 1.3 Support and interventions for family members or carers

- 1.3.1 Involve family members or carers in developing and delivering the support and intervention plan for children, young people and adults with a learning disability and behaviour that challenges. Give them information about support and interventions in a format and language that is easy to understand, including NICE's 'Information for the public'.
- 1.3.2 Advise family members or carers about their right to carer assessment, and assessment for respite care and other support (see the NICE guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers).

1.3.3 When providing support to family members or carers (including siblings):

- recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges
- explain how to access family advocacy
- consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging
- consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges
- provide skills training and emotional support, or information about these, to help them take part in and support interventions for the person with a learning disability and behaviour that challenges.

1.3.4 If a family member or carer has an identified mental health problem, consider:

- interventions in line with existing NICE guidelines or
- referral to a mental health professional who can provide interventions in line with existing NICE guidelines.

## 1.4 Early identification of the emergence of behaviour that challenges

1.4.1 Everyone involved in caring for and supporting children, young people and adults with a learning disability (including family members and carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record factors that may increase this risk, including:

- personal factors, such as:
  - a severe learning disability
  - autism
  - dementia
  - communication difficulties (expressive and receptive)
  - visual impairment (which may lead to increased self-injury and stereotypy)
  - physical health problems
  - variations with age (peaking in the teens and twenties)
- environmental factors, such as:
  - abusive or restrictive social environments
  - environments with little or too much sensory stimulation and those with low engagement levels (for example, little interaction with staff)
  - developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person)
  - environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs
  - changes to the person's environment (for example, significant staff changes or moving to a new care setting).

1.4.2 Consider using direct observation and recording or formal rating scales (for example, the Adaptive Behavior Scale or Aberrant Behavior Checklist) to monitor the development of behaviour that challenges.

## 1.5 Assessment of behaviour that challenges

### The assessment process

1.5.1 When assessing behaviour that challenges shown by children, young

people and adults with a learning disability follow a phased approach, aiming to gain a functional understanding of why the behaviour occurs. Start with initial assessment and move on to further assessment if, for example, intervention has not been effective or the function of the behaviour is not clear (see recommendations 1.5.4–1.5.11). Develop a behaviour support plan (see recommendation 1.6.1) as soon as possible.

1.5.2 When assessing behaviour that challenges ensure that:

- the person being assessed remains at the centre of concern and is supported throughout the process
- the person and their family members and carers are fully involved in the assessment process
- the complexity and duration of the assessment process is proportionate to the severity, impact, frequency and duration of the behaviour
- everyone involved in delivering assessments understands the criteria for moving to more complex and intensive assessment (see recommendation 1.5.8)
- all current and past personal and environmental factors (including care and educational settings) that may lead to behaviour that challenges are taken into account
- assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change over time
- assessments are reviewed after any significant change in behaviour
- assessments are focused on the outcomes of reducing behaviour that challenges and improving quality of life
- the resilience, resources and skills of family members and carers are taken into account
- the capacity, sustainability and commitment of the staff delivering the behaviour support plan (see recommendation 1.6.1) are taken into account.

1.5.3 Explain to the person and their family members or carers how they will be told about the outcome of any assessment of behaviour that challenges. Ensure that feedback is personalised and involves a family member, carer

or advocate to support the person and help them to understand the feedback if needed.

## Initial assessment of behaviour that challenges

- 1.5.4 If behaviour that challenges is emerging or apparent, or a family member, carer or member of staff (such as a teacher or care worker), has concerns about behaviour, carry out initial assessment that includes:
- a description of the behaviour (including its severity, frequency, duration and impact on the person and others) from 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 developing or maintaining the behaviour from the person (if possible) and a family member, carer or a member of staff (such as a teacher or care worker)
  - the role of the service, staff, family members or carers in developing or maintaining the behaviour.
- Consider using a formal rating scale (for example, the Aberrant Behavior Checklist or Adaptive Behavior Scale) to provide baseline levels for the behaviour and a scale (such as the Functional Analysis Screening Tool) to help understand its function.
- 1.5.5 As part of initial assessment of behaviour that challenges, take into account:
- the person's abilities and needs (in particular, their expressive communication and receptive communication)
  - any physical or mental health problems, and the effect of medication, including side effects
  - developmental history, including neurodevelopmental problems (including the severity of the learning disability and the presence of autism or other behavioural phenotypes)
  - response to any previous interventions for behaviour that challenges

- the impact of the behaviour that challenges on the person's:
  - quality of life and that of their family members or carers
  - independent living skills and educational or occupational abilities
- social and interpersonal history, including relationships with family members, carers, staff (such as teachers) or other people with a learning disability (such as those the person lives with)
- aspects of the person's culture that could be relevant to the behaviour that challenges
- life history, including any history of trauma or abuse
- recent life events and changes to routine
- the person's sensory profile, preferences and needs
- the physical environment, including heat, light, noise and smell
- the care environment, including the range of activities available, how it engages people and promotes choice, and how well structured it is.

1.5.6 After initial assessment, develop a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and the function of the behaviour. Use this to develop a behaviour support plan (see recommendation 1.6.1).

## Risk assessment

1.5.7 Assess and regularly review the following areas of risk during any assessment of behaviour that challenges:

- suicidal ideation, self-harm (in particular in people with depression) and self-injury
- harm to others
- self-neglect
- breakdown of family or residential support

- exploitation, abuse or neglect by others
- rapid escalation of the behaviour that challenges.

Ensure that the behaviour support plan includes risk management (see recommendation 1.6.1).

## Further assessment of behaviour that challenges

1.5.8 If the behaviour that challenges is severe or complex, or does not respond to the behaviour support plan, review the plan and carry out further assessment that is multidisciplinary and draws on skills from specialist services (see recommendation 1.1.5), covering any areas not fully explored by initial assessment (see recommendation 1.5.5). Carry out a functional assessment (see recommendations 1.5.9–1.5.11), identifying and evaluating any factors that may provoke or maintain the behaviour. Consider using formal (for example, the Adaptive Behavior Scale or the Aberrant Behavior Checklist) and idiographic (personalised) measures to assess the severity of the behaviour and the progress of any intervention.

## Functional assessment of behaviour

1.5.9 Carry out a functional assessment of the behaviour that challenges to help inform decisions about interventions. This should include:

- a clear description of the behaviour, including classes or sequences of behaviours that typically occur together
- identifying the events, times and situations that predict when the behaviour will and will not occur across the full range of the person's daily routines and usual environments
- identifying the consequences (or reinforcers) that maintain the behaviour (that is, the function or purpose that the behaviour serves)
- developing summary statements or hypotheses that describe the relationships between personal and environmental triggers, the behaviour and its reinforcers

- collecting direct observational data to inform the summary statements or hypotheses.

1.5.10 Include the following in a functional assessment:

- a baseline measurement of current behaviour, and its frequency and intensity, and repeated measurements in order to evaluate change
- measurements including direct observations and scales such as the Aberrant Behavior Checklist and self-reporting
- a baseline measurement of quality of life (such as the Life Experiences Checklist and the Quality of Life Questionnaire)
- assessment of the impact of current or past interventions, including reactive strategies.

1.5.11 Vary the complexity and intensity of the functional assessment according to the complexity and intensity of behaviour that challenges, following a phased approach as set out below.

- Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
- For recent-onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool or Motivation Assessment Scale to identify relationships between the behaviour and what triggers and reinforces it.
- For recent-onset behaviour that challenges, or marked changes in patterns of existing behaviours, take into account whether any significant alterations to the person's environment and physical or psychological health are associated with the development or maintenance of the behaviour.
- Consider in-depth assessment involving interviews with family members, carers and others, direct observations, structured record keeping, questionnaires and reviews of case records.

- If a mental health problem may underlie behaviour that challenges, consider initial screening using assessment scales such as the Diagnostic Assessment Schedule for the Severely Handicapped-II, Psychiatric Assessment Schedule for Adults with a Developmental Disability or the Psychopathology Instrument for Mentally Retarded Adults and seek expert opinion.

## After further assessment

- 1.5.12 After further assessment, re-evaluate the written statement (formulation) and adjust the behaviour support plan if necessary.

## 1.6 Behaviour support plan

- 1.6.1 Develop a written behaviour support plan for children, young people and adults with a learning disability and behaviour that challenges that is based on a shared understanding about the function of the behaviour.

This should:

- identify proactive strategies designed to improve the person's quality of life and remove the conditions likely to promote behaviour that challenges, including:
  - changing the environment (for example, reducing noise, increasing predictability)
  - promoting active engagement through structured and personalised daily activities, including adjusting the school curriculum for children and young people
- identify adaptations to a person's environment and routine, and strategies to help them develop an alternative behaviour to achieve the function of the behaviour that challenges 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, including:
  - individual relaxation techniques
  - distraction and diversion onto activities they find enjoyable and rewarding

- identify reactive strategies to manage any behaviours that are not preventable (see section 1.9), including how family members, carers or staff should respond if a person's agitation escalates and there is a significant risk of harm to them or others
- 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 can be implemented within these resources
- be supported by data that measure the accurate implementation of the plan
- be monitored using the continuous collection of objective outcome data
- be reviewed frequently (fortnightly for the first 2 months and monthly thereafter), particularly if behaviour that challenges or use of restrictive interventions increases, or quality of life decreases
- identify any training for family members, carers or staff to improve their understanding of behaviour that challenges shown by people with a learning disability
- identify those responsible for delivering the plan and the designated person responsible for coordinating it.

## 1.7 Psychological and environmental interventions

### Early intervention for children and their parents or carers

- 1.7.1 Consider parent-training programmes for parents or carers of children with a learning disability who are aged under 12 years with emerging, or at risk of developing, behaviour that challenges.
- 1.7.2 Parent-training programmes should:
  - be delivered in groups of 10 to 15 parents or carers

- be accessible (for example, take place outside normal working hours or in community-based settings with childcare facilities)
- focus on developing communication and social functioning
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow the relevant treatment manual
- employ materials to ensure consistent implementation of the programme.

1.7.3 Consider preschool classroom-based interventions for children aged 3–5 years with emerging, or at risk of developing, behaviour that challenges.

1.7.4 Preschool classroom-based interventions should have multiple components, including:

- curriculum design and development
- social and communication skills training for the children
- skills training in behavioural strategies for parents or carers
- training on how to mediate the intervention for preschool teachers.

## Interventions for behaviour that challenges

1.7.5 Consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:

- clear targeted behaviours with agreed outcomes
- assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
- addressing staff and family member or carer responses to behaviour that challenges

- a clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
  - a specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).
- 1.7.6 Consider individual psychological interventions for adults with an anger management problem. These interventions should be based on cognitive-behavioural principles and delivered individually or in groups over 15 to 20 hours.
- 1.7.7 Do not offer sensory interventions (for example, Snoezelen rooms) before carrying out a functional assessment to establish the person's sensory profile. Bear in mind that the sensory profile may change.
- 1.7.8 Consider developing and maintaining a structured plan of daytime activity (as part of the curriculum if the person is at school) that reflects the person's interests and capacity. Monitor the effects on behaviour that challenges and adjust the plan in discussion with the person and their family members or carers.

## 1.8 Medication

- 1.8.1 Consider medication, or optimise existing medication (in line with the NICE guideline on medicines optimisation), for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges shown by children, young people and adults with a learning disability (see also recommendation 1.10.1).
- 1.8.2 Consider antipsychotic medication to manage behaviour that challenges only if:
- psychological or other interventions alone do not produce change within an agreed time or
  - treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or

- the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

Only offer antipsychotic medication in combination with psychological or other interventions.

- 1.8.3 When choosing which antipsychotic medication to offer, take into account the person's preference (or that of their family member or carer, if appropriate), side effects, response to previous antipsychotic medication and interactions with other medication.
- 1.8.4 Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician) who should:
- identify the target behaviour
  - decide on a measure to monitor effectiveness (for example, direct observations, the Aberrant Behavior Checklist or the Adaptive Behavior Scale), including frequency and severity of the behaviour and impact on functioning
  - start with a low dose and use the minimum effective dose needed
  - only prescribe a single drug
  - monitor side effects as recommended in the NICE guidelines on psychosis and schizophrenia in adults and psychosis and schizophrenia in children and young people
  - review the effectiveness and any side effects of the medication after 3–4 weeks
  - stop the medication if there is no indication of a response at 6 weeks, reassess the behaviour that challenges and consider further psychological or environmental interventions
  - only prescribe p.r.n. (as-needed) medication for as short a time as possible and ensure that its use is recorded and reviewed

- review the medication if there are changes to the person's environment (for example, significant staff changes or moving to a new care setting) or their physical or mental health.

1.8.5 Ensure that the following are documented:

- a rationale for medication (explained to the person with a learning disability and everyone involved in their care, including their family members and carers)
- how long the medication should be taken for
- a strategy for reviewing the prescription and stopping the medication.

1.8.6 If there is a positive response to antipsychotic medication:

- record the extent of the response, how the behaviour has changed and any side effects or adverse events
- conduct a full multidisciplinary review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping)
- only continue to prescribe medication that has proven benefit.

1.8.7 When prescribing is transferred to primary or community care, or between services, the specialist should give clear guidance to the practitioner responsible for continued prescribing about:

- which behaviours to target
- monitoring of beneficial and side effects
- taking the lowest effective dose
- how long the medication should be taken for
- plans for stopping the medication.

1.8.8 For the use of rapid tranquillisation, follow the NICE guideline on violence and aggression.

## 1.9 Reactive strategies

- 1.9.1 Only use reactive strategies for children, young people and adults with a learning disability and behaviour that challenges as a last resort and together with the proactive interventions described in section 1.7. When risks to the person with a learning disability or others are significant, or breakdown in their living arrangements is very likely, consider using reactive strategies as an initial intervention and introduce proactive interventions once the situation stabilises.
- 1.9.2 Ensure that reactive strategies, whether planned or unplanned, are delivered on an ethically sound basis. Use a graded approach that considers the least restrictive alternatives first. Encourage the person and their family members or carers to be involved in planning and reviewing reactive strategies whenever possible.
- 1.9.3 If a restrictive intervention is used as part of a reactive strategy, follow the NICE guideline on violence and aggression for the safe use of restrictive interventions and carry out a thorough risk assessment. Take into account:
- any physical health problems and physiological contraindications to the use of restrictive interventions, in particular manual and mechanical restraint
  - any psychological risks associated with the intervention, such as a history of abuse
  - any known biomechanical risks, such as musculoskeletal risks
  - any sensory sensitivities, such as a high or low threshold for touch.
- Document and review the delivery and outcome of the restrictive intervention and discuss these with everyone involved in the care of the person, including their family members and carers, and with the person if possible.
- 1.9.4 Ensure that any restrictive intervention is accompanied by a restrictive intervention reduction programme, as part of the long-term behaviour support plan, to reduce the use of and need for restrictive interventions.

1.9.5 Ensure that planned restrictive interventions:

- take place within the appropriate legal framework of the Human Rights Act 1998, the relevant rights in the European Convention on Human Rights, the Mental Health Act 1983 and the Mental Capacity Act 2005, including the supplementary code of practice on deprivation of liberty safeguards
- are in the best interest of the person to protect them or others from immediate and significant harm
- are a reasonable, necessary and proportionate response to the risk presented.

1.9.6 Regularly review and reassess the safety, efficacy, frequency of use, duration and continued need for reactive strategies, including restrictive interventions (follow the NICE guideline on violence and aggression for the safe use of restrictive interventions). Document their use as part of an incident record and use this in personal and organisational debrief procedures to inform future behaviour support planning and organisational learning.

## 1.10 Interventions for coexisting health problems

1.10.1 Offer children, young people and adults with a learning disability and behaviour that challenges interventions for any suspected or coexisting mental or physical health problems in line with the relevant NICE guideline for that condition (see also recommendation 1.8.1). Adjust the nature, content and delivery of the interventions to take into account the impact of the person's learning disability and behaviour that challenges.

## 1.11 Interventions for sleep problems

1.11.1 Consider behavioural interventions for sleep problems in children, young people and adults with a learning disability and behaviour that challenges that consist of:

- a functional analysis of the problem sleep behaviour to inform the intervention (for example, not reinforcing non-sleep behaviours)
- structured bedtime routines.

1.11.2 Do not offer medication to aid sleep unless the sleep problem persists after a behavioural intervention, and then only:

- after consultation with a psychiatrist (or a specialist paediatrician for a child or young person) with expertise in its use in people with a learning disability
- together with non-pharmacological interventions and regular reviews (to evaluate continuing need and ensure that the benefits continue to outweigh the risks).

If medication is needed to aid sleep, consider melatonin. In May 2015, this was an off-label use of melatonin in people aged 55 years and under. See [NICE's information on prescribing medicines](#).

## Terms used in this guideline

### Adults

Aged 18 years or older.

### Behavioural phenotypes

The expression of distinctive physiological and behavioural characteristics that have a chromosomal or genetic cause.

### Carer

A person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or has a disability. This does not include paid carers (care workers), who are included in the definition of staff.

### Children

Aged 12 years or younger.

## **Expressive communication**

The ability to express thoughts, feelings and needs verbally (using words and sentences) and non-verbally (for example, using gestures, facial expressions, gaze, signing and other methods that supplement or replace speech or writing).

## **Functional assessment**

An assessment of the function of behaviour that challenges, including functional analyses and other methods of assessing behavioural functions.

## **Reactive strategies**

Any strategy used to make a situation or a person safe when they behave in a way that challenges. This includes procedures for increasing personal space, disengagement from grabs and holds, p.r.n. (as-needed) medication and more restrictive interventions.

## **Receptive communication**

The ability to understand or comprehend language (either spoken or written) or other means of communication (for example, through signing and other methods that supplement or replace speech or writing).

## **Reinforcer**

An event or situation that is dependent on a behaviour and increases the likelihood of that behaviour happening again.

## **Restrictive interventions**

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.

## **Self-harm**

When a person intentionally harms themselves, which can include cutting and self-poisoning. It may be an attempt at suicide.

## **Self-injury**

Frequently repeated, self-inflicted behaviour, such as people hitting their head or biting themselves, which can lead to tissue damage. This behaviour is usually shown by people with a severe learning disability. It may indicate pain or distress, or it may have another purpose, such as the person using it to communicate.

## **Staff**

Healthcare professionals and social care practitioners, including those working in community teams for adults or children (such as psychologists, psychiatrists, social workers, speech and language therapists, nurses, behavioural analysts, occupational therapists, physiotherapists), paid carers (care workers) in a variety of settings (including residential homes, supported living settings and day services) and educational staff.

## **Stereotypy**

Repeated behaviours, such as rocking or hand flapping, that may appear to have no obvious function but often serve a purpose for the person (for example, to provide sensory stimulation or indicate distress or discomfort).

## **Treatment manual**

Detailed advice and guidance on how to deliver an intervention, including its content, duration and frequency. A treatment manual may also include materials to support the delivery of the intervention for staff and people receiving the intervention.

## **Young people**

Aged 13 to 17 years.

## Recommendations for research

### Preventing behaviour that challenges from developing in children aged under 5 years with a learning disability

Can positive behaviour support provided for children aged under 5 years with a learning disability reduce the risk of developing behaviour that challenges?

#### Why this is important

Behaviour that challenges is common in children with a learning disability and can have a considerable impact on them and their family members or carers. It is a common reason for residential placement with associated high costs. Positive behaviour support aims to reduce behaviour that challenges and increase quality of life through teaching new skills and adjusting the environment to promote positive behaviour changes. Early intervention with children at risk of developing behaviour that challenges offers an opportunity to significantly enhance their life and that of their family members or carers.

The question should be addressed by a programme of research that includes:

- developing interventions to prevent behaviour that challenges from developing in children aged under 5 years
- assessing the feasibility of the formal evaluation of the interventions in a randomised controlled trial
- testing the clinical and cost effectiveness of the interventions in a large scale randomised controlled trial with long-term follow-up
- evaluating the implementation of the interventions in routine care.

### Interventions to reduce the frequency and extent of moderate to severe behaviour that challenges in

## community settings

Are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?

### Why this is important

Behaviour that challenges is common in adults with a learning disability and can have a considerable impact on them and their family members or carers. It is also a common reason for hospital or residential placement. There is limited evidence for the effectiveness of either applied behaviour analysis or antipsychotic medication, or a combination of these in community settings. Little is known about which people respond best to which interventions or about the duration of the interventions. There is considerable evidence of the over use of medication and of limited skills and competence in delivering behavioural interventions.

The question should be addressed by a programme of research evaluating these interventions that includes:

- developing a protocol for assessing moderate to severe behaviour that challenges that:
  - characterises the nature and function of the behaviour
  - assesses all coexisting problems that may contribute to the behaviour developing or being maintained
- developing protocols for delivering and monitoring the interventions to be tested (including how any currently provided interventions will be stopped)
- assessing the feasibility of the formal evaluation of the interventions in a randomised controlled trial (in particular, recruitment)
- testing the comparative clinical effectiveness (including moderators and mediators) and cost effectiveness of the interventions in a large-scale randomised controlled trial.

## Locally accessible care

Does providing care where people live compared with out-of-area placement lead to improvements in both the clinical and cost effectiveness of care for people with a learning disability and behaviour that challenges?

### Why this is important

Many out-of-area care placements for people with a learning disability and behaviour that challenges are a long way from their home. This can have a considerable impact, limiting a family member or carer's ability to care for the person and leading to poorer outcomes and increased costs. It is widely recognised that locally accessible care settings could be beneficial and could reduce costs but there is no strong empirical evidence to support this. In the absence of such evidence significant numbers of out-of-area care placements continue to be made.

The question should be addressed by a programme of research that includes:

- a needs assessment and the care costs of a consecutive cohort of 250 people who have been placed in out-of-area care in a 2-year period
- developing standards for a range of support programmes designed to meet people's needs, which would provide detailed information on:
  - the needs to be met
  - the nature of the care environments
  - the support, including specialist staff, needed
- testing the clinical and cost effectiveness of 'close to home' or home-based care that meet the developed standards (compared with consecutive cohorts in out-of-area placements).

## Factors associated with sustained, high-quality residential care

What factors (including service organisation and management, staff composition, training and supervision, and the content of care and support) are associated with sustained

high-quality residential care for people with a learning disability and behaviour that challenges?

## Why this is important

The quality of residential care for people with a learning disability and behaviour that challenges remains an issue of national concern. Reviews (most recently of Winterbourne View Hospital) have identified failings in care. Although recommendations have been made this has not led to a significant and sustained improvement in care. It is important to understand how improvement can be maintained.

The question should be addressed by a programme of research that includes:

- a systematic review of the factors associated with sustained and beneficial change in health and social care organisations
- designing service-level interventions to support the implementation of standards of care developed from the systematic review
- testing the clinical and cost effectiveness of service-level interventions in residential units through the formal evaluation of a quality improvement programme established to introduce the new standards (the follow-up period should be for a minimum of 3 years after the implementation of the intervention).

# Finding more information and committee details

NICE has produced an [easy read version](#) of this guideline for people with a learning disability.

You can see everything NICE says on this topic in the [NICE Pathway on learning disabilities and behaviour that challenges](#).

To find NICE guidance on related topics, including guidance in development, see our [topic page for mental health and wellbeing](#).

For full details of the evidence and the guideline committee's discussions, see the [full guideline](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources](#) to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see [resources to help you put guidance into practice](#).

# Update information

## Minor changes since publication

**August 2020:** We have linked to the NICE guideline on supporting adult carers in recommendation 1.3.2. We have incorporated footnote text into the recommendations to meet accessibility requirements.

ISBN 978-1-4731-1232-2

## Accreditation

