

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

NICE guideline

Published: 28 May 2015

[nice.org.uk/guidance/ng11](https://www.nice.org.uk/guidance/ng11)

## Contents

Introduction .....	4
Safeguarding children .....	5
Safeguarding adults.....	5
Medication.....	5
Person-centred care .....	7
Key priorities for implementation .....	8
General principles of care.....	8
Support and interventions for family members or carers.....	9
Early identification of the emergence of behaviour that challenges.....	9
Assessment of behaviour that challenges.....	10
Psychological and environmental interventions .....	12
Medication.....	13
1 Recommendations .....	14
Children, young people and adults.....	14
Terms used in this guideline .....	14
1.1 General principles of care.....	16
1.2 Physical healthcare .....	21
1.3 Support and interventions for family members or carers .....	22
1.4 Early identification of the emergence of behaviour that challenges .....	23
1.5 Assessment of behaviour that challenges .....	24
1.6 Behaviour support plan.....	29
1.7 Psychological and environmental interventions.....	30
1.8 Medication .....	32
1.9 Reactive strategies.....	34
1.10 Interventions for coexisting health problems .....	36
1.11 Interventions for sleep problems .....	36
2 Research recommendations .....	37

2.1 Preventing behaviour that challenges from developing in children aged under 5 years with a learning disability .....	37
2.2 Interventions to reduce the frequency and extent of moderate to severe behaviour that challenges in community settings .....	38
2.3 Locally accessible care .....	39
2.4 Factors associated with sustained, high-quality residential care .....	39
3 Other information .....	41
3.1 Scope and how this guideline was developed.....	41
3.2 Related NICE guidance.....	41
4 The Guideline Development Group, National Collaborating Centre and NICE project team, and declarations of interests.....	43
4.1 Guideline Development Group .....	43
4.2 National Collaborating Centre for Mental Health .....	44
4.3 NICE project team .....	45
4.4 Declarations of interests .....	46
About this guideline .....	55
Strength of recommendations.....	55
Other versions of this guideline .....	56
Implementation .....	56
Your responsibility.....	57
Copyright.....	57

## Introduction

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.

## *Medication*

The guideline will assume that prescribers will use a medication's summary of product characteristics to inform decisions made with people offered medication (or their family members or carers, as appropriate).

This guideline recommends some medications for indications for which they do not have a UK marketing authorisation at the date of publication, if there is good evidence to support that use.

The prescriber should follow relevant professional guidance, taking full responsibility for the decision. The person offered the medication (or those with authority to give consent on their behalf) should provide informed consent, which should be documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information. Where recommendations have been made for the use of medicines outside their licensed indications ('off-label use'), these medicines are marked with a footnote in the recommendations.

## Person-centred care

This guideline offers best practice advice on the care of children, young people and adults with a learning disability and behaviour that challenges.

People who use health services and healthcare professionals have rights and responsibilities as set out in the [NHS Constitution for England](#) – all NICE guidance is written to reflect these. In addition, adults, [carers](#) and local authorities have rights and responsibilities set out in the [Care Act 2014](#) (the majority of which took effect from April 2015). Treatment and care should take into account individual needs and preferences. People who use health and social care services should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals and social care practitioners. If the person is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment. If it is clear that the child or young person fully understands the treatment and does not want their family or carers to be involved, they can give their own consent. Healthcare professionals should follow the [Department of Health's advice on consent](#). If someone does not have capacity to make decisions, healthcare professionals should follow the [code of practice that accompanies the Mental Capacity Act](#) and the supplementary [code of practice on deprivation of liberty safeguards](#).

NICE has produced guidance on the components of good patient experience in adult NHS services. All healthcare professionals should follow the recommendations in [patient experience in adult NHS services](#).

NICE has also produced guidance on the components of good service user experience. All healthcare professionals and social care practitioners working with people using adult NHS mental health services should follow the recommendations in [service user experience in adult mental health](#).

If a young person is moving between child and adult services, care should be planned and managed according to the best practice guidance described in the Department of Health's [Transition: getting it right for young people](#).

Adult and child health and social care teams should work jointly to provide assessment and services to young people with a learning disability and behaviour that challenges. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.

## Key priorities for implementation

The following recommendations have been identified as priorities for implementation. The full list of recommendations is in [section 1](#).

### *General principles of care*

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

- 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.



## Delivering effective care

- 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.

## *Support and interventions for family members or carers*

- 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.

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

- 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).

## *Assessment of behaviour that challenges*

### **The assessment process**

- 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.

## Risk assessment

- 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](#)).

## Functional assessment of behaviour

- 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.

## *Psychological and environmental interventions*

### **Interventions for behaviour that challenges**

- 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).

## *Medication*

- 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 Recommendations

The following guidance is based on the best available evidence. The [full guideline](#) gives details of the methods and the evidence used to develop the guidance.

The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation). See [about this guideline](#) for details.

### *Children, young people and adults*

This guideline covers people of all ages with a learning disability and behaviour that challenges. All recommendations relate to children, young people and adults unless specified otherwise. These terms are defined as follows:

- children: aged 12 years or younger
- young people: aged 13 to 17 years
- adults: aged 18 years or older.

### *Terms used in this guideline*

#### **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.

#### **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.

### 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)<sup>[1]</sup>. 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).

### 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, and explain how to get:
- a formal carer's assessment of their own needs (including their physical and mental health)
  - short breaks and other respite care.
- 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 15–20 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<sup>[2]</sup>.

---

<sup>[1]</sup> See the Royal College of General Practitioners' guide for GP practices on [annual health checks for people with a learning disability](#) for further information.

<sup>[2]</sup> At the time of publication (May 2015), melatonin did not have a UK marketing authorisation for use in people aged under 55 years for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

## 2 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and the care and treatment people receive in the future.

### 2.1 *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.

## 2.2 *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.

## 2.3 *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).

## 2.4 *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).



## 3 Other information

### 3.1 *Scope and how this guideline was developed*

NICE guidelines are developed in accordance with a [scope](#) that defines what the guideline will and will not cover.

#### How this guideline was developed

NICE commissioned the National Collaborating Centre for Mental Health to develop this guideline. The Centre established a Guideline Development Group (see [section 4](#)), which reviewed the evidence and developed the recommendations.

The methods and processes for developing NICE clinical guidelines are described in [the guidelines manual](#).

### 3.2 *Related NICE guidance*

Details are correct at the time of publication of the guideline (May 2015). Further information is available on the [NICE website](#).

#### Published

##### *General*

- [Medicines optimisation](#) (2015) NICE guideline NG5
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

##### *Condition-specific*

- [Violence and aggression](#) (2015) NICE guideline NG10
- [Psychosis and schizophrenia in adults](#) (2014) NICE guideline CG178
- [Autism: the management and support of children and young people on the autism spectrum](#) (2013) NICE guideline CG170

- [Antisocial behaviour and conduct disorders in children and young people \(2013\) NICE guideline CG158](#)
- [Psychosis and schizophrenia in children and young people \(2013\) NICE guideline CG155](#)
- [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum \(2012\) NICE guideline CG142](#)
- [Self-harm: longer term management \(2011\) NICE guideline CG133](#)
- [Autism diagnosis in children and young people \(2011\) NICE guideline CG128](#)
- [Common mental health disorders \(2011\) NICE guideline CG123](#)
- [Attention deficit hyperactivity disorder \(2008\) NICE guideline CG72](#)
- [Dementia \(2006\) NICE guideline CG42](#)
- [Self-harm \(2004\) NICE guideline CG16](#)

## Under development

NICE is [developing](#) the following guidance:

- Children's attachment. NICE guideline. Publication expected October 2015.
- Mental health problems in people with learning disabilities. NICE guideline. Publication expected September 2016.

## **4 The Guideline Development Group, National Collaborating Centre and NICE project team, and declarations of interests**

### **4.1 *Guideline Development Group***

#### **Glynis Murphy (Chair)**

Professor of Clinical Psychology and Disability, University of Kent; Co-Director, Tizard Centre, University of Kent

#### **David Allen**

Clinical Director, Positive Response Training and Consultancy; Professor, Tizard Centre, University of Kent

#### **David Branford**

Chief Pharmacist, Derbyshire Healthcare Foundation NHS Trust (retired)

#### **Alick Bush**

Lead Psychologist, St Andrew's Healthcare

#### **Carole Buckley**

GP, The Old School Surgery, Bristol

#### **Vivien Cooper**

Carer representative and Chief Executive Officer, The Challenging Behaviour Foundation

#### **Jo Dwyer**

Clinical Specialist Occupational Therapist, Lewisham Team for Adults with Learning Disabilities, Guy's and St Thomas' NHS Foundation Trust

#### **Angela Hassiotis**

Professor, University College London and Honorary Consultant Psychiatrist, Camden and Islington Foundation Trust

#### **Phil Howell**

Physical Interventions Accreditation Scheme Manager and Positive Behaviour Support Consultant, British Institute of Learning Disabilities

**Simon Jones**

Head of Behavioural Support, Care UK

**Richard Mills**

Research Director, Research Autism

**David Newton**

Team Manager, Adult Safeguarding Quality Assurance Team, Adult Social Care Directorate, Nottingham City Council

**Steve Noone**

Consultant Clinical Psychologist, Northumberland, Tyne and Wear Foundation NHS Trust

**Phil Perkins**

Senior Community Learning Disability Nurse for Children and Young People, Surrey and Borders Partnership NHS Foundation Trust

**Victoria Slonims**

Senior Consultant Speech and Language Therapist, and Honorary Senior Lecturer, Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust

**Keith Wyncoll**

Carer representative

## **4.2 *National Collaborating Centre for Mental Health***

**Steve Pilling**

Director

**Katherine Andrea**

Senior Project Manager

**David Glynn (from September 2014)**

Health Economist

**Bronwyn Harrison**

Systematic Reviewer

**Elena Marcus** (from August 2014)

Research Assistant

**Ifigeneia Mavranouzouli**

Senior Health Economist

**Cheryl Palmer**

Research Assistant

**Clare Taylor**

Senior Editor

**Craig Whittington** (from September 2014)

Associate Director (Clinical Effectiveness); Senior Systematic Reviewer

### **4.3** *NICE project team*

**Sarah Willett**

Guideline Lead

**Martin Allaby**

Clinical Adviser

**Clifford Middleton**

Guideline Commissioning Manager

**Rebecca Pye**

Guideline Coordinator

**Nichole Taske**

Technical Lead

**Bhash Naidoo**

Health Economist

**Katie Prickett**

Editor

## 4.4 Declarations of interests

The following members of the Guideline Development Group made declarations of interests. All other members of the Group stated that they had no interests to declare. The conflicts of interest policy (2007) was followed until September 2014, when an [updated policy](#) was published.

Member	Interest declared	Type of interest	Decision taken
Glynis Murphy (Chair)	Until October 2012 employed part-time by NHS. Conduct consultancy for NHS, police, lawyers. Co-editor Journal of Applied Research in Intellectual Disability. Member Care Quality Commission panel. Member National Offender Management Service accreditation panel.	Personal pecuniary interest	Declare and participate
Glynis Murphy (Chair)	Co-director Tizard Centre in receipt of grants (National Institute for Health Research/ charities). Tizard Centre training for staff from Learning Disabilities. Tizard Centre research grant; treatment of sexually abusive behaviour in young people with a learning disability.	Non-personal pecuniary interest	Declare and participate
Glynis Murphy (Chair)	Conducted own research into challenging behaviour. Chair Sexual Offender Treatment South East Collaborative-Intellectual Disability Immediate Past President International Association for the Scientific Study of Intellectual and Developmental Disabilities.	Personal non-pecuniary interest	Declare and participate

<p>Steve Pilling (Facilitator)</p>	<p>Medical Research Council, research funding looking at psilocybin.</p> <p>Grant from National Alliance for Research on Schizophrenia and Depression to look at transcranial direct-current stimulation in treatment of depression.</p>	<p>Personal family interest</p>	<p>Declare and participate</p>
<p>David Allen</p>	<p>Positive Response Training and Consultancy provides training to health and social care staff and families supporting people with learning disabilities and challenging behaviour. It uses an over-arching positive behaviour support model and provides training in both proactive, preventative strategies and reactive strategies. The physical intervention training component of the latter is accredited by the British Institute of Learning Disabilities.</p> <p>Editor of International Journal of Positive Behavioural Support.</p> <p>Collaborator in randomised controlled trial of Training in Positive Behavioural Support (Hassiotis, 2013).</p> <p>Joint applicant, Reduction in Anti-psychotic Medication in People with Learning Disability and Challenging Behaviour (Kerr, Felce 2013).</p>	<p>Personal pecuniary interest</p>	<p>Declare and participate</p>
<p>David Allen</p>	<p>Honorary Professor, University of Kent</p>	<p>Non-personal pecuniary interest</p>	<p>Declare and participate</p>
<p>David Allen</p>	<p>Member of various working groups set up as part of Positive and Safe Programme.</p> <p>Member of Positive and Safe Programme Board.</p> <p>Member of group that recently produced competence framework for positive behaviour support.</p>	<p>Personal non-pecuniary interest</p>	<p>Declare and participate</p>

David Brandford	<p>Development of guideline on dysphagia in learning disabilities supported by Rosemont Pharmaceuticals.</p> <p>Opinion on lisdexamphetamine supported by Pharmacy management.</p> <p>Opinion on lurasidone supported by Sunovion Pharmaceuticals.</p>	Personal pecuniary interest	Declare and participate
David Brandford	<p>PhD on antipsychotic drugs in learning disabilities.</p> <p>Chairman of the English Pharmacy Board of the Royal Pharmaceutical Society.</p> <p>Elected member of the College of Mental Health Pharmacy.</p> <p>Editor of Frith prescribing guidelines for adults with learning disability (no financial interest).</p>	Non-personal pecuniary interest	Declare and participate
Alick Bush	<p>Employed 0.6 whole time equivalent by St Andrews Healthcare, a charity that provides inpatient care to adults with learning disabilities and autism.</p> <p>Provides a clinical psychology service to patients in the hospital.</p>	Personal pecuniary interest	Declare and participate



<p>Alick Bush</p>	<p>Policy lead, British Psychological Society Faculty of Learning Disabilities – promoted the use of predominantly psychosocial interventions for adults who challenge services, including positive behaviour support.</p> <p>Until December 2014, Chair of the Learning Disabilities Professional Senate – an alliance of the Professional Bodies that provide support to people with learning disabilities. Representative of the Professional Senate on the Learning Disability Programme Board. On a range of sub-committees and working groups that are responsible for delivering the Transforming Care action plan following the Winterbourne View review. This includes being a member of the Expert Advisory Group on the promotion of positive behaviour support.</p> <p>Co-editor of Challenging Behaviour: a unified approach.</p> <p>Acted as a special advisor on a Care Quality Commission inspection.</p>	<p>Personal non-pecuniary interest</p>	<p>Declare and participate</p>
<p>Carole Buckley</p>	<p>Non-Executive Director GP Care (UK) Ltd. Private provider of NHS services to patients.</p> <p>Chair St Mathias holdings Ltd Practice based pharmacy offering services to residential care homes.</p>	<p>Personal pecuniary interest</p>	<p>Declare and participate</p>

---

<p>Carole Buckley</p>	<p>Member Royal College of General Practitioners intellectual disability professional network.</p> <p>Clinical Champion for Autism by the Royal College of General Practitioners.</p> <p>Joint recipient of a grant from Bristol University to implement focus groups for service users and carers in order to inform GP practice.</p> <p>Grant from the Academic Health Science Network South West to hold a conference in Taunton 19/11/14 for commissioners and providers of autism services.</p>	<p>Non-personal pecuniary interest</p>	<p>Declare and participate</p>
-----------------------	--	--	--------------------------------

<p>Vivien Cooper</p>	<p>Member, Transforming Care Assurance Board (formerly Winterbourne View Joint Improvement Board).</p> <p>Member, Engagement Steering Group for Joint Improvement team (from June 2014 formerly Chair).</p> <p>Respond Steering Group for support for Winterbourne View families.</p> <p>Department of Health Advocacy Group.</p> <p>Department of Health Medication Collaborative Group, Steering Group.</p> <p>Care Quality Commission Learning Disability Advisory Group.</p> <p>Hassiotis University College London Positive Behaviour Support Research Group.</p> <p>Tizard E-Pats Fellowship Steering Group.</p> <p>Chair, Challenging Behaviour National Strategy Group.</p> <p>Member, Council for Disabled Children Restrictive Physical Intervention Steering Group.</p> <p>Member, Department of Health Winterbourne View Capital Funding Panel.</p> <p>Member, Learning Disabilities Professional Senate.</p> <p>Member, School for Social Care Research User Carer Practitioner Reference Group.</p> <p>Member, Learning Disabilities Voluntary and Community Sectors Steering Group (July – November 2014).</p> <p>Member, Children and Young People Collaborative Steering Group.</p>	<p>Personal non-pecuniary interest</p>	<p>Declare and participate</p>
----------------------	--	--	--------------------------------

<p>Angela Hassiotis</p>	<p>Current National Institute for Health Research Health Technology Assessment grant on the evaluation of positive behaviour support.</p> <p>Honoraria received by Novartis for consultancy on treatments for Fragile X syndrome.</p> <p>Other research funding (National Institute for Health Research – Research for Patient Benefit).</p> <p>Associate Editor of Journal of Policy and Practice in Intellectual and Developmental Disabilities.</p> <p>Associate Editor of Journal of Applied Research in Intellectual Disabilities.</p> <p>Editorial Board of Advances in Mental Health Intellectual Disabilities.</p> <p>Treasurer Faculty of the Psychiatry of Intellectual Disabilities.</p> <p>Honoraria for lectures.</p> <p>Conducting a study looking at music therapy and people with a learning disability. Co-applicant on a National Institute for Health Research Health Technology Assessment funded study evaluating music therapy for children with autism.</p>	<p>Non-pecuniary interest</p>	<p>Declare and participate</p>
<p>Angela Hassiotis</p>	<p>Published on challenging behaviour for some years following research carried out under own supervision.</p>	<p>Personal non-pecuniary interest</p>	<p>Declare and participate</p>
<p>Simon Jones</p>	<p>Positive Range of Options to Avoid Crisis and use Therapy, Strategies for Crisis Intervention and Prevention (PROACT-SCIPr-UK) trainer, which is a British Institute of Learning Disabilities accredited physical intervention methodology.</p>	<p>Personal pecuniary interest</p>	<p>Declare and participate</p>

Richard Mills	<p>Research Director at Research Autism.</p> <p>AT-Autism (Autism Training Ltd) – Associate.</p> <p>London Borough of Redbridge – training in clinical interviewing techniques for Approved Mental Health Professionals when working with individuals with Asperger's syndrome and autism in conjunction with AT-Autism.</p> <p>Laskaridou Foundation Athens, Greece – Mentor teacher programme for children with autism and challenging behaviour in conjunction with AT-Autism.</p> <p>Associate, Tizard Centre, University of Kent at Canterbury – Curriculum development Social Work Training.</p>	Personal pecuniary interest	Declare and participate
Richard Mills	<p>Joint recipient of a grant from Bristol University to implement focus groups for service users and carers in order to inform GP practice.</p> <p>Staff training Jersey Employment Trust –through Research Autism.</p>	Non-personal pecuniary interest	Declare and participate
Richard Mills	<p>Fellow – Royal Society of Medicine.</p> <p>Member – International Society for Autism Research.</p> <p>Honorary Research Fellow at the Department of Psychology, University of Bath.</p> <p>Senior Research Fellow, Bond University, Queensland, Australia.</p> <p>Member – Northern Ireland Advisory Committee on Autism Research.</p>	Personal non-pecuniary interest	Declare and participate
David Newton	<p>Employed by a local authority; involves liaison with local authority and local clinical commissioning group contracts and commissioning groups and quality assurance. Some incidental input into local authority core contract and service specification content.</p>	Personal pecuniary interest	Declare and participate

Victoria Slonims	Autism Diagnostic Observation Schedule trainer.	Personal pecuniary interest	Declare and participate
Craig Whittington	Member of the scientific steering committee for a US company, Doctor Evidence Llc. Doctor Evidence is a specialty software platform and services company with clients from across the healthcare ecosystem. The role includes a share option (3 year vesting) and a meeting stipend.	Personal pecuniary interest	Declare and participate
Keith Wyncoll	Occasional trainer – The Challenging Behaviour Foundation. Lay member of NHS England Patient and Public Voice Assurance Group – Specialised Commissioning.	Personal pecuniary interest	Declare and participate

## About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions.

NICE guidelines are developed in accordance with a [scope](#) that defines what the guideline will and will not cover.

This guideline was developed by the National Collaborating Centre for Mental Health, which is based at the Royal College of Psychiatrists. The Collaborating Centre worked with a Guideline Development Group, comprising healthcare professionals (including consultants, GPs and nurses), carers and technical staff, which reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in [the guidelines manual](#).

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.

## *Strength of recommendations*

Some recommendations can be made with more certainty than others. The Guideline Development Group makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the Guideline Development Group is confident that, given the information it has looked at, most people would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

For all recommendations, NICE expects that there is discussion with the person about the risks and benefits of the interventions, and their values and preferences. This discussion aims to help them to reach a fully informed decision (see also [person-centred care](#)).

## **Interventions that must (or must not) be used**

We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

## **Interventions that should (or should not) be used – a 'strong' recommendation**

We use 'offer' (and similar words such as 'refer' or 'advise') when we are confident that, for the vast majority of people, an intervention will do more good than harm, and be cost effective. We use similar forms of words (for example, 'Do not offer...') when we are confident that an intervention will not be of benefit for most people.

## **Interventions that could be used**

We use 'consider' when we are confident that an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

## *Other versions of this guideline*

The full guideline, 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Mental Health.

The recommendations from this guideline have been incorporated into a [NICE pathway](#).

We have produced [information for the public](#) about this guideline.

NICE has produced an [Easy Read version](#) for people with a learning disability.

## *Implementation*

[Implementation tools and resources](#) to help you put the guideline into practice are also available.



## *Your responsibility*

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summaries of product characteristics of any drugs.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, 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 guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

## *Copyright*

© National Institute for Health and Care Excellence 2015. All rights reserved. NICE copyright material can be downloaded for private research and study, and may be reproduced for educational and not-for-profit purposes. No reproduction by or for commercial organisations, or for commercial purposes, is allowed without the written permission of NICE.

ISBN 978-1-4731-1232-2

## *Accreditation*

