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

NICE guideline

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If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

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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 support a person with a learning disability needs will depend 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 is essential.

Some people with learning disabilities display behaviour that challenges. ‘Behaviour that challenges’ is not a diagnosis and is used in this guideline to indicate that while such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability. This behaviour often results from the interaction between individual and environmental factors and includes aggression, self-injury, stereotypic behaviour, 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.

Behaviour that challenges is relatively common in people with a learning disability, and more common in 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). Behaviour that challenges may be more likely in people who have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems.

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. Some care environments increase the likelihood of behaviour that challenges. This includes those with limited social interaction and meaningful occupation, lack of choice and sensory input or excessive noise, those that are crowded, unresponsive or unpredictable, and those characterised by neglect and abuse.

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 at multiple levels (including the environmental level). The aim should always be to improve the person's overall quality of life.

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

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 challenging behaviour in children with a learning disability. Abuse may also coexist with challenging behaviour. 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.

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).

Person-centred care

This guideline offers best practice advice on the care of adults, children and young people with learning disabilities 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 takes 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 paediatric 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 paediatric 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.

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.

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 and their developmental stage
  - aim to provide support and interventions in the person's home, or as close to their home as possible, in the least restrictive setting
  - aim to prevent the development of future episodes of behaviour that challenges
  - offer support and interventions respectfully, and ensure that the focus is on improving the person's support 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. **[1.1.2]**

Team working

- 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 routine assessment and interventions have access to:
  - specialist assessment
  - specialist support and intervention services
  - advice, supervision and training to support the implementation of any care or intervention.

Specialist support and intervention services should include nurses, psychologists, psychiatrists, social workers, and speech and language therapists. Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists may also be involved. **[1.1.5]**

Support and interventions for family members or carers

- When providing support to family members or carers:
  - recognise the impact of 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. **[1.3.3]**

Early identification of the emergence of initial behaviour that challenges

- Be aware of the risk of behaviour that challenges when working with people with a learning disability and their family members or carers, and that it often develops gradually. Pay attention to factors that may increase this risk, including:
  - personal factors, such as
    - a severe learning disability
    - autism
    - communication difficulties (expressive or 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 sensory stimulation and those with low engagement levels
- ◊ 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. **[1.4.1]**

Assessment

The assessment process

- When assessing behaviour that challenges ensure that:
  - the person and their family members or carers are engaged in the assessment process
  - the complexity and duration of the assessment is proportionate to the severity, impact, frequency and duration of the behaviour
  - everyone involved in delivering an assessment understands the criteria for moving to more complex and intensive assessment
  - the person being assessed remains at the centre of concern and is supported throughout the process
  - all individual and environmental factors that may lead to behaviour that challenges are taken into account
  - assessment is a flexible rather than fixed process, because factors that trigger and maintain behaviour may change over time
  - assessments are repeated after any change in behaviour
  - assessment is outcome focused
  - the resilience and resources of family members and carers are assessed
  - the capacity, sustainability and commitment of the staff delivering the behaviour support plan (see recommendation 1.5.13) are assessed. **[1.5.2]**

Risk assessment

- Assess the following risks during any assessment of behaviour that challenges:
  - self-harm (in particular in people with depression) and self-injury

- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others
- rapid escalation of the behaviour that challenges or level of risk.

Ensure that the behaviour support plan includes risk management (see recommendation 1.5.13). **[1.5.7]**

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 graduated approach as set out below.
  - 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.
  - Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
  - 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.

- If the behaviour poses a risk to the person or others, carry out a risk assessment (see recommendation 1.5.7). **[1.5.12]**

Psychosocial, psychological and environmental interventions

Interventions for behaviour that challenges

- Consider personalised psychosocial interventions that are based on behavioural principles and a functional assessment of behaviour, 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 escape-motivated behaviours and providing a person's preferred member of staff).
  - addressing staff and family member or carer responses to behaviour that challenges
  - clearly defined intervention strategies
  - 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). **[1.6.5]**

Medication

- Consider medication for people with a learning disability and behaviour that challenges if:
  - the person has a coexisting mental or physical health problem (see recommendation 1.9.1) **or**
  - psychosocial, psychological or other interventions alone do not produce change within the specified time **or**
  - the risk to the person or others is very severe.

Only offer medication in combination with psychosocial, psychological or other interventions. **[1.7.1]**

1 Recommendations

The following guidance is based on the best available evidence. The full guideline [hyperlink to be added for final publication] gives details of the methods and the evidence used to develop the guidance.

Adults, children and young people

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

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

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.

Expressive communication The ability to express thoughts using words and sentences, in a way that makes sense and is grammatically accurate.

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 (heard or read).

Reinforcer A reward that follows 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. It usually occurs in people with a severe learning disability. It may indicate 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 therapists, nurses, occupational therapists, physiotherapists), care workers in a variety of settings (including residential homes, supported living settings and day services) and teachers.

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 doing them (for example, to provide sensory stimulation).

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 people 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 (environmental, psychosocial, psychological and pharmacological) and services available to them, in an appropriate language or format (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 and what maintains it
- 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 and their developmental stage
- aim to provide support and interventions in the person's home, or as close to their home as possible, in the least restrictive setting
- aim to prevent the development of future episodes of behaviour that challenges
- offer support and interventions respectfully, and ensure that the focus is on improving the person's support 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 delivering support and interventions for people with a learning disability and behaviour that challenges (including family members and carers) should understand:

- the nature, development and course of learning disabilities
- individual and environmental factors related to the development and maintenance of behaviour that challenges
- that behaviour that challenges is communicating 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.

Team working

1.1.4 Health and social care provider organisations should ensure that the assessment and management of behaviour that challenges in people with a learning disability are undertaken by teams that have skills and competencies in routine assessment and intervention methods.

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 routine assessment and interventions have access to:

- specialist assessment
- specialist support and intervention services
- advice, supervision and training to support the implementation of any care or intervention.

Specialist support and intervention services should include nurses, psychologists, psychiatrists, social workers, and speech and language therapists. Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists may also be involved.

Staff training and supervision

1.1.6 All staff working with people with a learning disability and behaviour that challenges should be 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
- developing 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.

Training should also include delivering reactive strategies to manage behaviour that is not preventable.

1.1.7 All interventions for people with learning disabilities and behaviour that challenges should be 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 manuals
- use routine sessional outcome measures (for example, the Adaptive Behaviour Scale and the Aberrant Behaviour Checklist)
- take part in monitoring and evaluating adherence to interventions and practitioner competence (for example, by using

Periodic Service Review methods, video and audio recording, and external audit and scrutiny).

Delivering effective care

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

1.1.8 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 levels of the care pathways)
- focused on outcomes (including measures of quality, service-user experience and harm).

1.1.9 A designated leadership team of primary and secondary care professionals, managers and commissioners 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.

1.1.10 Primary and secondary care professionals, managers and commissioners should work together to design care pathways that promote a range of evidence-based interventions at each step and support people in their choice of interventions.

1.1.11 Primary and secondary care professionals, managers and commissioners 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.

1.1.12 Primary and secondary care professionals, managers and commissioners should work together to design care pathways that provide an integrated programme of care across both primary and secondary 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.

1.1.13 Primary and secondary care professionals, managers and commissioners 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 professionals (including GPs)

- with all the services provided in the care pathway
- with services outside the care pathway.

1.2 Physical healthcare

1.2.1 Offer an annual physical health check to people with a learning disability in all settings. Carry out the physical health check together with a family member, carer or healthcare professional or social care practitioner who knows the person. Ensure that it takes into account any known or emerging behaviour that challenges and how it may be linked to any physical health problems, and contains:

- a physical health review
- a review of all current health interventions, including medication and any side effects
- an agreed and shared care plan for managing any physical health problems.

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 the person with a learning disability and behaviour that challenges. Give them information about support and interventions in an appropriate language and format, including NICE's 'Information for the public'.

1.3.2 Advise family members or carers about their right to a formal carer's assessment of their own needs (including their physical and mental health) and explain how to obtain it.

1.3.3 When providing support to family members or carers:

- recognise the impact of 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.

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 initial behaviour that challenges

1.4.1 Be aware of the risk of behaviour that challenges when working with people with a learning disability and their family members or carers, and that it often develops gradually. Pay attention to factors that may increase this risk, including:

- personal factors, such as
  - a severe learning disability
  - autism
  - communication difficulties (expressive or 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 sensory stimulation and those with low engagement levels

- 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.

1.4.2 Consider changing the physical and social environment to prevent the development, exacerbation or maintenance of behaviour that challenges.

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

1.5 Assessment

The assessment process

1.5.1 When assessing behaviour that challenges in people with a learning disability, follow a graduated approach (see recommendations 1.5.4–1.5.12). Aim to gain a functional understanding of why the behaviour occurs and develop a behaviour support plan (see recommendation 1.5.13) as soon as possible.

1.5.2 When assessing behaviour that challenges ensure that:

- the person and their family members or carers are engaged in the assessment process
- the complexity and duration of the assessment is proportionate to the severity, impact, frequency and duration of the behaviour
- everyone involved in delivering an assessment understands the criteria for moving to more complex and intensive assessment
- the person being assessed remains at the centre of concern and is supported throughout the process

- all individual and environmental factors that may lead to behaviour that challenges are taken into account
- assessment is a flexible rather than fixed process, because factors that trigger and maintain behaviour may change over time
- assessments are repeated after any change in behaviour
- assessment is outcome focused
- the resilience and resources of family members and carers are assessed
- the capacity, sustainability and commitment of the staff delivering the behaviour support plan (see recommendation 1.5.13) are assessed.

1.5.3 Explain how the person and their family members or carers 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, including a teacher, has concerns about behaviour, carry out an 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, including a teacher
- an explanation of the individual 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, including a teacher

- the role of the service, staff or family in developing or maintaining the behaviour.

Consider using a formal rating scale (for example, the Aberrant Behaviour Checklist) to provide baseline levels for the behaviour and a scale (such as the Functional Analysis Screening Tool) to understand its function.

1.5.5 As part of initial assessment of behaviour that challenges, take into account:

- developmental history
- any previous interventions for behaviour that challenges
- social and interpersonal history, including relationships with family members, carers or staff, including teachers
- the person's abilities and needs (in particular, their expressive and receptive communication)
- recent life events
- any physical or mental health problems, and the effect of prescribed and other medication
- the person's sensory sensitivities, 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 organised 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, the function of the behaviour and what maintains it. Use this to develop a behaviour support plan (see recommendation 1.5.13).

Risk assessment

1.5.7 Assess the following risks during any assessment of behaviour that challenges:

- self-harm (in particular in people with depression) and self-injury
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation or abuse by others
- rapid escalation of the behaviour that challenges or level of risk.

Ensure that the behaviour support plan includes risk management (see recommendation 1.5.13).

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 a further assessment, integrated with an assessment of need. Carry out a functional assessment (see recommendations 1.5.10–1.5.12) and identify and evaluate any factors that may provoke or maintain the behaviour. Consider including the following in the further assessment:

- any physical health problems
- the social environment (including contact and relationships with friends, family members, carers and staff, including teachers)
- the physical environment, including sensory needs and any restrictions imposed by the environment
- any coexisting mental health problems
- response to previous or current treatment for a mental or physical health problem or intervention for behaviour that challenges, including side effects of medication
- receptive and expressive communication problems
- life history, including any history of trauma or abuse
- current functioning at home, in education or in the care environment

- neurodevelopmental problems (including the severity of the learning disability and the presence of autism or other behavioural phenotypes)
- sensory abnormalities or sensitivities (for example, to heat, light, noise, smell or touch)
- changes to routine or personal circumstances.

Consider using formal (for example, the Adaptive Behaviour Scale or the Aberrant Behaviour Checklist) and idiographic (personalised) measures to assess the severity of the behaviour and the progress of any intervention.

1.5.9 After further assessment, develop a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and what maintains it. Use this with the functional assessment of behaviour to develop a behaviour support plan (see recommendation 1.5.13).

Functional assessment of behaviour

1.5.10 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.

1.5.11 Include the following in all functional assessments:

- a baseline measure of current behaviour, and its frequency and intensity, and repeated measurements in order to evaluate change
- measures taken using direct observations and scales such as the Aberrant Behaviour Checklist and self-reporting
- a baseline measure 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.

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

- 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.
- Carry out pre-assessment data gathering to help shape the focus and level of the assessment.
- 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.

- If the behaviour poses a risk to the person or others, carry out a risk assessment (see recommendation 1.5.7).

Behaviour support plan

1.5.13 If the behaviour that challenges continues after assessment, develop a behaviour support plan based on a shared understanding about the function of the behaviour and what maintains it. This should:

- identify proactive strategies designed to stop the conditions likely to promote behaviour that challenges, including changing the environment (for example, reducing noise, increasing predictability) and promoting active engagement through structured and personalised daily activities, including 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 secondary prevention 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 1.8), 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 monitored using data collection and reviewed regularly
- identify any training for family members, carers or staff to improve their understanding of behaviour that challenges in people with a learning disability.

1.6 Psychosocial, psychological and environmental interventions

Primary and secondary prevention

1.6.1 Consider parent-training programmes for parents or carers of children with a learning disability who are aged under 12 years and at risk of developing behaviour that challenges.

1.6.2 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 the parent or carer's home or other community-based settings with childcare facilities)
- focus on developing communication and social functioning
- typically consist of 8 to 12 sessions lasting 90 minutes
- follow a developer's manual
- employ materials to ensure consistent implementation of the programme.

1.6.3 Consider preschool classroom-based interventions for children aged 3–5 years.

1.6.4 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 teachers.

Interventions for behaviour that challenges

1.6.5 Consider personalised psychosocial interventions that are based on behavioural principles and a functional assessment of behaviour, 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 escape-motivated behaviours and providing a person's preferred member of staff)
- addressing staff and family member or carer responses to behaviour that challenges
- clearly defined intervention strategies
- 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).

1.6.6 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.

1.6.7 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.

1.6.8 Consider developing 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.

1.7 Medication

1.7.1 Consider medication for people with a learning disability and behaviour that challenges if:

- the person has a coexisting mental or physical health problem (see recommendation 1.9.1) **or**
- psychosocial, psychological or other interventions alone do not produce change within the specified time **or**
- the risk to the person or others is very severe.

Only offer medication in combination with psychosocial, psychological or other interventions.

1.7.2 When prescribing medication for behaviour that challenges, take into account side effects and develop a care plan that includes:

- a rationale for medication, explained to family members and carers
- how long the medication should be taken for
- a strategy for reviewing the prescription and stopping the medication.

1.7.3 Consider antipsychotic medication for behaviour that challenges if psychological or other interventions are insufficient or cannot be delivered alone because of the severity of risk to self or others. Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist, or a neurodevelopmental paediatrician with expertise in learning disabilities) who should:

- identify the target behaviour
- decide on a measure to monitor effectiveness (for example, direct observations, the Aberrant Behaviour Checklist or the Adaptive Behaviour 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
- 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
- not prescribe p.r.n. (as-needed) medication for more than 4 weeks
- review the medication if the person's environmental or personal circumstances change.

1.7.4 When choosing which antipsychotic medication to offer, take into account side effects, acquisition costs, the person's preference (or that of their family member or carer, if appropriate) and response to previous antipsychotic medication.

1.7.5 If there is a positive response to antipsychotic medication:

- 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 offer medication that has proven benefit.

1.7.6 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.

1.7.7 For the use of rapid tranquillisation, follow the NICE guideline on violence and aggression (update in progress; publication expected May 2015).

1.8 Reactive strategies

1.8.1 Only use reactive strategies for people with a learning disability and behaviour that challenges as a last resort and together with the proactive interventions described in section 1.6. When risks to self or others are significant or breakdown in the person's living arrangements is very likely, consider using reactive strategies as an initial intervention and introduce proactive interventions once the situation stabilises.

1.8.2 Plan reactive strategies from an ethically sound basis and use a graded approach that considers the least aversive and restrictive alternatives first. Encourage the person and their family members or carers to be involved in planning and reviewing reactive strategies whenever possible.

1.8.3 If a restrictive intervention is used as part of a reactive strategy, 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
- any known biomechanical risks, such as cardiovascular and musculoskeletal risks
- any sensory sensitivities, such as a high or low threshold for pain or touch.

1.8.4 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.

1.8.5 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.

1.8.6 Regularly review and reassess the safety, efficacy, frequency of use and continued need for reactive strategies. 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.

1.9 Interventions for coexisting health problems

1.9.1 Offer people with a learning disability and behaviour that challenges interventions for any coexisting mental or physical health problems in line with the relevant NICE guideline for that condition. 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.

1.10 Interventions for sleep problems

1.10.1 Consider behavioural interventions for sleep problems in people 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.

1.10.2 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.

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. The Guideline Development Group's full set of research recommendations is detailed in the full guideline. [hyperlink to be added for final publication]

2.1 Preventing the development of behaviour that challenges 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 the onset of behaviour that challenges in children aged under 5 years at risk of behaviour that challenges
- testing 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
- testing the implementation of the interventions in routine care.

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

Are applied behavioural analysis interventions and antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges in 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 behavioural analysis or antipsychotic medication, or a combination of these. 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 the assessment of 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)
- testing 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 residential 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 residential placements would be beneficial and reduce costs but there is no strong empirical evidence to support this.

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

- a needs assessment and the care costs of a representative national 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 meet
  - the nature of the residential environments

  - the support, including specialist staff, needed
- testing the clinical and cost effectiveness of 'close to home' residential placements that meet the developed standards (compared with consecutive cohorts in out-of-area placements)
- establishing a national register of people who need out-of-area placement.

2.4 Factors associated with sustained, high-quality residential care

What factors (including service 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 these factors
- testing the clinical and cost effectiveness of sustainable service-level interventions in a randomised controlled trial of residential units that are identified as performing poorly or well (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 consultation on the guideline (December 2014). Further information is available on the NICE website.

Published

General

- 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

- 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.

- 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.
- Attention deficit hyperactivity disorder (2008) NICE guideline CG72.
- Violence (2005) NICE guideline CG25.
- Self-harm (2004) NICE guideline CG16.

Under development

NICE is developing the following guidance:

- Violence and aggression (update). NICE guideline. Publication expected May 2015.
- Children's attachment. NICE guideline. Publication expected October 2015.
- Mental health problems in people with learning disabilities. NICE guideline. Publication expected September 2016.

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