

Learning disabilities and behaviour that challenges overview

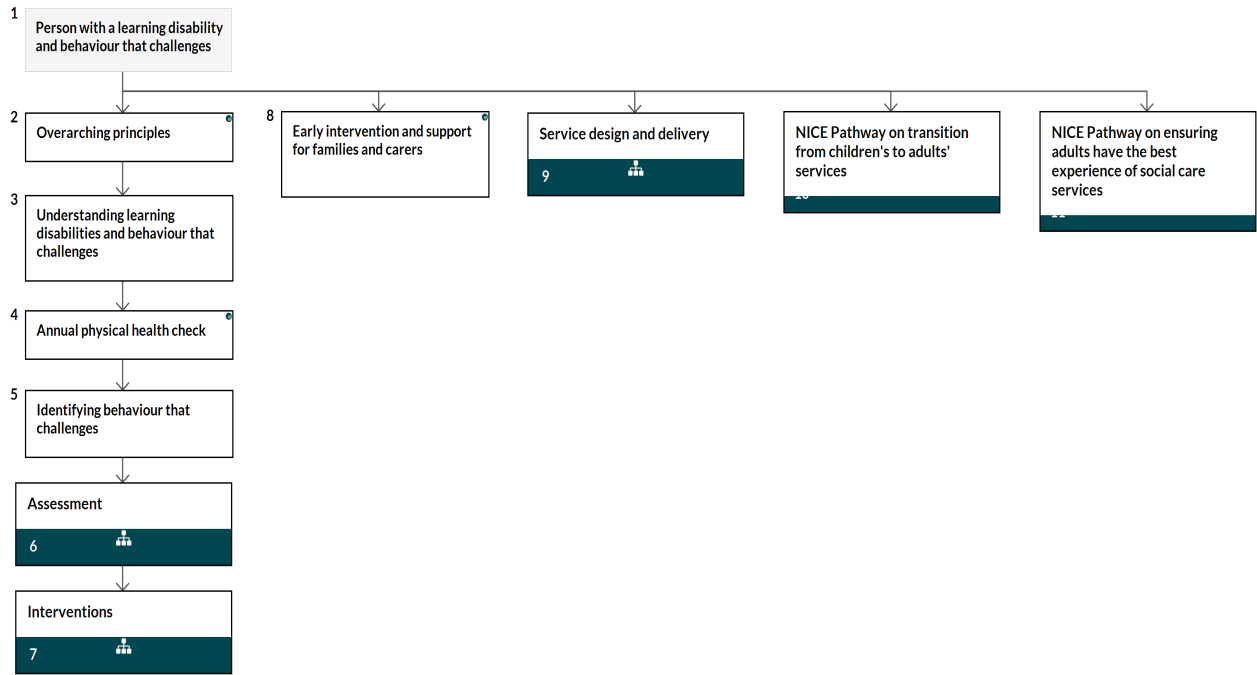
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/learning-disabilities-and-behaviour-that-challenges>

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This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Person with a learning disability and behaviour that challenges

No additional information

2 Overarching principles

Involving people with a learning disability and behaviour that challenges

Practitioners working with children, young people and adults and their families and carers

Practitioners working with children, young people and adults with a [learning disability](#) [See page 12] and behaviour that challenges, and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services.

Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the [Mental Capacity Act 2005](#).

Assess whether a child or young person under the age of 16 is Gillick competent and work in partnership with all children and young people. Include them in decisions about their treatment and ask them how they would like their families or carers to be involved.

Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the [Mental Capacity Act 2005](#). This should be done unless there is a compelling reason not to (for example, if there are safeguarding concerns).

Support children, young people and adults with a learning disability and behaviour that challenges to live where and how they want. Give them support that:

- is person-centred, reflecting their individual needs and choices, and maximising their control
- helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do
- takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history
- respects their cultural, religious and sexual identity

- helps them before problems occur or as soon as they emerge, not just when crisis has been reached
- encourages people to speak out if they have any worries
- promotes continuity of relationships.

Find out children, young people and adults' information and communication needs, record them and share this information with everyone working with them in line with the [Accessible Information Standard](#).

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.

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 (see [the NICE Pathway on multimorbidity](#))
- 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.

Commissioners and practitioners working with children, young people and adults

Ensure that people with a learning disability and behaviour that challenges have access to speech and language therapy when they need it.

Advocacy

Local authorities

Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum, it must be offered by local authorities as described in the [Care Act 2014](#), [Mental Capacity Act 2005](#) and [Mental Health Act 2007](#).

Ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services.

See also recommendations on independent advocacy in relation to inpatient admissions in [making the right use of inpatient services](#).

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Learning disability: behaviour that challenges

9. Housing

3 Understanding learning disabilities and behaviour that challenges

Everyone involved in commissioning or delivering support and interventions for people with a

[learning disability \[See page 12\]](#) 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.

4 Annual physical health check

GPs should offer an annual physical health check to children, young people and adults with a [learning disability \[See page 12\]](#) in all settings, using a standardised template (such as the Cardiff health check template). This should be carried out together with a family member, carer or healthcare professional or social care practitioner who knows the person and include:

- a review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems
- a physical health review
- a review of all current health interventions, including medication and related side effects, adverse events, drug interactions and adherence
- an agreed and shared care plan for managing any physical health problems (including pain).

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

See also [early detection: annual health check in the NICE Pathway on mental health problems in people with learning disabilities](#).

Hearing assessments

Consider referring people with a diagnosed learning disability to an audiology service for a hearing assessment when they transfer from child to adult services, and then every 2 years.

See [the NICE Pathway on hearing loss](#).

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Learning disability: behaviour that challenges

2. Annual health check

Learning disabilities: identifying and managing mental health problems

2. Annual health check

5 Identifying behaviour that challenges

Everyone involved in caring for and supporting children, young people and adults with a [learning disability \[See page 12\]](#) (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 (see [the NICE Pathway on autism spectrum disorder](#))
 - dementia (see [the NICE Pathway on dementia](#))
 - communication difficulties (expressive communication and receptive communication)
 - 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).

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.

6 Assessment

[See Learning disabilities and behaviour that challenges / Assessing behaviour that challenges shown by people with learning disabilities](#)

7 Interventions

[See Learning disabilities and behaviour that challenges / Interventions for people with learning disabilities and behaviour that challenges](#)

8 Early intervention and support for families and carers

Involve family members or carers in developing and delivering the support and intervention plan for children, young people and adults with a [learning disability \[See page 12\]](#) 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](#).

Advise family members or carers about their right to carer assessment, and assessment for respite care and other support (see [the NICE Pathway on supporting adult carers](#) for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and 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.

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.

Local authorities

Ensure that families and carers of children, young people and adults with a learning disability and behaviour that challenges are given support that helps them to:

- manage their role as carers
- care for the person and meet their needs, in relation to behaviour, care and support, communication, physical health, mental health, educational needs or any offending behaviour
- access support from specialist services when needed.

Provide information, guidance and ongoing support for families and carers of children, young people and adults with a learning disability and behaviour that challenges, which address different aspects of their life. Sources of support could include:

- peer support
- parent and carer groups or forums
- email support
- individual phone and face-to-face support
- family networks
- independent advocacy
- managed email networks (a shared discussion forum)
- social media groups.

Give family members and carers information listed above. This could be in the form of a 'welcome pack'. Provide this information:

- at the first point of contact with families
- through the local authority website, local libraries and universal services such as GP

- surgeries.

Named worker

Help people and their families to understand information about available support (see recommendation above) from first contact onwards.

Advise family members and carers how to access:

- short break services
- specialist behaviour support
- training as set out in recommendations about parent-training programmes in [psychological and environmental interventions](#)
- support in an emergency
- community resources, including voluntary organisations, networks and support groups
- local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.

Ensure that family members and carers have information such as contact details of staff and key dates and appointments.

For more recommendations on services for children and young people see [making the right use of residential placements for children and young people](#), [organising effective care and support](#) and [services for children and young people](#).

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Learning disability: behaviour that challenges

8. Services in the community

9 Service design and delivery

See [Learning disabilities and behaviour that challenges / Learning disabilities and behaviour that challenges: service design and delivery](#)

10 NICE Pathway on transition from children's to adults' services

[See Transition from children's to adults' services](#)

11 NICE Pathway on ensuring adults have the best experience of social care services

[See People's experience in adult social care services](#)

A learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

A person's learning disability may be described as mild, moderate, severe or profound. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

Glossary

Adults

(aged 18 and over)

Behaviour that challenges

(behaviour of such an intensity, frequency or duration that the physical safety of the person, or others around them, is likely to be placed in serious jeopardy; it also includes behaviour that is likely to severely limit or deny access to and use of ordinary community facilities)

Carers

(people who provide informal care and support to a child, young person or adult with a learning disability (it does not cover staff who are paid to provide care or support))

Children

(aged 12 and under)

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))

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))

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)

Short break

(also known as respite care, these involve a person with care and support needs spending regular short periods away from their main carer, to give the carer a break and the person a chance to do something different (these breaks may take place in the person's own home, in the home of an approved carer or in a residential placement))

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))

Young people

(aged 13 to 17)

Sources

[Hearing loss in adults: assessment and management](#) (2018) NICE guideline NG98

Learning disabilities and behaviour that challenges: service design and delivery (2018) NICE guideline NG93

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (2015) NICE guideline NG11

Your responsibility

Guidelines

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

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

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

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the

recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

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

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart 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.

Commissioners and/or providers have a responsibility to implement the recommendations, 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 interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

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