

# Learning disabilities and behaviour that challenges: service design and delivery

NICE guideline

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## Your responsibility

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

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

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

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This guideline should be read in conjunction with NG11.

## Overview

This guideline covers services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. It aims to promote a lifelong approach to supporting people and their families and carers, focusing on prevention and early intervention and minimising inpatient admissions.

This guideline should be read alongside the NICE guideline on [challenging behaviour and learning disabilities: prevention and interventions](#).

NICE has produced an [EasyRead version](#) and video for people with a learning disability.

## Who is it for?

- Commissioners and providers of health and social care services for children, young people and adults with a learning disability and behaviour that challenges
- Health and social care practitioners working with children, young people and adults with a learning disability and behaviour that challenges
- Providers of related services, including housing, education, employment and criminal justice services
- Practitioners working with children, young people and adults with a learning disability and behaviour that challenges in other services or settings, including education, housing, voluntary and community services, employment and criminal justice services
- Children, young people and adults with a learning disability and behaviour that challenges and their families and carers, including people who pay for their own care

## Context

### *Background*

An estimated 1.2 million children, young people and adults in England have a learning disability, and of these it is estimated that 10–17% display behaviour that challenges ([Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour](#) Allen et al. 2007). A more recent report suggested that there are over 40,000 children with learning disabilities who display behaviour that challenges ([Estimating the number of children with learning disabilities in England whose behaviour challenges](#) Emerson et al. 2014). In addition, approximately 1% of the adult population has an autism spectrum condition and 60–70% of these also have a learning disability ([Estimating the prevalence of autism spectrum conditions in adults](#) Brugha et al. 2012).

The most commonly used definition of behaviour that challenges is: 'behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities' (Emerson et al. 1987<sup>[1]</sup>). Later definitions have highlighted the role of cultural context in determining whether behaviour is perceived as challenging (Emerson 1995<sup>[2]</sup>).

This guideline was developed in a context of changes to policy and practice for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. The support needs of these vulnerable groups were set out in 1992 in the Mansell report<sup>[3]</sup>, which identified the need to invest in developing local services with appropriate levels of skilled staff to meet people's needs. This was restated in a later review, the so-called 'Mansell 2 report' ([Services for people with learning disabilities and challenging behaviour or mental health needs](#) Department of Health), which also highlighted the increased use of placements away from people's homes.

The exposure of widespread abuse at Winterbourne View hospital in 2011 led to a review of care provided in this hospital, and across England more widely, for people with a learning disability and behaviour that challenges. The resulting report [Transforming care: a national response to Winterbourne View hospital](#) (Department of Health) started a programme of work to improve services for people with a learning disability or autism who also have mental health conditions or behaviours described as challenging. In particular, this aimed to shift emphasis from inpatient care in mental health hospitals towards care based on people's individual needs and wishes and those of their families, provided by general and specialist services in the community. The programme did not

meet its original targets, as highlighted in a report by the National Audit Office ([Care services for people with learning disabilities and challenging behaviour](#)), and was reconfigured in 2015.

The 'transforming care programme' is now led jointly by NHS England, the Association of Directors of Adult Social Services, the Care Quality Commission, Local Government Association, Health Education England and the Department of Health. The national plan [Building the right support](#) (2015) included plans for 48 'transforming care partnerships' to pilot new arrangements of services. The national plan was followed by NHS England's [national service model](#) (October 2015) that set out the range of support that should be in place no later than March 2019. To support implementation of the interim service model, NHS England developed 3 [Model service specifications](#) (January 2017) and supplementary guidance on [Developing support and services for children and young people with a learning disability, autism or both](#) (September 2017). This guidance also supports the recommendations of [Dame Christine Lenehan's review](#) (January 2017) on providing care and support for children and young people with complex needs who display challenging behaviour.

### *The aim of this guideline*

This guideline takes into account the direction of travel in the transforming care programme. It complements this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges to live their lives in the community like everyone else.

It is based on evidence about effectiveness and cost effectiveness of different support and services, and how those services are coordinated. It is also informed by the views of people who use services and their families on what is important to them in their care and support.

### *What is the status of this guidance?*

The application of the recommendations in this guideline is not mandatory. Although there is no legal obligation to implement our guidance, health and social care practitioners, and practitioners in related services, are actively encouraged to follow our recommendations to help them deliver the highest-quality care.

## *How does it relate to legal duties and other guidance?*

This guideline complements statutory duties and good practice as set out in relevant legislation and guidance. The recommendations cross-refer to legislation and other guidance where appropriate.

Relevant legislation and guidance includes:

- [Accessible Information Standard](#)
- [Autism Act 2009](#)
- [Care Act 2014](#) and associated guidance
- [Children Act 1989](#) and associated guidance
- [Children and Families Act 2014](#)
- [Children and Young Peoples Act 2008](#)
- [Chronically Sick and Disabled Persons Act 1970](#)
- [Human Rights Act 1998](#)
- [Mental Health Act 1983, 2007](#)
- [Mental Capacity Act 2005](#) (amended 2007) and associated guidance on [Deprivation of liberty safeguards](#).

## *How has it been developed?*

The guideline has been developed by a committee of people who use services; family members and carers of children, young people and adults with a learning disability who display behaviour that challenges; and professionals. It has used information from an extensive review of research evidence, and from expert witnesses. The development followed the methods outlined in [developing NICE guidelines: the manual](#) and the [interim methods guide for developing service guidance](#) (2014).

Equality and diversity issues have been considered throughout the development of the guideline. The committee also gave careful consideration to the potential resource impact of the recommendations.



## More information

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

To find out what NICE has said on topics related to this guideline, see our web page on [people with learning disabilities](#).

See also the guideline committee's discussion and the evidence reviews (in the [full guideline](#)), and information about [how the guideline was developed](#), including details of the committee.

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<sup>[1]</sup> Emerson E et al. (1987) Developing services for severe learning difficulties and challenging behaviours. Canterbury: Institute of Social and Applied Psychology. University of Kent.

<sup>[2]</sup> Emerson E (1995) Challenging behaviour: analysis and intervention in people with learning disabilities. Cambridge: Cambridge University Press.

<sup>[3]</sup> Mansell Report (1992) Services for people with learning disabilities and challenging behaviour or mental health needs. Report of a project group (Chairman: Professor JL Mansell). HMSO, London.

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [your care](#).

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

## *Aims and principles*

This guideline is based on the principle that children, young people and adults with a [learning disability](#) and [behaviour that challenges](#) should have the support they need to live where and how they want. It will help local areas shift their focus towards prevention and early intervention, enabling children, young people and adults to live in their communities, and increasing support for families and carers. This should reduce the need for people to move away from their home or community for care, education or treatment.

The guideline recommends ways of designing and delivering services that aim to:

- help people to have a good quality of life
- support people to have good physical and mental health and emotional wellbeing
- maximise people's choice and control
- promote person-centred care and support
- help children, young people and adults 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
- respect people's cultural, religious and sexual identity
- identify when children, young people and adults are at risk of developing behaviour that challenges, so that support can be offered as early as possible
- promote continuity of relationships
- take a 'whole life' approach.

## 1.1 *Achieving change: strategic planning and infrastructure*

### Local leadership

#### *Recommendations for local authorities and clinical commissioning groups*

- 1.1.1 Local authorities and clinical commissioning groups should jointly designate a lead commissioner to oversee strategic commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.
- 1.1.2 Ensure that the lead commissioner:
- plans and oversees joined-up commissioning arrangements
  - has in-depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services
  - plans services that take a 'whole life' approach from early childhood onwards and enable smooth transitions.

### Joint commissioning and funding

#### *Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)*

- 1.1.3 The lead commissioner should ensure that budgets and other resources are pooled to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges. These should be pooled:
- across health, social care and education and
  - with neighbouring authorities.
- 1.1.4 Consider jointly commissioning the most specialised behaviour support services across areas for children, young people and adults with particularly complex needs.

- 1.1.5 Ensure that funding mechanisms for service providers support creative and flexible community-based responses, for example, a contingency fund that service providers can draw on quickly if there is a crisis.

## Planning and delivering services according to local need

### *Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)*

- 1.1.6 Ensure that service planning and delivery is based on an assessment of current and future service needs using:
- the local population prevalence of learning disabilities in children, young people and adults and the proportion who are likely to display behaviour that challenges
  - an analysis of assessed needs in education, health and social care plans, to provide an early view of likely service needs and enable prevention and early intervention
  - other sources of information, such as registers of people at risk of admission and other dynamic risk data; disabled children's registers; and records of referrals from liaison and diversion teams, youth offending teams and police.
- 1.1.7 Ensure that services are planned and delivered in a way that:
- is co-produced with children, young people and adults using services and their families, carers and independent advocates
  - enables person-centred planning and provision
  - addresses the needs of different age groups but also takes a 'whole life' approach to planning
  - includes planning for a range of future housing and employment support needs
  - integrates health, social care and other relevant services.
- 1.1.8 Develop local and regional plans that have a single care pathway and point of access for children, young people and adults with a learning disability and behaviour that challenges, and their families and carers. Make sure this is reflected in local authorities' commissioning strategies and key documents such as the Market Position Statement.

For further information on how to develop care pathways, see [organising effective care](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

## Managing risk

### *Recommendation for local authorities and clinical commissioning groups*

- 1.1.9 Take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person.

## Quality assurance

### *Recommendations for commissioners and service providers*

- 1.1.10 Ensure services meet set service-level and individual outcomes, and that service providers show evidence of achieving these outcomes. This evidence could include:
- satisfaction and quality-of-life ratings of children, young people and adults who have used the service, and their family members, friends and carers
  - outcomes measured by personalised and validated tools such as the 'measure of processes of care' (MPOC) tool, or the 'patient feedback questionnaire' (PFQ)
  - a reduction in duration and frequency of behaviour that challenges
  - stability of placements
  - participation in education by children and young people
  - reports on the use of restrictive interventions, including medication
  - contact time with specialist professionals
  - evidence from quality reviews and spot checking involving [experts by experience](#)
  - quality checks by user-led organisations.

- 1.1.11 Inpatient services should provide the evidence in recommendation 1.1.10 in addition to evidence of detailed assessments, treatment outcomes and time to discharge.
- 1.1.12 Commissioners should establish a multi-agency group, or make use of an existing group, including experts by experience and service providers, to monitor the quality of services and the outcomes achieved.
- 1.1.13 Service providers should use evidence gathered to continuously improve services. They should record the results and make them available to people who use services, and their families and carers.

## **Involving people in commissioning and service improvement**

### ***Recommendation for commissioners***

- 1.1.14 Commissioners should make use of expertise from experts by experience to inform decision-making and quality assurance of services.

## **1.2 *Enabling person-centred care and support***

### **Involving people with a learning disability and behaviour that challenges**

#### ***Recommendations for practitioners working with children, young people and adults, and their families and carers***

- 1.2.1 Practitioners working with children, young people and adults with a [learning disability](#) 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.

For more information on involving people in their care and support, see [working with people with a learning disability and behaviour that challenges, and their families and carers](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

- 1.2.2 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](#).

- 1.2.3 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.
- 1.2.4 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).
- 1.2.5 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.
- 1.2.6 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.

## ***Recommendation for commissioners and practitioners working with children, young people and adults***

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

## **Advocacy**

### ***Recommendations for local authorities***

- 1.2.8 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](#).
- 1.2.9 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 1.8.3 and 1.8.4](#) on independent advocacy in relation to inpatient admissions.

## **Coordinating care and support**

### ***Recommendations for local authorities, clinical commissioning groups and service providers***

- 1.2.10 Local authorities working in partnership with healthcare professionals should assign a single practitioner, for example, a social worker (in a disabled children's team or community learning disability team) or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to meet their needs over the long term.
- 1.2.11 The local authority, clinical commissioning group and [service providers](#) should liaise regularly with the named worker, keeping them informed and involved in decision-making.



### ***Recommendations for the named worker***

- 1.2.12 Arrange regular meetings to discuss the person's care and support, and invite people in their support network, including family members, carers, independent advocates and practitioners from all services that support them. This could build on existing processes, for example, the education, health and care planning and review process for children (see Gov.uk's [children with special educational needs and disabilities](#)).
- 1.2.13 Recognise and use the expertise brought by all members of the person's support network (not only those who are paid).

### **Care and support planning**

#### ***Recommendations for community learning disability teams and service providers***

- 1.2.14 Community learning disability teams (or relevant children's services, for example, disabled children's teams) and service providers should work in partnership with the child, young person or adult, their family members, carers and independent advocates and their named worker to develop, deliver and review their care and support plan. Develop a care plan that:
- meets the person's needs and preferences
  - works to support and maximise the person's mental capacity
  - takes into account people's fluctuating mental capacity and needs
  - adopts a 'whole life' approach that covers what they want to achieve in both the short and long term, and supports smooth transitions
  - takes a positive approach to managing risk
  - sets out what to do to prevent or respond to a crisis.
- 1.2.15 Service providers and agencies responsible for commissioning and planning services (including specialist services) should match the specific skills of staff to the characteristics of the person with a learning disability and behaviour that challenges. Do this as soon as care and support planning begins.

- 1.2.16 Community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers should review children, young people and adults' care and support with their named worker:
- according to timings agreed in their plan and
  - whenever there is a significant change, for example, if the person is placed out of area.
- 1.2.17 When reviewing plans:
- involve people as set out in [recommendations 1.2.1 to 1.2.4](#)
  - take account of people's fluctuating mental capacity
  - check that staff are following the [behaviour support plan](#) recommendations in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
  - think about plans for the future, including whether changes might be needed to the person's housing or support.
- 1.2.18 As soon as a child, young person or adult develops behaviour that challenges, community learning disability teams (or relevant children's services, for example, child and adolescent mental health learning disability teams) and service providers should offer to work with them and their family or carers to develop a behaviour support plan.

For more information on what this should include, see the recommendations on [behaviour support plan](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

## Supporting people to use personal budgets

### *Recommendations for local authorities and clinical commissioning groups*

- 1.2.19 Ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences.
- 1.2.20 Offer people a choice of funding arrangements (see recommendation 1.2.19) and support people to use these budgets, where they wish to, by:

- telling them how each element of their support will be funded
- telling them how much money is available and how much control they have over how the money is spent
- giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer
- supporting them to try out different mechanisms for managing their budget
- offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded
- offering information about benefits entitlement
- ensuring that carers' needs are taken fully into account.

[This recommendation is adapted from NICE's guideline on [older people with social care needs and multiple long-term conditions](#).]

## Delivering care and support

### *Recommendations for staff in all settings*

1.2.21 In all settings, staff working with children, young people and adults with a learning disability, and their families and carers, should aim to reduce the risk of behaviour that challenges developing by:

- identifying health or sensory problems early
- providing strategies and interventions to support communication.

Follow recommendations on [psychological and environmental interventions](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.22 For people taking medicines:

- follow recommendations in NICE's guideline on [managing medicines for adults receiving social care in the community and](#)

- if the reason for the medicine relates to the person's behaviour or mental health, ensure it is reviewed regularly in line with recommendations on [medication](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions, and recommendations in [mental health problems in people with learning disabilities: prevention, assessment and management](#).

1.2.23 Ensure that children, young people and adults with a learning disability and behaviour that challenges know about and are able to use services to support their health and wellbeing. These should include:

- services helping people to make and maintain friends, relationships and social networks in their community and take part in community activities
- access to employment and pre-employment opportunities
- day opportunities where activities can be tailored to the person's interests, preferences, strengths and abilities
- universal healthcare services and health checks
- peer support opportunities.

### 1.3 *Early intervention and support for families and carers*

See [section 1.6](#) for more recommendations on services for children and young people.

#### Recommendations for local authorities

1.3.1 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.

1.3.2 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.

1.3.3 Give family members and carers information in line with [support and interventions for family members or carers](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. 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.

## Recommendations for the named worker

1.3.4 Help people and their families to understand information about available support (see recommendation 1.3.3) from first contact onwards.

1.3.5 Advise family members and carers how to access:

- [short break](#) services
- specialist behaviour support

- training as set out in [recommendations 1.7.1 and 1.7.2](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and 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.

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

## 1.4 *Services in the community – prevention, early intervention and response*

### Developing services in the community

#### ***Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)***

1.4.1 The [lead commissioner](#) should commission services in the community for people with a [learning disability](#) and [behaviour that challenges](#) (including for people in contact with, or at risk of contact with, the criminal justice system). These services:

- should be able to cater for lower-level needs up to intensive, complex or fluctuating needs
- could be set up either as 1 large team with different subteams or as several separate teams
- should be provided wherever possible as an alternative to, and to reduce the potential need for:
  - inpatient care for children, young people and adults or
  - [residential placements](#) for children and young people.

1.4.2 Services in the community should fulfil the following core functions:

- specialist prevention and early intervention

- developing capacity in non-specialist community services to prevent unnecessary inpatient admissions
- giving support and training to families and carers (by following the recommendations on [support and interventions for family members or carers](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
- quality assurance and service development
- short-term assessment and intervention
- longer-term complex intervention
- crisis response and intervention.

1.4.3 Ensure that children, young people and adults with a learning disability can get specialist support through their community learning disability team that meets their needs, for example, in relation to:

- behaviour
- communication
- social care and support needs
- physical health
- mental health
- education
- offending behaviour.

This could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.

### ***Recommendations for community learning disability teams and service providers***

1.4.4 Services who provide support through the community learning disability team should work together and provide consultancy and support to each other. They should work with children, young people and adults, and their family members and carers, in a way that is:

- personalised
- flexible
- responsive
- accessible
- reflective.

1.4.5 If a child, young person or adult develops, or is at risk of developing, offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community forensic or youth justice services, as soon as possible (see recommendations 1.4.12 to 1.4.16). These services should:

- provide evidence-based early interventions that are adapted for people with a learning disability and address the specific behaviour
- work in an ongoing partnership with each other and with the community learning disability team whenever needed.

1.4.6 Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that:

- they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable
- people who need support can be diverted from the criminal justice service to community learning disability teams.

## Specialist behavioural support

### ***Recommendations for the lead commissioner (acting on behalf of local authorities and clinical commissioning groups)***

1.4.7 Ensure that specialist assessment and behavioural support are available in the community so that children, young people and adults can stay where they currently live and avoid moving.

1.4.8 Ensure that specialist services for behaviour that challenges are available to everyone with a learning disability and behaviour that challenges, based on an



assessment of each person's need and risk and taking into account the benefit of early intervention.

1.4.9 The lead commissioner should:

- set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support
- ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards.

### **Intensive behavioural support during a crisis**

#### ***Recommendations for local authorities, clinical commissioning groups, community learning disability teams and specialist services***

1.4.10 Provide a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should:

- focus on keeping people in their own home
- have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems
- provide face-to-face support within 4 hours if needed, based on initial triage
- involve partnership with other commissioners, service providers and family members and carers
- include giving staff access to the person's information if they are already in contact with services
- provide short-term support to achieve aims that are agreed with the person
- include clear contact details for children's services (as set out in the Local Offer) and adults' services.

1.4.11 Use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. Learn from what happened

and use this knowledge to inform future early intervention and prevention services and support crisis plans.

## Services for people in contact with, or at risk of contact with, the criminal justice system

### *Recommendation for local authorities and clinical commissioning groups*

1.4.12 Commission local community forensic services for children, young people and adults with a learning disability and behaviour that challenges who are in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement. These could be provided as stand-alone teams, or as a specialism within an existing team, for example, a community learning disability team, or a learning disability specialism within a community forensic team.

### *Recommendations for service providers, including forensic services*

- 1.4.13 When forensic community learning disability services are supporting children, young people and adults with a learning disability (for example, if they are subject to a forensic community rehabilitation order or a community treatment order), they should enable them to live in the community, as close to home as possible, and in the least restrictive setting.
- 1.4.14 Forensic community learning disability services should stay in frequent contact with the person they are supporting, including those who are in out-of-area placements or criminal justice settings, and help them build and maintain social links in their community.
- 1.4.15 Forensic learning disability services and probation services should work together to agree who is best able to support the person in meeting the requirements of their treatment or rehabilitation order.
- 1.4.16 Forensic learning disability services, mental health, specialist voluntary sector organisations, learning disability services and social care services should establish care pathways and close links with each other to help them refer people quickly between these services to get the right support and effectively manage risk.

## 1.5 *Housing and related support*

### Giving people a choice of housing

#### ***Recommendations for local authorities, clinical commissioning groups and service providers***

- 1.5.1 Commissioners should work with local housing and social care providers to identify the specific housing needs of adults with a [learning disability](#) and [behaviour that challenges](#). They should ensure areas have a range of housing and care options available that meet these needs and cater for different preferences and person-centred support needs (see also [section 1.2](#)).
- 1.5.2 Enable adults to live close to their family, friends and community unless they choose not to or there is a compelling reason not to.
- 1.5.3 Where possible ensure that, wherever people live, they have security of tenure in line with the [Real Tenancy Test](#).
- 1.5.4 When helping adults with a learning disability and behaviour that challenges choose where to live:
- provide information on the range of possible options
  - take into account their preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation on [environmental factors](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
  - give them advice on adapting their current home if needed.
- 1.5.5 Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them.
- 1.5.6 If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. Involve people in choosing how many people, and who, they live with.
- 1.5.7 Offer adults housing outside their local community only:

- if it is what the person wants
- if it is indicated after a full assessment and planning process, which takes into account the person's preferences, needs and risks
- for a specified time that has been agreed with the person, or agreed in their best interests if they lack capacity to decide this – for example, if they are in crisis and there is no local placement available.

1.5.8 If someone is moving outside their local area, local authorities, clinical commissioning groups and commissioners should:

- establish the commissioner who is responsible for paying for the person's care and support
- ensure they will still have the support they need
- make a plan that enables them to return to their local area if they want to, or if it is in their best interests if they lack capacity to decide this.

## 1.6 *Services for children and young people*

### Recommendations for local authorities, clinical commissioning groups and the lead commissioner

- 1.6.1 Local authorities should ensure that parents and carers of children and young people with a [learning disability](#) and [behaviour that challenges](#) have support to care for their child (see [section 1.3](#)).
- 1.6.2 Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with [section 17](#) of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to [residential placements](#) away from home and to reduce the potential need for such placements.
- 1.6.3 The [lead commissioner](#) should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have

skills and experience in working with children and young people with a learning disability and behaviour that challenges.

## Recommendations for local authorities, service providers and practitioners

1.6.4 Health, mental health and behaviour support practitioners should work with other services, for example, education and social care, to:

- deliver the outcomes agreed in a child or young person's education, health and care plan
- provide support and interventions in line with NICE's guideline on [challenging behaviour and learning disabilities: prevention and interventions](#)
- maximise life opportunities for children and young people, including by ensuring they have access to meaningful education
- support smooth transitions between services in line with [organising effective care in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions](#)
- support children and young people to develop skills for independence
- take a positive approach to managing risk.

This applies to children and young people in residential placements, as well as those living at home.

1.6.5 If a child or young person's behaviour that challenges is deteriorating or causing concern, the local authority should carry out a multi-agency review of their education, health and care plan (or other relevant plan) and involve the child or young person and their parents or carers. Review whether the plan needs to be updated and additional support provided if the child or young person's needs have changed.

## Exploring alternatives to residential placements for children and young people

### *Recommendations for the lead commissioner, service providers and practitioners*

1.6.6 Support parents and carers to understand the full range of options for education, care and support for their child.

1.6.7 When considering a residential placement, arrange a multi-agency review to explore all options and to review the child or young person's education, health and care plan. Include in this discussion:

- the child or young person, and their parents or carers
- the lead commissioner on behalf of the local authority and clinical commissioning group
- at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging
- an independent expert by experience
- special educational needs staff, or staff from their school or college.

1.6.8 Only offer children and young people a residential placement:

- if assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted, or
- following a request by the child or young person's family, which has been considered under the Children and Families Act 2014.

## Living in residential placements

### *Recommendations for local authorities, clinical commissioning groups and service providers*

1.6.9 Commission residential placements for children and young people as close to home as possible. Take into account in local authority contracts that some families may need financial support to help them see their child and for their child to visit them.

1.6.10 Support children and young people to maintain links with their family, friends and community (for example, members of their religious community) while they are in a residential placement.

1.6.11 Local authorities and service providers must promote maximum contact between children and young people living in residential placements and their

family members and carers (in line with [schedule 2](#) of the Children Act 1989). If a placement lasts longer than 3 months, the [Visiting Regulations 2011](#) must be followed, for both local and out-of-area placements. Help families stay in touch between visits, for example, using Skype.

## Planning and review to support children and young people leaving a residential placement

### *Recommendations for local authorities, clinical commissioning groups and practitioners*

- 1.6.12 As soon as a child or young person moves into a residential placement, local authorities and clinical commissioning groups should ensure that:
- a plan is developed for how they will progress towards returning to their family home, if appropriate, and towards greater independence
  - they continue to be supported to meet the outcomes identified in their education, health and care plan.
- 1.6.13 Review the plan in recommendation 1.6.12 at least every 6 months to check that progress is being made. This could be done as part of a looked-after child review, an education, health and care plan review, or sooner if needed.
- 1.6.14 Plans should be reviewed by the practitioner responsible for overseeing the child or young person's education health and care plan and all other practitioners involved in their care and support, including a specialist in behaviour that challenges.
- 1.6.15 If progress towards the outcomes in the plan has not been made, explore and address the reasons for this. If the child, young person or their family disagrees with the decision made at the review meeting, explain how they can challenge the decision if they want to.

## 1.7 *Short break services*

### Recommendations for local authorities, commissioners and service providers

- 1.7.1 Local authorities must, in line with the [Breaks for Carers of Disabled Children Regulations 2011](#) and the [Children and Families Act 2014](#):

- provide a range of short breaks for children and young people with a learning disability and behaviour that challenges and
- publish as part of their Local Offer a statement of the range of services available and how eligibility will be assessed.

1.7.2 Commissioners in health and social care should provide sufficient, reliable, flexible and varied short break options, including both breaks away and support at home, for adults with a learning disability and behaviour that challenges.

1.7.3 Ensure that short breaks are:

- community-based and close to home
- available based on need, and at short notice both in crisis and to prevent a crisis
- tailored to the needs of the person and their family or carers, taking into account the person's interests and preferences
- able to provide a positive experience for the person being supported
- able to deliver what is agreed in the education, health and care plan or care and support plan; carer's assessment; or behaviour support plan
- planned in advance wherever possible and involve people and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it
- provided by staff who understand and respect people's cultural norms and values and their choices about personal care, private life and lifestyle.

## 1.8 *Making the right use of inpatient services*

### Exploring alternatives to inpatient admission

#### *Recommendations for commissioners, service providers and practitioners*

1.8.1 Admit children, young people and adults with a learning disability and behaviour that challenges to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted.



1.8.2 When thinking about inpatient admission, arrange a discussion to explore all other viable options. Include in this discussion:

- the person and their family members and carers
- at least 1 practitioner with clinical expertise in learning disability and the specific behaviour that is challenging
- at least 1 independent expert by experience.

For further guidance, see NHS England's information on community [Care and treatment reviews](#) or, for children and young people, community [Care, education and treatment reviews](#).

## Providing information

### *Recommendations for local authorities, clinical commissioning groups and service providers*

1.8.3 When there is a possibility that someone will be admitted to hospital, including as an informal admission, local authorities and clinical commissioning groups should give them and their family and carers accessible, independent information and advice about their rights, access to independent advocacy and other possible options for treatment, and care and support.

1.8.4 Service providers must provide information about independent mental health advocacy as required by the [Mental Health Act 1983](#).

## When a placement is needed

### *Recommendation for local authorities and clinical commissioning groups*

1.8.5 Provide an inpatient placement that is as close as possible to where the person usually lives.

### *Recommendations for inpatient services and community learning disability teams, including the named worker*

1.8.6 The named worker should support the person to maintain links with their family, friends and community (for example, members of their religious community)

while they are in hospital, and give their family and friends information about their progress.

- 1.8.7 If people are admitted as inpatients outside their local area, social workers in the community learning disability team and the named worker should stay in contact with the person, and help them stay in contact with other key practitioners in their own area.
- 1.8.8 When someone is admitted as an inpatient, offer them interventions in line with recommended [psychological and environmental interventions](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. Ensure that these interventions specifically address their needs and the reason for their admission.

## Planning and review to support discharge

### *Recommendations for inpatient services and community learning disability teams*

- 1.8.9 As soon as the person is admitted, the hospital and community learning disability team should work together to develop a discharge plan.
- 1.8.10 Practitioners involved in the child, young person or adult's care and support should review the person's discharge plan at least every 3 months. Include in these reviews:
- the person and their family members or carers
  - the practitioner responsible for agreeing discharge
  - a specialist in behaviour that challenges.
- 1.8.11 Think about using NHS England's [Care and treatment review](#) process or the [Care programme approach](#) as a framework for reviews to support discharge for adults. For children and young people think about using the [Care, education and treatment review](#) or education, health and care planning process.
- 1.8.12 If the person is not discharged after the meeting with practitioners involved in their care and support, provide sufficient reason for this and develop a new plan towards discharge. Explain to the person and their family or carers how they can challenge the decision if they want to.

1.8.13 Tell people who might apply to, or are referred for, a first-tier mental health tribunal relating to being an inpatient, about their right to request an independent clinician (in line with [section 76](#) of the Mental Health Act 1983) to:

- visit them at any reasonable time and examine them in private
- inspect any records relating to their conditions and treatment.

## 1.9 *Staff skills and values*

### Recommendations for commissioners, local authorities and service providers

1.9.1 As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support the children, young people and adults they are working with. This includes:

- the skills and knowledge recommended in [staff training, supervision and support](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- being resilient and compassionate
- showing that they care
- understanding and respecting the person's human rights, faith, culture, identity and values.

1.9.2 Ensure that staff providing direct support to children, young people and adults with a [learning disability](#) and [behaviour that challenges](#) have the 'direct contact' level competencies of the Positive Behavioural Support Academy's [Positive behaviour support competence framework](#).

1.9.3 Give staff providing direct support access to advice from [behaviour support specialists](#) with 'consultant' level competencies of the Positive Behavioural Support Academy's [Positive behaviour support competence framework](#).

1.9.4 Local authorities and clinical commissioning groups should plan for and resource training among service providers who provide day-to-day support about how to work with young people and adults with a learning disability who are at risk of offending.

- 1.9.5 Organisations should ensure that staff have supervision and support, in line with the recommendations on [staff training, supervision and support](#) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.
- 1.9.6 Involve young people and adults with a learning disability and behaviour that challenges in staff recruitment. Involve their family members and carers too if the person agrees, unless there is a compelling reason not to.
- 1.9.7 Think about how to involve children with a learning disability in staff recruitment.

### *Terms used in this guideline*

The Think Local, Act Personal [care and support jargon buster](#) explains many of the social care terms used in this guideline.

#### **Adult**

In this guideline, 'adults' are aged 18 years or older.

#### **Behaviour support specialist**

A practitioner who has training in helping people and their family members and carers to understand and change their behaviour if it is causing problems for them.

#### **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 delay access to and use of ordinary community facilities.

#### **Carer**

Someone who provides 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

In this guideline, 'children' are aged 12 years or younger.

## Contingency fund

A sum of money set aside to fund any unforeseen expenditure, and to respond quickly in an emergency.

## Experts by experience

People with lived experience of using services, including people with a learning disability themselves and their family members and carers.

## Forensic services

Specialist services that work with people in contact with, or at risk of contact with, the criminal justice system.

## Lead commissioner

A commissioner appointed by the local authority and clinical commissioning group who oversees strategic joint commissioning arrangements for health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges.

## Learning disability

In line with NICE's guideline on [challenging behaviour and learning disabilities](#), 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.

## Positive behaviour support

Positive behavioural support is a person-centred approach that uses a multi-element format to better understand and so reduce behaviour that challenges. It can include changing the person's environment, developing their skills, providing focused support and developing reactive strategies.

## Real Tenancy Test

The Real Tenancy Test is a quick test to check that a person who lives in supported accommodation enjoys the same rights and protections in law as a person who has a full tenancy agreement for their rented home.

## Residential placement

Examples of residential placements include residential care homes for adults and, for children and young people, placements that involve living away from their family home, for example, in residential schools and colleges.

## Service providers

This can be any organisation in the public, private or voluntary sector that offers a service to people with a learning disability and behaviour that challenges. This can include services such as hospitals, care homes and organisations that provide support for people to live in their own homes or with their family.

## Short breaks

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.

## Young people

In this guideline, 'young people' are aged 13 to 17 years.

## Putting this guideline into practice

NICE has produced [tools and resources](#) to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Children, young people and adults with a learning disability and behaviour that challenges are likely to use both health and care services throughout their lives. However, a lack of integration across services, including children's and adults' services, can impact on quality of care. Local authorities, working together with clinical commissioning groups, can provide a more joined-up and person-centred approach by designating a lead commissioner who is responsible for commissioning health, social care and education services for both adults and children with a learning disability, including for people whose behaviour is described as challenging. For some services, creating this role may involve a significant change in practice.
- Family members and carers often play a significant role in supporting people with a learning disability and behaviour that challenges, but they can find it difficult to access information, guidance and support. Many families need ongoing training and support for their caring role from specialist services, including [positive behaviour support](#) services. Families may also benefit from services such as peer support. Local authorities and health services need to provide this information and support, and tell families how to get it. For areas that do not currently provide comprehensive support for families, this will involve a significant change in practice.
- Developing good general and specialist community services is important for supporting children, young people and adults with a learning disability and behaviour that challenges to live how and where they want, and to avoid the need for hospital admission or residential placements. Developing capacity in services and housing to support people in the community is likely to be a challenge in areas where resources are focused on inpatient care. Clear plans will need to be developed, agreed and put in place to make this change.
- Children, young people and adults with a learning disability and behaviour that challenges should not be admitted to inpatient units unless all other possible options have been considered and exhausted. Similarly, children and young people should only be provided with a residential placement if all other possibilities have been considered. Where inpatient care or residential placements are used, planning should begin immediately for the person to return to their family or community. The plan should be reviewed regularly. Where this is not current practice, significant change will be needed.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.
2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.
3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.
4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.
5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.
6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.



**7. Implement the action plan with oversight from the lead and the project group.** Big projects may also need project management support.

**8. Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our [into practice](#) pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) [Achieving high quality care – practical experience from NICE](#). Chichester: Wiley.

## Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the [full guideline](#).

### *1 Models of person-centred support*

What models of delivering person-centred support are effective and cost effective for people with a learning disability and behaviour that challenges, and their families and carers?

What are the views and experiences of people with a learning disability and behaviour that challenges and their family members and carers, of different models of delivering person-centred support?

#### **Why this is important**

Person-centred support is the current recommended approach and is at the centre of this service guideline. However, there is little published research about what configurations of services and resources provide the best person-centred support for people with a learning disability and behaviour that challenges, and their families and carers. There is also limited research from the point of view of people with a learning disability and their families and carers on what good person-centred support looks like, how it can be measured or benchmarked or what it means for them.

### *2 Supporting family members, carers and staff*

What types of services or approaches are effective in supporting family members, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?

#### **Why this is important**

Enabling family members, carers and staff to provide continuing care and support can help prevent placements from breaking down, which can lead to out-of-area placements. Investment in carers, support networks, initiatives that support independent living, and community networks are key to helping people develop greater resilience. This is especially important if new approaches to service delivery, such as personalisation, are to succeed. However, there is no direct empirical evidence of the social and economic benefits associated with investment in such approaches and services.

### *3 Models of supported living*

What is the effectiveness and cost effectiveness of models of shared, supported living, such as Shared Lives?

What are the views and experiences of people sharing their home and people who live with them under programmes such as Shared Lives?

#### **Why this is important**

It is important that people with a learning disability and behaviour that challenges have more choice and control over where they live. Models of supported living, such as Shared Lives, are promising models for people with a learning disability. However, the support needs of people with a learning disability and behaviour that challenges are more complex and there is very limited evidence about which types of supported living are effective specifically for them. It would be useful to know what kinds of supported living are acceptable and feasible for people with a learning disability and behaviour that challenges and their families and carers, as well as for Shared Lives families.

### *4 Effective components of integrated regional services for people with a learning disability and behaviour that challenges*

What are the effective components of an integrated regional service for people with a learning disability and behaviour that challenges across health and social care (including pooling budgets and other resources)?

What are the barriers and facilitators to pooling budgets and other resources across regions?

#### **Why this is important**

The Winterbourne View Review Action Group and the Transforming care programme recommended that health and social care services should pool budgets. However, reports from the National Audit Office highlight that there has been little evidence of this happening in practice. Research is needed to know what mechanisms enable or stop this practice from happening, and whether the practice results in better outcomes for people with a learning disability.

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## Accreditation

