Learning disabilities and behaviour that challenges: service design and delivery

NICE guideline: short version
Draft for consultation October 2017

This guideline covers services for people with a learning disability and behaviour that challenges, and their family members and carers. It recommends providing a range of services, including specialist support, in the community to minimise the need for inpatient admissions. It also promotes a lifelong approach to supporting people which emphasises prevention and early intervention. Recommendations cover services for children, young people and adults across health and social care.

The guideline should be read alongside NICE’s clinical guideline on challenging behaviour and learning disabilities: prevention and interventions.

Who is it for?

- Commissioners of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges
- Providers of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges
- Health and social care practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers.

It is also relevant for:

- Providers of related services, including housing, education, employment and criminal justice services
- Practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers in other
services or settings, including education, housing, voluntary and community services, employment, and criminal justice services

- Children, young people and adults with learning disabilities and behaviour that challenges and their families and carers, including people who purchase their own care.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the guideline’s page on the NICE website. This includes the guideline committee’s discussion and the evidence reviews (in the full guideline), the scope, and details of the committee and any declarations of interest.
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Context

Background

An estimated 1.2 million people in England have a learning disability, and of these it is estimated that 10–17% behave in a way 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).

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. 1987¹). Later definitions have highlighted the role of cultural context in determining whether behaviour is perceived as challenging (Emerson 1995²).

This guideline was developed in a context of changing policy and practice for people with a learning disability and behaviour that challenges. The support needs of this vulnerable group were set out in 1992 in the Mansell Report³ 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 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
and behaviour that challenges. In particular this aims to shift emphasis from inpatient
care in mental health hospitals, towards care 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, Care Quality Commission, Local
Government Association, Health Education England and Department of Health. They
formed the national plan, Building the right support (2015), which included the plans
for 48 Transforming Care Partnerships to pilot new arrangements of services. The
national plan was followed by NHS England developing a 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).

This guideline takes into account the direction of travel in Transforming Care. It aims
to complement this work by providing evidence-based recommendations to support
children, young people and adults with 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. While
there is no legal obligation to implement our health and social care guidance, health
and social care and other 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:

- Care Act 2014 and associated guidance
- Children Act 1989 and associated guidance
- Children and Families Act 2014
- Mental Capacity Act 2005
- Accessible Information Standard.

How has it been developed?

The guideline has been developed by a guideline committee of people who use services; family members and carers of children, young people and adults with learning disabilities 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.

More information

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

This guideline covers people of all ages with a learning disability and behaviour that challenges. All recommendations referring to ‘people with a learning disability’ relate to children, young people and adults unless specified otherwise.

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 be supported to live where and how they want. The guideline recommends ways of designing and delivering services that aim to:

- maximise people’s choice and control
- promote person-centred care
- help people 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
- help people as soon as problems emerge, not just when crisis has been reached
- promote continuity of relationships.

The guideline aims to help local areas rebalance their services by shifting the focus towards enabling people to live in their communities and increasing support for families and carers. This should reduce the need for people to move away for care and treatment.
1.1 Achieving change: strategic planning and infrastructure

Local leadership

1.1.1 Local authorities and clinical commissioning groups should jointly designate a single lead commissioner who is responsible for commissioning health, social care and education services for children, young people and adults with a learning disability, including for those whose behaviour is described as challenging. This commissioner should have in-depth knowledge and experience of working with people with a learning disability and behaviour that challenges.

1.1.2 Local authorities and clinical commissioning groups, acting through the single lead commissioner, should consider jointly commissioning the most specialised behaviour support services across areas for people with particularly complex needs.

Planning budgets

1.1.3 The lead commissioner should work to pool budgets or other resources for health, social care and education with neighbouring authorities, to develop local and regional services for people with a learning disability and behaviour that challenges.

1.1.4 Commissioners should ensure that funding mechanisms for providers support creative and flexible community-based responses, for example a ‘contingency fund’ that providers can draw on quickly if there is a crisis.

Planning and delivering services according to local need

1.1.5 Local authorities and clinical commissioning groups, acting through the single lead commissioner, should develop and provide services for people with a learning disability and behaviour that challenges based on local need. Make sure that planning and delivery:

- is based on an assessment of the likely current and future local service needs for people with a learning disability and behaviour that challenges using:
1. population prevalence rates of children, young people and adults with learning disabilities and
2. known data on the proportion of this population who are likely to have different types of challenging behaviour

- uses an analysis of assessed needs in education, health and social care plans, including data which provides an early view of likely service needs and enables prevention and early intervention
- makes use of other sources of information, such as registers of people at risk of admission and records of referrals from liaison and diversion teams, youth offending teams and police
- 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
- are integrated.

1.1.6 The lead commissioner should 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. 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 [general principles of care](#) in NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.)

### Managing risk

1.1.7 The lead commissioner should take joint responsibility with providers for managing risk when developing and delivering care for people with a learning disability and behaviour that challenges. They should aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person.
Quality assurance

1.1.8 Commissioners of services for people with a learning disability and behaviour that challenges should commission services to meet set service level and individual outcomes, and require service providers to show evidence of achieving these outcomes. This evidence could include:

- satisfaction ratings of people who have used the service, and their family members 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)
- stability of placements
- reports on the use of restraint
- contact time with specialist professionals
- evidence from quality reviews and spot checking involving experts by experience.

1.1.9 Inpatient services should provide the evidence in recommendation 1.1.8 in addition to evidence of detailed assessments, treatment outcomes and time to discharge.

1.1.10 Commissioners should establish a multi-agency group, including experts by experience and providers, to monitor the quality of services and the outcomes achieved. Commissioners should use these as part of their performance management of services.

1.1.11 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.

Involving people in commissioning and service improvement

1.1.12 Commissioners should employ experts by experience in their commissioning teams in order to inform decision-making and quality assurance of services.
1.2 **Enabling person-centred care**

**Involving people and their family members and carers**

1.2.1 Staff 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 see ‘working with people with a learning disability and behaviour that challenges, and their families and carers’ in general principles of care in NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.)

1.2.2 Involve people’s families, friends and carers if this is what the person wants, or unless there is a compelling reason not to (for example if there are safeguarding concerns).

1.2.3 Support people 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 the person’s learning disability, their developmental stage, and any communication difficulties or physical or mental health problems
- respects their cultural, religious and sexual identity
- helps them as soon as problems emerge, not just when crisis has been reached
- encourages people to speak out if they have any worries
- promotes continuity of relationships.

1.2.4 Staff working with people with a learning disability should actively involve the person 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.

1.2.5 Practitioners should 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, including them in decisions about their treatment and how they would like their families or carers to be involved.

1.2.6 Staff working with people with a learning disability should find out their information and communication needs, record them and share this information with everyone working with them.

1.2.7 All staff working with people with a learning disability and behaviour that challenges should have access to specialists in communication when needed.

1.2.8 Local authorities must offer independent advocacy as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007. Think about offering it whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. Local authorities should 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 liaising with specialist learning disability services.

Coordinating care

1.2.9 Local authorities should assign a single practitioner, such as a social worker in the community learning disability team, to be the person’s ‘named worker’ and coordinate their support.

1.2.10 The named worker should arrange regular meetings to discuss the person's care and support and invite people in their support network, including family members, carers, advocates and practitioners from all services that support them. Recognise and use the expertise brought by all members of the network (not only those who are paid).
### Care and support planning

1.2.11 Community learning disability teams and service providers should work in partnership with the person and their family members and carers to develop and deliver their care and support plan. Develop a care plan that:

- meets the person's needs and preferences
- takes into account people's fluctuating capacity and needs
- adopts a lifespan approach that covers what they want to achieve in both the short- and long-term
- takes a positive approach to managing risk
- sets out what to do to prevent or respond to a crisis.

1.2.12 Community learning disability teams and service providers should work with the person who displays behaviour that challenges and their family and carers to develop a behaviour support plan. For more information on what this should include, see the [behaviour support plan](#) recommendations in section 1.6 of NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.13 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 planning begins.

1.2.14 In all settings, staff should provide people with a learning disability and behaviour that challenges (and their families and carers) with strategies and interventions to increase communication and other skills to reduce their risk of developing behaviour that challenges. Follow the recommendations on [psychological and environmental interventions](#) in section 1.7 of NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.2.15 Community learning disability teams should review people’s care and support as agreed within their plan as well as when there is a significant
change, for example if the person is placed out of area. When reviewing people’s plans:

- take account of people’s fluctuating 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 if changes might be needed to the person’s housing or support.

**Supporting people to use personal budgets**

1.2.16 Local authorities should offer people a choice of direct payments, personal health budgets or individual service funds, depending on their needs and preferences.

1.2.17 Local authorities should help people to use their personal budgets, continuing healthcare budgets, individual service funds and direct payments (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, as well as to those whose care is publicly funded
- offering information about benefits entitlement
- ensuring that carers’ needs are taken fully into account.

[Adapted from NICE’s guideline on older people with social care needs and multiple long-term conditions]
1.3 Support for families and carers

1.3.1 Local authorities should ensure that parents and carers of children, young people and adults with a learning disability and behaviour that challenges have support to care for that person from the following specialist services:

- psychology
- speech and language therapy
- occupational therapy
- behaviour analysis and positive behaviour support, including training on restrictive interventions and how to reduce their use.

1.3.2 Specialist staff should provide information and training to families and foster carers of children and young people in line with recommendations 1.7.1 and 1.7.2 in NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.3.3 Local authorities should provide information, guidance and support for families and carers of people with a learning disability and behaviour that challenges which addresses different aspects of their life. This support could include:

- peer support
- parent and carer groups
- email support
- individual phone and in-person support
- family networks
- managed email networks (a shared discussion forum).

For more information on how to provide support for families see support and interventions for family members or carers in section 1.3 of NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.3.4 Local authorities should give family members and carers information in line with support and interventions for family members or carers in section
1.3 of 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.

1.3.5 The named worker in the community learning disability team should make regular offers of support to understand this information from the first point of contact onwards. Advise family members or carers about their right to, and explain how to get:

- respite care services
- specialist behaviour support
- support in an emergency and who to contact
- contact details of staff, including the named worker and key dates and appointments
- community resources, including voluntary organisations, networks and support groups
- local safeguarding procedures and how to raise safeguarding concerns or make a complaint.

### 1.4 Services in the community

#### Developing community capacity

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
• wherever possible should be provided 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 (for more information on how to support families see support and interventions for family members or carers in section 1.3 of 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.

Community learning disability teams

1.4.3 Local authorities and clinical commissioning groups, acting through the single lead commissioner, should ensure people can get support when needed through their team from:

• occupational therapists
• psychologists
• psychiatrists
• physiotherapists
• speech and language therapists
• community learning disability nurses
• healthcare facilitators
• social workers
• educational psychologists (for children and young people)
• behaviour therapists
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 people and their family members and carers in a way that is:

- personalised
- flexible
- responsive
- accessible.

1.4.5 If a person develops risky or offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community forensic teams, as soon as possible to reduce the likelihood of this behaviour repeating. These teams should provide early, evidence-based interventions which are adapted for people with a learning disability and address the specific behaviour.

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

1.4.7 The lead commissioner should ensure that specialist assessment and behavioural support are available in the community so that people can stay where they currently live and avoid moving.

1.4.8 The lead commissioner should make specialist services for behaviour that challenges available to everyone with a learning disability and behaviour that challenges, based on individual need. People should never wait longer than 18 weeks.

Intensive behavioural support during a crisis

1.4.9 Provide a local, personalised response to people 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, staffed by people with skills and knowledge about the needs of people with a learning disability and behaviour that challenges, and specialist skills in mental health problems
- have sufficient capacity to provide a response within 1 hour
- involve partnership with other commissioners, providers and family members
- 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 adults' and children's services.

1.4.10 Local authorities, community learning disability teams and specialist support services should use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. They should learn from what happened and use this to inform future crisis plans.
1. **Services for people in contact with, or at risk of contact with, the criminal justice system**

1.4.11 The lead commissioner should commission local forensic services for people in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement.

1.4.12 Forensic community learning disability teams should support people with a learning disability who are subject to a forensic community rehabilitation order or a community treatment order to live in the community, as close to home as possible and in the least restrictive setting.

1.4.13 Community forensic teams should stay in frequent contact with the person they are supporting, and help them build and maintain social links in their community.

1.4.14 Forensic learning disability teams 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.

1.4.15 Forensic learning disability services, mental health, learning disability and social care services should establish close links with each other and refer people quickly between these services to get the right support.

1.5 **Housing and day-to-day support**

1.5.1 Commissioners should work with local housing providers to identify the specific housing needs of people with a learning disability and behaviour that challenges. They should ensure areas have a range of housing options available that meet these needs and cater for different preferences and support needs.

1.5.2 Support people to live close to their family, friends and community unless they choose not to or there is a compelling reason not to.
Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test.

When helping adults with a learning disability and behaviour that challenges choose where to live:

- take into account their preferences and any specific support needs or risks
- give them advice on adapting their home if needed
- offer them the option to live alone with appropriate support if they prefer this and it is suitable for them.

If people prefer not to live alone, or it is not suitable for them, offer them the option to live in shared housing with up to 3 other residents.

The lead commissioner should offer people housing outside their local community only:

- if that 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.

If someone is moving outside their local area, the lead commissioner should:

- establish the 'responsible commissioner' who will be responsible for paying for that person’s care
- 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 it is in the best interests if they lack capacity to decide this.
Providing day-to-day support

1.5.8 Ensure that people know about and are able to use services to support their health and wellbeing. These should include:

- primary care and health checks
- services helping people to make and maintain social networks in their community and take part in community activities
- day care services where activities can be tailored to the person’s interests, preferences, strengths and abilities
- peer support opportunities.

1.6 Services for children and young people

1.6.1 Local authorities and clinical commissioning groups, acting through the single 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.

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 both 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 Health, mental health and behaviour support practitioners should work with other services, for example education services and practitioners, 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
1.6.4 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 and involve their parents and carers. Review whether the plan needs to be updated and additional support provided if the child or young person’s needs have changed.

Living in residential placements

1.6.5 Only offer children and young people a residential placement if assessment and care planning show that their needs cannot be safely met in the community and all possibilities for doing so have been considered and exhausted.

Exploring alternatives to residential placements

1.6.6 When considering a residential placement arrange a multi-agency review to explore all other viable 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 family members and carers
- the single lead commissioner on behalf of the local authority and clinical commissioning group
- at least one practitioner with clinical expertise in learning disability and the person’s specific behaviour that is challenging.

Planning and review to support leaving residential placements

1.6.7 The lead commissioner should 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. Support them to maintain links with family, friends and community (for example, members of their religious community) while they are in a residential placement.
1.6.8 Local authorities and 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 when they want to, for example using Skype.

1.6.9 The lead commissioner should ensure a plan is developed as soon as a child or young person moves into the placement for how they will move towards a less restrictive setting (including returning to their family if appropriate) and towards greater independence.

1.6.10 Review the plan in recommendation 1.6.9 at least every 6 months to check that progress is being made. This could be done as part of the education, health and care plan review, or sooner if needed. It should be reviewed by the practitioner responsible for overseeing the child or young person's education health and care plan and all practitioners involved in the child or young person’s care, including a specialist in behaviour that challenges.

1.6.11 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 Respite care

1.7.1 Commissioners in health and social care should provide reliable, flexible and varied respite options for children, young people and adults with a learning disability and behaviour that challenges. These should include both breaks away and support at home. Make sure these are:

- community-based and close to home
- available at short notice, in crisis and to prevent a crisis
- available based on need
- tailored to the needs of the person and their family or carers
1.7.2 Ensure that respite care:

- takes into account the person’s interests and preferences
- delivers what is agreed in the education, health and care plan or care and support plan; carer’s assessment; or behaviour support plan
- is planned in advance and involves people and their family members and carers visiting respite services before using them to see if they are suitable
- involves people getting to know the staff providing their respite before it begins
- is provided by staff who understand and respect people’s cultural norms and values.

1.8 Making the right use of inpatient services

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 safely met in the community and all possibilities for doing so have been considered and exhausted.

1.8.2 When considering 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 one practitioner with clinical expertise in learning disability and the person’s specific behaviour that is challenging
- at least one independent expert by experience.

An example of this is a community Care and Treatment Review or, for children and young people, a community Care, Education and Treatment Review.

Providing information

1.8.3 When there is a possibility that someone will be admitted to hospital, including as an informal admission, give them and their families and
carers accessible, independent information and advice about their rights
and other possible options for care and treatment.

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

Selecting a placement when required

1.8.5 Local authorities and clinical commissioning groups, acting through the
single lead commissioner, should provide an inpatient placement that is
as close as possible to where the person usually lives.

1.8.6 The named worker should support the person to maintain links with 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 Social workers in community learning disability teams should support
people who are admitted as inpatients outside their local area to maintain
contact with key practitioners in their home area. This should include their
named worker.

1.8.8 When someone is admitted as an inpatient, offer them interventions in line
with early identification of the emergence of behaviour that challenges in
NICE’s guideline on challenging behaviour and learning disabilities:
prevention and interventions. Ensure that interventions specifically
address their needs and the reason for their admission.

Planning and review to support discharge

1.8.9 The lead commissioner should ensure that hospitals work together with
community learning disability teams to develop a discharge plan as soon
as the person is admitted.

1.8.10 The practitioners involved in the person’s care, including the practitioner
responsible for agreeing discharge, should review the person’s discharge
plan at least every 3 months. Reviews should include the person and their
family members and carers as well as a specialist in behaviour that
challenges. Think about using the Care Programme Approach as a framework for these reviews. For children and young people think about using the Care, Education and Treatment Review process.

1.8.11 If the person is not discharged after the meeting with practitioners involved in their care, provide sufficient reason for this and develop a new plan towards discharge. Explain to the person or their family and carers how they can challenge the decision if they want to.

1.8.12 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 to:

- visit them at any reasonable time and examine them in private
- inspect any records relating to their conditions and treatment (in line with section 76 of the Mental Health Act)

1.9 Staff skills and values

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

- the skills and knowledge in ‘staff training, supervision and support’ in the general principles of care section of 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 faith, culture, identity and values.

1.9.2 Ensure that staff providing direct support to people with a learning disability and behaviour that challenges have the 'direct contact' level competencies of the 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 behaviour support competence framework.

1.9.4 Commissioners should plan for and resource training among service providers who provide day-to-day support about how to work with people with learning disabilities 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 the general principles of care section of NICE’s guideline on challenging behaviour and learning disabilities: prevention and interventions.

1.9.6 Involve people 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.

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.

Behaviour support specialist

A practitioner (for example a behaviour analyst) 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 is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit or delay access to and use of ordinary community facilities.

Children

In this guideline ‘children’ are aged 12 years or younger.
Expert by experience
People with lived experience of using services for people with a learning disability and behaviour that challenges, 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.

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 mild, moderate, severe or profound in severity.
Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.

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 support for people to live in their own homes or with their family.

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 such as residential schools and colleges.

Young people

In this guideline ‘young people’ are aged 13 to 17 years.

Putting this guideline into practice

[This section will be finalised after consultation]

NICE has produced tools and resources [link to tools and resources tab] 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 learning disabilities 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 the quality of care. Local authorities, working together with clinical commissioning groups, can provide a more joined-up and person-centred approach by designating a single lead commissioner who is responsible for commissioning learning disability health, social care and education services for both adults and children, 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 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 they can access 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 people 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 away from home. 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.

- People 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 placed in residential placements if all other possibilities have been considered. When people are admitted to hospital, or children and young people are placed in a residential placement, planning for them to return to the community or a less restrictive placement should begin immediately. 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 on what good person-centred support looks like 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 developing resilience and are needed if new approaches to service delivery, such as personalisation, are to
succeed. 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 behaviour that challenges are more complex and there is very limited evidence about which types of supported living are effective specifically for people with a learning disability and behaviour that challenges. 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, as well as for Shared Lives families.

### 4 Effective components of integrated regional challenging behaviour services

What are the effective components of an integrated regional challenging behaviour service 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 Review Action Group and Transforming Care 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 the practice
from happening and if the practice results in better outcomes for people with a learning disability.