

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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1 **Context**

2 ***Background***

3 An estimated 1.2 million people in England have a learning disability, and of these it
4 is estimated that 10–17% behave in a way that challenges ([Predictors, costs and
5 characteristics of out of area placement for people with intellectual disability and
6 challenging behaviour](#) Allen et al. 2007). A more recent report suggested that there
7 are over 40,000 children with learning disabilities who display behaviour that
8 challenges ([Estimating the number of children with learning disabilities in England
9 whose behaviour challenges](#) Emerson et al. 2014).

10 The most commonly used definition of behaviour that challenges is: ‘behaviour of
11 such an intensity, frequency or duration that the physical safety of the person or
12 others is likely to be placed in serious jeopardy, or behaviour which is likely to
13 seriously limit or delay access to and use of ordinary community facilities’ (Emerson
14 et al. 1987¹). Later definitions have highlighted the role of cultural context in
15 determining whether behaviour is perceived as challenging (Emerson 1995²).

16 This guideline was developed in a context of changing policy and practice for people
17 with a learning disability and behaviour that challenges. The support needs of this
18 vulnerable group were set out in 1992 in the Mansell Report³ which identified the
19 need to invest in developing local services with appropriate levels of skilled staff to
20 meet people’s needs. This was restated in a later review, the so-called ‘Mansell 2
21 report’ ([Services for people with learning disabilities and challenging behaviour or
22 mental health needs](#) Department of Health), which also highlighted the increased
23 use of placements away from people’s homes.

24 The exposure of widespread abuse at Winterbourne View in 2011 led to a review of
25 care provided in this hospital, and across England more widely, for people with a

¹ Emerson E., Barrett S., Bell, C., Cummings R., McCool C., Toogood A., Mansell, J., (1987)
Developing services for severe learning difficulties and challenging behaviours. Canterbury: Institute
of Social and Applied Psychology. University of Kent

² Emerson E (1995) Challenging behaviour: Analysis and intervention in people with learning
disabilities. Cambridge: Cambridge University Press

³ 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.

1 learning disability and behaviour that challenges. The resulting report [Transforming](#)
2 [Care: a national response to Winterbourne View hospital](#) (Department of Health)
3 started a programme of work to improve services for people with a learning disability
4 and behaviour that challenges. In particular this aims to shift emphasis from inpatient
5 care in mental health hospitals, towards care provided by general and specialist
6 services in the community. The programme did not meet its original targets as
7 highlighted in a report by the National Audit Office ([Care services for people with](#)
8 [learning disabilities and challenging behaviour](#)), and was reconfigured in 2015.

9 The Transforming Care Programme is now led jointly by NHS England, the
10 Association of Directors of Adult Social Services, Care Quality Commission, Local
11 Government Association, Health Education England and Department of Health. They
12 formed the national plan, [Building the right support](#) (2015), which included the plans
13 for 48 Transforming Care Partnerships to pilot new arrangements of services. The
14 national plan was followed by NHS England developing a [national service model](#)
15 (October 2015) that set out the range of support that should be in place no later than
16 March 2019. To support implementation of the interim service model, NHS England
17 developed 3 [Model service specifications](#) (January 2017).

18 This guideline takes into account the direction of travel in Transforming Care. It aims
19 to complement this work by providing evidence-based recommendations to support
20 children, young people and adults with a learning disability and behaviour that
21 challenges to live their lives in the community like everyone else.

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

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

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

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

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

- 5 • [Care Act 2014](#) and associated guidance
- 6 • [Children Act 1989](#) and associated guidance
- 7 • [Children and Families Act 2014](#)
- 8 • [Mental Capacity Act 2005](#)
- 9 • [Accessible Information Standard](#).

10 ***How has it been developed?***

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

18 Equality and diversity issues have been considered throughout the development of
19 the guideline.

20 ***More information***

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

21

1 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.

2

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

6 ***Aims and principles***

7 This guideline is based on the principle that children, young people and adults with a
8 [learning disability](#) and [behaviour that challenges](#) should be supported to live where
9 and how they want. The guideline recommends ways of designing and delivering
10 services that aim to:

- 11 • maximise people’s choice and control
- 12 • promote person-centred care
- 13 • help people take an active part in all aspects of daily life that they choose, based
14 both on what they can do and what they want to do
- 15 • respect people’s cultural, religious and sexual identity
- 16 • help people as soon as problems emerge, not just when crisis has been reached
- 17 • promote continuity of relationships.

18 The guideline aims to help local areas rebalance their services by shifting the focus
19 towards enabling people to live in their communities and increasing support for
20 families and carers. This should reduce the need for people to move away for care
21 and treatment.

22

1 **1.1 *Achieving change: strategic planning and infrastructure***

2 **Local leadership**

3 1.1.1 Local authorities and clinical commissioning groups should jointly
4 designate a single lead commissioner who is responsible for
5 commissioning health, social care and education services for [children](#),
6 [young people](#) and adults with a [learning disability](#), including for those
7 whose behaviour is described as challenging. This commissioner should
8 have in-depth knowledge and experience of working with people with a
9 learning disability and [behaviour that challenges](#).

10 1.1.2 Local authorities and clinical commissioning groups, acting through the
11 single lead commissioner, should consider jointly commissioning the most
12 specialised behaviour support services across areas for people with
13 particularly complex needs.

14 **Planning budgets**

15 1.1.3 The lead commissioner should work to pool budgets or other resources
16 for health, social care and education with neighbouring authorities, to
17 develop local and regional services for people with a learning disability
18 and behaviour that challenges.

19 1.1.4 Commissioners should ensure that funding mechanisms for [providers](#)
20 support creative and flexible community-based responses, for example a
21 ‘contingency fund’ that providers can draw on quickly if there is a crisis.

22 **Planning and delivering services according to local need**

23 1.1.5 Local authorities and clinical commissioning groups, acting through the
24 single lead commissioner, should develop and provide services for people
25 with a learning disability and behaviour that challenges based on local
26 need. Make sure that planning and delivery:

- 27 • is based on an assessment of the likely current and future local service
28 needs for people with a learning disability and behaviour that
29 challenges using:

- 1 – population prevalence rates of children, young people and adults
2 with learning disabilities and
3 – known data on the proportion of this population who are likely to
4 have different types of challenging behaviour
- 5 • uses an analysis of assessed needs in education, health and social
6 care plans, including data which provides an early view of likely service
7 needs and enables prevention and early intervention
 - 8 • makes use of other sources of information, such as registers of people
9 at risk of admission and records of referrals from liaison and diversion
10 teams, youth offending teams and police
 - 11 • enables person-centred planning and provision
 - 12 • addresses the needs of different age groups but also takes a 'whole life'
13 approach to planning
 - 14 • includes planning for a range of future housing and employment
15 support needs
 - 16 • are integrated.

17 1.1.6 The lead commissioner should develop local and regional plans that have
18 a single care pathway and point of access for children, young people and
19 adults with a learning disability and behaviour that challenges and their
20 families. Make sure this is reflected in local authorities' commissioning
21 strategies and key documents such as the Market Position Statement.
22 (For further information on how to develop care pathways see 'organising
23 effective care' in [general principles of care](#) in NICE's guideline on
24 challenging behaviour and learning disabilities: prevention and
25 interventions.)

26 **Managing risk**

27 1.1.7 The lead commissioner should take joint responsibility with providers for
28 managing risk when developing and delivering care for people with a
29 learning disability and behaviour that challenges. They should aim to
30 manage risks and difficulties without resorting to changing placements or
31 putting greater restrictions on the person.

1 **Quality assurance**

2 1.1.8 Commissioners of services for people with a learning disability and
3 behaviour that challenges should commission services to meet set service
4 level and individual outcomes, and require service providers to show
5 evidence of achieving these outcomes. This evidence could include:

- 6 • satisfaction ratings of people who have used the service, and their
7 family members and carers
- 8 • outcomes measured by personalised and validated tools such as the
9 Measure of Processes of Care (MPOC) tool, or the Patient Feedback
10 Questionnaire (PFQ)
- 11 • stability of placements
- 12 • reports on the use of restraint
- 13 • contact time with specialist professionals
- 14 • evidence from quality reviews and spot checking involving [experts by](#)
15 [experience](#).

16 1.1.9 Inpatient services should provide the evidence in recommendation 1.1.8 in
17 addition to evidence of detailed assessments, treatment outcomes and
18 time to discharge.

19 1.1.10 Commissioners should establish a multi-agency group, including experts
20 by experience and providers, to monitor the quality of services and the
21 outcomes achieved. Commissioners should use these as part of their
22 performance management of services.

23 1.1.11 Service providers should use evidence gathered to continuously improve
24 services. They should record the results and make them available to
25 people who use services, and their families.

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

27 1.1.12 Commissioners should employ experts by experience in their
28 commissioning teams in order to inform decision-making and quality
29 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

1 lacks the capacity to make a decision, staff must follow the [Mental](#)
2 [Capacity Act 2005](#).

3 1.2.5 Practitioners should assess whether a child or young person under the
4 age of 16 is [Gillick competent](#) and work in partnership with all children and
5 young people, including them in decisions about their treatment and how
6 they would like their families or carers to be involved.

7 1.2.6 Staff working with people with a learning disability should find out their
8 information and communication needs, record them and share this
9 information with everyone working with them.

10 1.2.7 All staff working with people with a learning disability and behaviour that
11 challenges should have access to specialists in communication when
12 needed.

13 1.2.8 Local authorities must offer independent advocacy as described in the
14 [Care Act 2014](#), [Mental Capacity Act 2005](#) and [Mental Health Act 2007](#).
15 Think about offering it whenever it is wanted or needed by a person with a
16 learning disability and behaviour that challenges. Local authorities should
17 ensure that independent advocates working with children, young people
18 and adults with a learning disability and behaviour that challenges have
19 skills and experience in working with these groups, and in liaising with
20 specialist learning disability services.

21 **Coordinating care**

22 1.2.9 Local authorities should assign a single practitioner, such as a social
23 worker in the community learning disability team, to be the person's
24 'named worker' and coordinate their support.

25 1.2.10 The named worker should arrange regular meetings to discuss the
26 person's care and support and invite people in their support network,
27 including family members, carers, advocates and practitioners from all
28 services that support them. Recognise and use the expertise brought by
29 all members of the network (not only those who are paid).

1 **Care and support planning**

2 1.2.11 Community learning disability teams and service providers should work in
3 partnership with the person and their family members and carers to
4 develop and deliver their care and support plan. Develop a care plan that:

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

11

12 1.2.12 Community learning disability teams and service providers should work
13 with the person who displays behaviour that challenges and their family
14 and carers to develop a behaviour support plan. For more information on
15 what this should include, see the [behaviour support plan](#)
16 recommendations in section 1.6 of NICE's guideline on challenging
17 behaviour and learning disabilities: prevention and interventions.

18 1.2.13 Providers and agencies responsible for commissioning and planning
19 services (including specialist services) should match the specific skills of
20 staff to the characteristics of the person with a learning disability and
21 behaviour that challenges. Do this as soon as care planning begins.

22 1.2.14 In all settings, staff should provide people with a learning disability and
23 behaviour that challenges (and their families and carers) with strategies
24 and interventions to increase communication and other skills to reduce
25 their risk of developing behaviour that challenges. Follow the
26 recommendations on [psychological and environmental interventions](#) in
27 section 1.7 of NICE's guideline on challenging behaviour and learning
28 disabilities: prevention and interventions.

29 1.2.15 Community learning disability teams should review people's care and
30 support as agreed within their plan as well as when there is a significant

1 change, for example if the person is placed out of area. When reviewing
2 people's plans:

- 3 • take account of people's fluctuating capacity
- 4 • check that staff are following the [behaviour support plan](#)
5 recommendations in NICE's guideline on challenging behaviour and
6 learning disabilities: prevention and interventions
- 7 • think about plans for the future, including if changes might be needed to
8 the person's housing or support.

9 **Supporting people to use personal budgets**

10 1.2.16 Local authorities should offer people a choice of direct payments,
11 personal health budgets or individual service funds, depending on their
12 needs and preferences.

13 1.2.17 Local authorities should help people to use their personal budgets,
14 continuing healthcare budgets, individual service funds and direct
15 payments (where they wish to) by:

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

28 [Adapted from NICE's guideline on [older people with social care needs](#)
29 [and multiple long-term conditions](#)]

1 1.3 of NICE's guideline on challenging behaviour and learning disabilities:
2 prevention and interventions. This could be in the form of a 'welcome
3 pack'. Provide this information:

- 4 • at the first point of contact with families
- 5 • through the local authority website, local libraries and universal
6 services such as GP surgeries.

7 1.3.5 The named worker in the community learning disability team should make
8 regular offers of support to understand this information from the first point
9 of contact onwards. Advise family members or carers about their right to,
10 and explain how to get:

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

20 **1.4 Services in the community**

21 **Developing community capacity**

22 1.4.1 The lead commissioner should commission services in the community for
23 people with a [learning disability](#) and [behaviour that challenges](#) (including
24 for people in contact with, or at risk of contact with, the criminal justice
25 system). These services:

- 26 • should be able to cater for lower-level needs up to intensive, complex
27 or fluctuating needs
- 28 • could be set up either as 1 large team with different subteams or as
29 several separate teams

1 • wherever possible should be provided as an alternative to, and to
2 reduce the potential need for:

- 3 – inpatient care for children, young people and adults **or**
4 – [residential placements](#) for children and young people.

5 1.4.2 Services in the community should fulfil the following core functions:

- 6 • specialist prevention and early intervention
7 • developing capacity in non-specialist community services to prevent
8 unnecessary inpatient admissions
9 • giving support and training to families (for more information on how to
10 support families see [support and interventions for family members or](#)
11 [carers](#) in section 1.3 of NICE’s guideline on challenging behaviour and
12 learning disabilities: prevention and interventions)
13 • quality assurance and service development
14 • short-term assessment and intervention
15 • longer-term complex intervention
16 • crisis response and intervention.

17 **Community learning disability teams**

18 1.4.3 Local authorities and clinical commissioning groups, acting through the
19 single lead commissioner, should ensure people can get support when
20 needed through their team from:

- 21 • occupational therapists
22 • psychologists
23 • psychiatrists
24 • physiotherapists
25 • speech and language therapists
26 • community learning disability nurses
27 • healthcare facilitators
28 • social workers
29 • educational psychologists (for children and young people)
30 • behaviour therapists

- 1 • forensic learning disabilities specialists
- 2 • independent reviewing officers (for looked-after children).

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

6 1.4.4 Services who provide support through the community learning disability
7 team should work together and provide consultancy and support to each
8 other. They should work with people and their family members and carers
9 in a way that is:

- 10 • personalised
- 11 • flexible
- 12 • responsive
- 13 • accessible.

14
15 1.4.5 If a person develops risky or offending behaviour, community learning
16 disability teams should refer them to appropriate specialists, such as
17 community forensic teams, as soon as possible to reduce the likelihood of
18 this behaviour repeating. These teams should provide early, evidence-
19 based interventions which are adapted for people with a learning disability
20 and address the specific behaviour.

21 1.4.6 Community learning disability teams should maintain good communication
22 and links with the police and liaison and diversion teams so that:

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

1 **Specialist behavioural support**

2 1.4.7 The lead commissioner should ensure that specialist assessment and
3 behavioural support are available in the community so that people can
4 stay where they currently live and avoid moving.

5 1.4.8 The lead commissioner should make specialist services for behaviour that
6 challenges available to everyone with a learning disability and behaviour
7 that challenges, based on individual need. People should never wait
8 longer than 18 weeks.

9 **Intensive behavioural support during a crisis**

10 1.4.9 Provide a local, personalised response to people who need intensive
11 support during a crisis. This response should:

- 12 • focus on keeping people in their own home
- 13 • have an out-of-hours helpline as a first option, staffed by people with
14 skills and knowledge about the needs of people with a learning
15 disability and behaviour that challenges, and specialist skills in mental
16 health problems
- 17 • have sufficient capacity to provide a response within 1 hour
- 18 • involve partnership with other commissioners, providers and family
19 members
- 20 • include giving staff access to the person's information if they are
21 already in contact with services
- 22 • provide short-term support to achieve aims that are agreed with the
23 person
- 24 • include clear contact details for adults' and children's services.

25
26 1.4.10 Local authorities, community learning disability teams and specialist
27 support services should use a clear, coordinated approach to reducing the
28 level of support from more intensive services in line with the person's
29 needs. They should learn from what happened and use this to inform
30 future crisis plans.

1 **Services for people in contact with, or at risk of contact with, the criminal**
2 **justice system**

3 1.4.11 The lead commissioner should commission local [forensic services](#) for
4 people in contact with, or at risk of contact with, the criminal justice
5 system to prevent out-of-area hospital placement.

6 1.4.12 Forensic community learning disability teams should support people with
7 a learning disability who are subject to a forensic community rehabilitation
8 order or a community treatment order to live in the community, as close to
9 home as possible and in the least restrictive setting.

10 1.4.13 Community forensic teams should stay in frequent contact with the person
11 they are supporting, and help them build and maintain social links in their
12 community.

13 1.4.14 Forensic learning disability teams and probation services should work
14 together to agree who is best able to support the person in meeting the
15 requirements of their treatment or rehabilitation order.

16 1.4.15 Forensic learning disability services, mental health, learning disability and
17 social care services should establish close links with each other and refer
18 people quickly between these services to get the right support.

19 **1.5 Housing and day-to-day support**

20 **Giving people a choice of housing**

21 1.5.1 Commissioners should work with local housing providers to identify the
22 specific housing needs of people with a [learning disability](#) and [behaviour](#)
23 [that challenges](#). They should ensure areas have a range of housing
24 options available that meet these needs and cater for different
25 preferences and support needs.

26 1.5.2 Support people to live close to their family, friends and community unless
27 they choose not to or there is a compelling reason not to.

- 1 1.5.3 Where possible ensure that, wherever people live, they have security of
2 tenure in line with the [Real Tenancy Test](#).
- 3 1.5.4 When helping adults with a learning disability and behaviour that
4 challenges choose where to live:
- 5 • take into account their preferences and any specific support needs or
6 risks
 - 7 • give them advice on adapting their home if needed
 - 8 • offer them the option to live alone with appropriate support if they prefer
9 this and it is suitable for them.
- 10 1.5.5 If people prefer not to live alone, or it is not suitable for them, offer them
11 the option to live in shared housing with up to 3 other residents.
- 12 1.5.6 The lead commissioner should offer people housing outside their local
13 community only:
- 14 • if that is what the person wants
 - 15 • if it is indicated after a full assessment and planning process, which
16 takes into account the person's preferences, needs and risks
 - 17 • for a specified time that has been agreed with the person, or agreed in
18 their best interests if they lack capacity to decide this – for example if
19 they are in crisis and there is no local placement available.
- 20 1.5.7 If someone is moving outside their local area, the lead commissioner
21 should:
- 22 • establish the 'responsible commissioner' who will be responsible for
23 paying for that person's care
 - 24 • ensure they will still have the support they need
 - 25 • make a plan that enables them to return to their local area if they want
26 to, or it is in the best interests if they lack capacity to decide this.

1 **Providing day-to-day support**

2 1.5.8 Ensure that people know about and are able to use services to support
3 their health and wellbeing. These should include:

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

10 **1.6 Services for children and young people**

11 1.6.1 Local authorities and clinical commissioning groups, acting through the
12 single lead commissioner, should ensure that specialist behavioural
13 support in the community for children and young people includes support
14 from education and child and adolescent mental health service (CAMHS)
15 practitioners who have skills and experience in working with children and
16 young people with a [learning disability](#) and [behaviour that challenges](#).

17 1.6.2 Local authorities must promote the upbringing of children and young
18 people with a learning disability and behaviour that challenges by their
19 families, in line with [section 17 of the Children Act 1989](#). This should
20 include providing both general and specialist learning disability support
21 services in the community, as an alternative to [residential placements](#)
22 away from home and to reduce the potential need for such placements.

23 1.6.3 Health, mental health and behaviour support practitioners should work
24 with other services, for example education services and practitioners, to:

- 25 • deliver the outcomes agreed in a child or young person's education,
26 health and care plan
- 27 • provide support and interventions in line with NICE's guideline on
28 [challenging behaviour and learning disabilities: prevention and](#)
29 [interventions](#)

- 1 • maximise life opportunities for children and young people, including
2 through access to meaningful education.

3
4 1.6.4 If a child or young person’s behaviour that challenges is deteriorating or
5 causing concern, the local authority should carry out a multi-agency
6 review of their education, health and care plan and involve their parents
7 and carers. Review whether the plan needs to be updated and additional
8 support provided if the child or young person’s needs have changed.

9 **Living in residential placements**

10 1.6.5 Only offer children and young people a [residential placement](#) if
11 assessment and care planning show that their needs cannot be safely met
12 in the community and all possibilities for doing so have been considered
13 and exhausted.

14 **Exploring alternatives to residential placements**

15 1.6.6 When considering a residential placement arrange a multi-agency review
16 to explore all other viable options and to review the child or young
17 person’s education, health and care plan. Include in this discussion:

- 18 • the child or young person and their family members and carers
19 • the single lead commissioner on behalf of the local authority and
20 clinical commissioning group
21 • at least one practitioner with clinical expertise in learning disability and
22 the person’s specific behaviour that is challenging.

23 **Planning and review to support leaving residential placements**

24 1.6.7 The lead commissioner should commission residential placements for
25 children and young people as close to home as possible. Take into
26 account in local authority contracts that some families may need financial
27 support to help them see their child and for their child to visit them.
28 Support them to maintain links with family, friends and community (for
29 example, members of their religious community) while they are in a
30 residential placement.

1 1.6.8 Local authorities and providers must promote maximum contact between
2 children and young people living in residential placements and their family
3 members and carers (in line with [schedule 2](#) of the Children Act 1989). If a
4 placement lasts longer than 3 months the [Visiting Regulations 2011](#) must
5 be followed, for both local and out-of-area placements. Help families stay
6 in touch between visits when they want to, for example using Skype.

7 1.6.9 The lead commissioner should ensure a plan is developed as soon as a
8 child or young person moves into the placement for how they will move
9 towards a less restrictive setting (including returning to their family if
10 appropriate) and towards greater independence.

11 1.6.10 Review the plan in recommendation 1.6.9 at least every 6 months to
12 check that progress is being made. This could be done as part of the
13 education, health and care plan review, or sooner if needed. It should be
14 reviewed by the practitioner responsible for overseeing the child or young
15 person's education health and care plan and all practitioners involved in
16 the child or young person's care, including a specialist in behaviour that
17 challenges.

18 1.6.11 If progress towards the outcomes in the plan has not been made, explore
19 and address the reasons for this. If the child, young person or their family
20 disagrees with the decision made at the review meeting, explain how they
21 can challenge the decision if they want to.

22 **1.7 Respite care**

23 1.7.1 Commissioners in health and social care should provide reliable, flexible
24 and varied respite options for children, young people and adults with a
25 [learning disability](#) and [behaviour that challenges](#). These should include
26 both breaks away and support at home. Make sure these are:

- 27 • community-based and close to home
- 28 • available at short notice, in crisis and to prevent a crisis
- 29 • available based on need
- 30 • tailored to the needs of the person and their family or carers

- 1 • able to provide a positive experience for the person being supported.

2 1.7.2 Ensure that respite care:

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

13 **1.8 *Making the right use of inpatient services***

14 1.8.1 Admit children, young people and adults with a [learning disability](#) and

15 [behaviour that challenges](#) to inpatient units only if assessment and care

16 planning show that their needs cannot be safely met in the community and

17 all possibilities for doing so have been considered and exhausted.

18 1.8.2 When considering inpatient admission, arrange a discussion to explore all

19 other viable options. Include in this discussion:

- 20 • the person and their family members and carers
- 21 • at least one practitioner with clinical expertise in learning disability and
- 22 the person’s specific behaviour that is challenging
- 23 • at least one independent [expert by experience](#).

24 An example of this is a community [Care and Treatment Review](#) or, for

25 children and young people, a community [Care, Education and Treatment](#)

26 [Review](#).

27 **Providing information**

28 1.8.3 When there is a possibility that someone will be admitted to hospital,

29 including as an informal admission, give them and their families and

1 carers accessible, independent information and advice about their rights
2 and other possible options for care and treatment.

3 1.8.4 Service providers must provide information about independent mental
4 health advocacy as required by the [Mental Health Act 1983](#).

5 **Selecting a placement when required**

6 1.8.5 Local authorities and clinical commissioning groups, acting through the
7 single lead commissioner, should provide an inpatient placement that is
8 as close as possible to where the person usually lives.

9 1.8.6 The named worker should support the person to maintain links with family,
10 friends and community (for example, members of their religious
11 community) while they are in hospital, and give their family and friends
12 information about their progress.

13 1.8.7 Social workers in community learning disability teams should support
14 people who are admitted as inpatients outside their local area to maintain
15 contact with key practitioners in their home area. This should include their
16 named worker.

17 1.8.8 When someone is admitted as an inpatient, offer them interventions in line
18 with [early identification of the emergence of behaviour that challenges](#) in
19 NICE's guideline on challenging behaviour and learning disabilities:
20 prevention and interventions. Ensure that interventions specifically
21 address their needs and the reason for their admission.

22 **Planning and review to support discharge**

23 1.8.9 The lead commissioner should ensure that hospitals work together with
24 community learning disability teams to develop a discharge plan as soon
25 as the person is admitted.

26 1.8.10 The practitioners involved in the person's care, including the practitioner
27 responsible for agreeing discharge, should review the person's discharge
28 plan at least every 3 months. Reviews should include the person and their
29 family members and carers as well as a specialist in behaviour that

- 1 challenges. Think about using the [Care Programme Approach](#) as a
2 framework for these reviews. For children and young people think about
3 using the [Care, Education and Treatment Review](#) process.
- 4 1.8.11 If the person is not discharged after the meeting with practitioners
5 involved in their care, provide sufficient reason for this and develop a new
6 plan towards discharge. Explain to the person or their family and carers
7 how they can challenge the decision if they want to.
- 8 1.8.12 Tell people who might apply to, or are referred for, a first-tier mental
9 health tribunal relating to being an inpatient, about their right to request an
10 independent clinician to:
- 11 • visit them at any reasonable time and examine them in private
 - 12 • inspect any records relating to their conditions and treatment (in line
13 with [section 76 of the Mental Health Act](#))
- 14 **1.9 Staff skills and values**
- 15 1.9.1 As part of staff recruitment and training, ensure that staff have the skills,
16 knowledge and qualities they need to support people. This includes:
- 17 • the skills and knowledge in 'staff training, supervision and support' in
18 the [general principles of care](#) section of NICE's guideline on
19 challenging behaviour and learning disabilities: prevention and
20 interventions
 - 21 • being resilient and compassionate
 - 22 • showing that they care
 - 23 • understanding and respecting the person's faith, culture, identity and
24 values.
- 25 1.9.2 Ensure that staff providing direct support to people with a [learning](#)
26 [disability](#) and [behaviour that challenges](#) have the 'direct contact' level
27 competencies of the [Positive behaviour support competence framework](#).

- 1 1.9.3 Give staff providing direct support access to advice from [behaviour](#)
2 [support specialists](#) with 'consultant' level competencies of the [Positive](#)
3 [behaviour support competence framework](#).
- 4 1.9.4 Commissioners should plan for and resource training among service
5 providers who provide day-to-day support about how to work with people
6 with learning disabilities who are at risk of offending.
- 7 1.9.5 Organisations should ensure that staff have supervision and support, in
8 line with the recommendations on 'staff training, supervision and support'
9 in the [general principles of care](#) section of NICE's guideline on challenging
10 behaviour and learning disabilities: prevention and interventions.
- 11 1.9.6 Involve people with a learning disability and behaviour that challenges in
12 staff recruitment. Involve their family members and carers too if the
13 person agrees, unless there is a compelling reason not to.

14 ***Terms used in this guideline***

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

17 **Behaviour support specialist**

18 A practitioner (for example a behaviour analyst) who has training in helping people
19 and their family members and carers to understand and change their behaviour, if it
20 is causing problems for them.

21 **Behaviour that challenges**

22 Behaviour of such an intensity, frequency or duration that the physical safety of the
23 person or others is likely to be placed in serious jeopardy, or behaviour that is likely
24 to seriously limit or delay access to and use of ordinary community facilities.

25 **Children**

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

1 **Expert by experience**

2 People with lived experience of using services for people with a learning disability
3 and behaviour that challenges, including people with a learning disability themselves
4 and their family members and carers.

5 **Forensic services**

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

8 **Learning disability**

9 In line with NICE's guideline on challenging behaviour and learning disabilities, a
10 learning disability is defined as meeting 3 core criteria:

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

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

17 **Providers**

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

22 **Real Tenancy Test**

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

1 **Residential placement**

2 Examples of residential placements include residential care homes for adults and, for
3 children and young people, placements that involve living away from their family
4 home such as residential schools and colleges.

5 **Young people**

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

7 **Putting this guideline into practice**

8 **[This section will be finalised after consultation]**

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

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

- 14 • Children, young people and adults with learning disabilities and behaviour that
15 challenges are likely to use both health and care services throughout their lives.
16 However, a lack of integration across services, including children's and adults'
17 services, can impact on the quality of care. Local authorities, working together
18 with clinical commissioning groups, can provide a more joined-up and person-
19 centred approach by designating a single lead commissioner who is responsible
20 for commissioning learning disability health, social care and education services for
21 both adults and children, including for people whose behaviour is described as
22 challenging. For some services creating this role may involve a significant change
23 in practice.
- 24 • Family members and carers often play a significant role in supporting people with
25 a learning disability and behaviour that challenges, but they can find it difficult to
26 access information, guidance and support. Many families need training and
27 support for their caring role from specialist services, including positive behaviour
28 support services. Families may also benefit from services such as peer support.
29 Local authorities and health services need to provide this information and support,
30 and tell families how they can access it. For areas that do not currently provide

1 comprehensive support for families this will involve a significant change in
2 practice.

- 3 • Developing good general and specialist community services is important for
4 supporting people with a learning disability and behaviour that challenges to live
5 how and where they want, and to avoid the need for hospital admission or
6 residential placements away from home. Developing capacity in services and
7 housing to support people in the community is likely to be a challenge in areas
8 where resources are focused on inpatient care. Clear plans will need to be
9 developed, agreed and put in place to make this change.
- 10 • People with a learning disability and behaviour that challenges should not be
11 admitted to inpatient units unless all other possible options have been considered
12 and exhausted. Similarly, children and young people should only be placed in
13 residential placements if all other possibilities have been considered. When
14 people are admitted to hospital, or children and young people are placed in a
15 residential placement, planning for them to return to the community or a less
16 restrictive placement should begin immediately. The plan should be reviewed
17 regularly. Where this is not current practice, significant change will be needed.

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

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

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

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

- 28 1. **Raise awareness** through routine communication channels, such as email or
29 newsletters, regular meetings, internal staff briefings and other communications with
30 all relevant partner organisations. Identify things staff can include in their own
31 practice straight away.

- 1 **2. Identify a lead** with an interest in the topic to champion the guideline and motivate
2 others to support its use and make service changes, and to find out any significant
3 issues locally.
 - 4 **3. Carry out a baseline assessment** against the recommendations to find out
5 whether there are gaps in current service provision.
 - 6 **4. Think about what data you need to measure improvement** and plan how you
7 will collect it. You may want to work with other health and social care organisations
8 and specialist groups to compare current practice with the recommendations. This
9 may also help identify local issues that will slow or prevent implementation.
 - 10 **5. Develop an action plan**, with the steps needed to put the guideline into practice,
11 and make sure it is ready as soon as possible. Big, complex changes may take
12 longer to implement, but some may be quick and easy to do. An action plan will help
13 in both cases.
 - 14 **6. For very big changes** include milestones and a business case, which will set out
15 additional costs, savings and possible areas for disinvestment. A small project group
16 could develop the action plan. The group might include the guideline champion, a
17 senior organisational sponsor, staff involved in the associated services, finance and
18 information professionals.
 - 19 **7. Implement the action plan** with oversight from the lead and the project group.
20 Big projects may also need project management support.
 - 21 **8. Review and monitor** how well the guideline is being implemented through the
22 project group. Share progress with those involved in making improvements, as well
23 as relevant boards and local partners.
- 24 NICE provides a comprehensive programme of support and resources to maximise
25 uptake and use of evidence and guidance. See our [into practice](#) pages for more
26 information.
- 27 Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care –
28 practical experience from NICE. Chichester: Wiley.

1 **Recommendations for research**

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

4 ***1 Models of person-centred support***

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

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

11 **Why this is important**

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

19 ***2 Supporting family members, carers and staff***

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

23 **Why this is important**

24 Enabling family members, carers and staff to provide continuing care and support
25 can help prevent placements from breaking down, which can lead to out-of-area
26 placements. Investment in carers, support networks, initiatives that support
27 independent living, and community networks are key to developing resilience and
28 are needed if new approaches to service delivery, such as personalisation, are to

1 succeed. There is no direct empirical evidence of the social and economic benefits
2 associated with investment in such approaches and services.

3 ***3 Models of supported living***

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

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

8 **Why this is important**

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

18 ***4 Effective components of integrated regional challenging*** 19 ***behaviour services***

20 What are the effective components of an integrated regional challenging behaviour
21 service across health and social care (including pooling budgets and other
22 resources)?

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

25 **Why this is important**

26 The Winterbourne Review Action Group and Transforming Care recommended that
27 health and social care services should pool budgets. However, reports from the
28 National Audit Office highlight that there has been little evidence of this happening in
29 practice. Research is needed to know what mechanisms enable or stop the practice

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- 1 from happening and if the practice results in better outcomes for people with a
- 2 learning disability.
- 3 **ISBN:**