

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Learning disabilities and behaviour that challenges: service guidance

Topic

The Department of Health in England and the Department for Education have asked NICE to develop a social care guideline on services for children, young people and adults with learning disabilities and behaviour that challenges.

Who the guideline is for

- 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.
- Children, young people and adults with learning disabilities and behaviour that challenges and their families and carers, including people who purchase their own care. It will also be relevant to:
 - Practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers in related services including housing, voluntary and community, education, employment, housing and criminal justice services.
 - Providers of related services, including housing, education, voluntary, employment and criminal justice services.
 - Commissioners of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges.

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](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope, if this was done.

1 What the guideline is about

1.1 Who is the focus?

Groups that will be covered

People with mild, moderate, severe or profound learning disabilities¹ and behaviour that challenges, and their families and carers. This includes those with autism who also have a learning disability and behaviour that challenges.

1.2 Settings

Settings that will be covered

All settings where a person receives care and support commissioned by health or social care, including:

Community

- People's own homes and other housing, including temporary accommodation.
- Foster care.

¹ NICE's guideline on [challenging behaviour and learning disabilities](#) specifies that: 'A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.' This definition of challenging behaviour and learning disabilities will also be used in this guideline.

- Extra care housing (such as warden-supported, sheltered or specialist accommodation).
- Shared Lives Scheme (formerly Adult Placement Scheme) living arrangements.
- Supported living.
- Day care.
- Specialist schools.

Residential

- All residential and nursing care homes.
- Care homes for children (including secure children's homes).
- Specialist residential schools.
- Respite care.
- Short break.

Inpatient

- Older people's mental health and learning disability inpatients.
- Adult mental health and learning disability inpatients (including secure).
- Children's mental health and learning disability inpatients (including secure and tier 4 child and adult mental health services).
- Crisis response.
- Specialist learning disability assessment and treatment units.

1.3 *Activities, services or aspects of care*

Key areas that will be covered

This service guidance will focus on what services should be provided and how these should be organised and configured to deliver these interventions effectively. We have produced a guideline on [prevention and interventions for people with learning disabilities whose behaviour challenges](#).

- 1 Integration of health and social care services for people with learning disabilities and behaviour that challenges.
- 2 Location of services.

- 3 Joint working with related services including:
 - housing
 - education
 - employment
 - criminal justice services
 - voluntary sector.
- 4 Strategic planning.
- 5 Types of service provision including:
 - intensive community support
 - liaison and diversion
 - crisis beds
 - crisis intervention
 - inreach and outreach team
 - supported housing schemes
 - intensive home support
 - short break and respite
 - community-based assessment and treatment
 - secure inpatient
 - specialist community forensic
 - advocacy.
- 6 Service capacity.
- 7 Timely access to services.
- 8 Risk management.
- 9 Safeguarding.

Areas that will not be covered

- 1 Treatment, therapy, prevention and management of behaviour that challenges in people with learning disabilities. This is covered in NICE's guideline on prevention and interventions for people with learning disabilities whose behaviour challenges.

1.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant and, if so, whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using a public sector perspective, as appropriate.

1.5 Key issues and questions

While writing this scope we have drafted the following review questions. These are only examples. A full list of review questions, covering all the key areas and issues, will be agreed by the guideline committee at the start of guideline development.

- 1 Types of service provision:
 - 1.1 What types of community-based services are effective and cost effective for people with learning disabilities and behaviour that challenges?
 - 1.2 What types of inpatient services are effective and cost effective for people with learning disabilities and behaviour that challenges?
- 2 Service capacity:
 - 2.1 What is the appropriate community-based service capacity for people with learning disabilities and behaviour that challenges, and their families and carers?
 - 2.2 What is the appropriate inpatient bed capacity for people with learning disabilities and behaviour that challenges, and their families and carers?
- 3 Service delivery:
 - 3.1 What models of service delivery are effective and cost effective for people with learning disabilities and behaviour that challenges, and their families and carers?

3.2 What models of service delivery facilitate timely access to effective and cost-effective services for people with learning disabilities and behaviour that challenges?

4 Integration of services:

4.1 What mechanisms enable effective joined-up working between service providers supporting people with learning disabilities and behaviour that challenges, and their families and carers?

1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

1 Person-focused outcomes:

- Capability to achieve desired, person-centred outcomes as listed in the 9 areas of wellbeing set out in the [Care Act 2014](#).
- Child development outcomes.
- Continuity of care.
- Families and carer stress and resilience.
- Frequency, severity and duration of behaviour that challenges.
- Health- and social-care-related quality of life.
- Inclusion in community life.
- Involvement of people using services, their families and carers in the planning, delivery and monitoring of services.
- Mental wellbeing and psychological health outcomes.
- Service user, family and carer satisfaction.

2 Service-focused outcomes:

- Availability, access and uptake of local services.
- Equity of access.
- Extent to which general and complex physical and mental health needs are met.
- Geographical variation in service provision (locally, regionally and nationally).
- Level and type of support from care workers and carers.

- Positive behaviour support.
- Timely discharge: length of hospital stay; delayed transfers of care from hospital.
- Use of health and social care services (inpatient, residential and community).
- Use of inpatient placements.
- Use of manual restraint.
- Use of medication.
- Use of out-of-area placements.
- Use of seclusion methods.

2 Links with other NICE guidance, NICE quality standards and NICE Pathways

2.1 NICE guidance

NICE guidance that is closely related to this guideline

- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) (2015) NICE guideline NG27.
- [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#) (2015) NICE guideline NG11.
- [Violence and aggression: short-term management in mental health, health and community settings](#) (2015) NICE guideline NG10.
- [Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes](#) (2015) NICE guideline NG5.
- [Autism: the management and support of children and young people on the autism spectrum](#) (2013) NICE guideline CG170.

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to people with learning disabilities and behaviour that challenges:

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138.
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136.

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

- [Transitions from children to adult services](#) NICE guideline. Publication expected February 2016.
- [Transitions between inpatient mental health settings and community and care home settings](#). NICE guideline. Publication expected August 2016.
- [Mental health problems in people with learning disabilities](#). NICE guideline. Publication expected September 2016.
- [Care and support of older people with learning disabilities](#) NICE guideline. Publication expected October 2017.

2.2 NICE quality standards

NICE quality standards that may need to be revised or updated when this guideline is published:

- [Learning disabilities and behaviour that challenges](#) (2015) NICE quality standard QS101.
- [Autism](#) (2013) NICE quality standard QS51.
- [Supporting people to live well with dementia](#) (2013) NICE quality standard QS30.

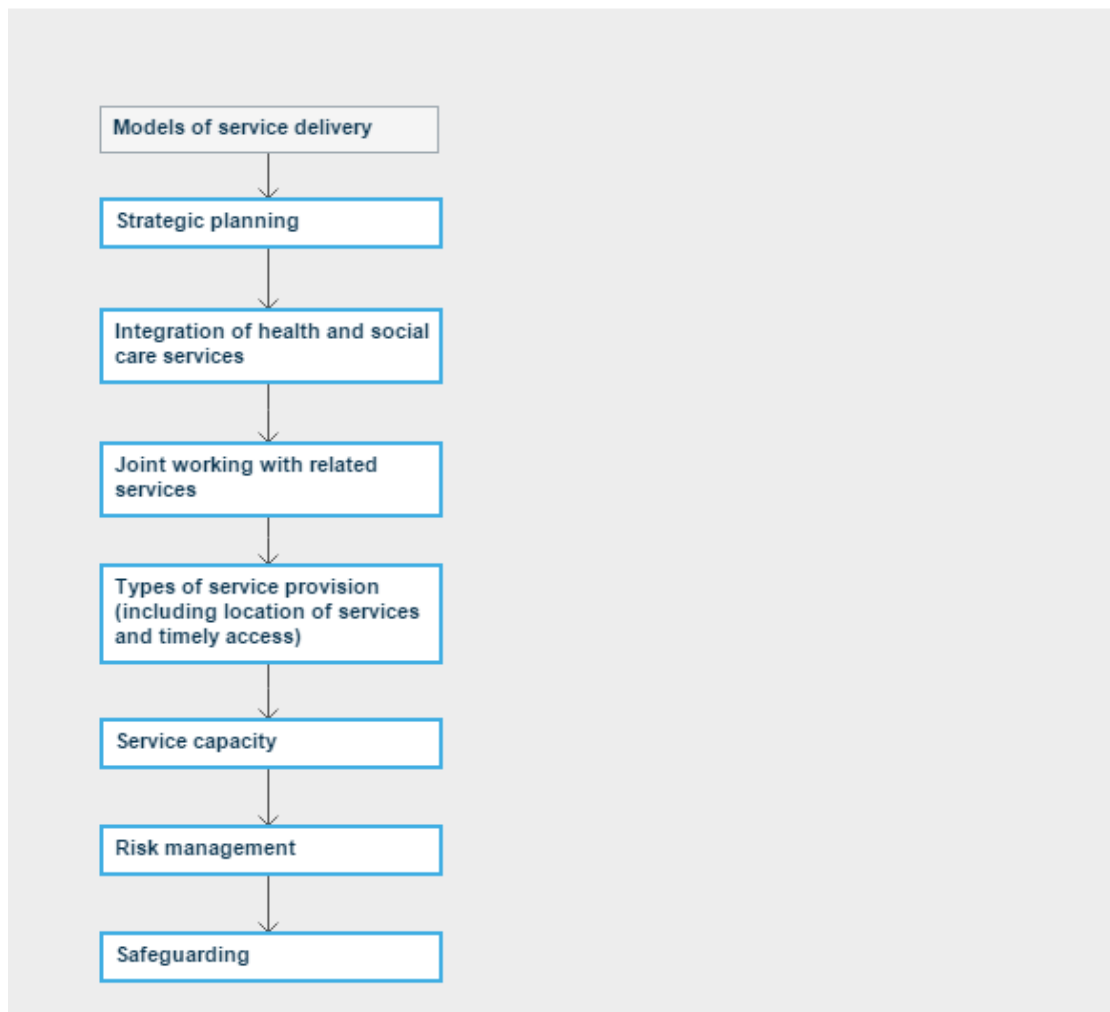
2.3 NICE Pathways

When this guideline is published, the recommendations will be added to [NICE Pathways](#). NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

A draft pathway outline on models of service delivery for people with learning disabilities and behaviour that challenges, based on the draft scope, is included below. It will be adapted and more detail added as the

recommendations are written during guideline development. The pathway will be integrated into the [challenging behaviour and learning disabilities pathway](#).

Models of service delivery for people with learning disabilities and behaviour that challenges overview



3 Context

3.1 Key facts and figures

Approximately 1 million people in England have a learning disability and of these people, 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). Rates are higher in teenagers and people in their early 20s.

It is estimated that between 60 and 70% of people with autism also have a learning disability ([Estimating the prevalence of autism spectrum conditions in adults](#) Department of Health).

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. 1987²).

The government strategy [Valuing People Now](#) identified that often these behaviours are the only way that people have of communicating that their needs are not being met. The report notes that it is essential to address these behaviours because 'ignoring them may put lives at risk'.

3.2 Current practice

Moving from hospital to community-based support

The exposure of widespread abuse at Winterbourne View in 2011 led to a full enquiry by the government. Following that enquiry, a number of national organisations signed up to the [Winterbourne View Concordat](#). As part of that, NHS England agreed to 'review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014'.

Progress has been slow and subsequent reporting ([Assuring Transformation, NHS England, March 2014](#)) showed that only 260 out of 2577 people in hospital with learning disabilities and challenging behaviour had a planned transfer date. Only 172 transfers are due before the 1 June 2014 deadline.

Not everyone in hospital is inappropriately placed and some may be under treatment orders from the Ministry of Justice. However, there are still a large

² Emerson E, Barrett S, Bell C et al. (1987) Developing services for severe learning difficulties and challenging behaviours. Canterbury: Institute of Social and Applied Psychology, University of Kent

number of people who were not given a planned transfer date when they were admitted.

Transforming care – next steps

A report by the Transforming Care and Commissioning Steering Group chaired by Stephen Bubb ([Winterbourne View: Time for Change](#) 2014) stated that clinicians 'are being asked to keep people in the community or discharge to the community when many will worry that the community-based support on offer is insufficient, or not there at all'.

Out-of-area placements

The Department of Health ([Winterbourne View: good practice examples](#)) notes that sending people to out-of-area placements can cause 'real harm to individuals by weakening their relationships with family and friends and taking them away from familiar places and community. It can damage continuity of care. It can also mean putting people into settings that they find stressful or frightening. This can impact negatively on mental health or increase the likelihood of challenging behaviour arising'.

Feedback from 13 learning disabilities commissioners found that young men with learning disabilities, challenging behaviour or autism continue to receive very high cost residential support, often in out-of-area residential care. There is limited evidence of plans to redirect resources to more local services.

According to the report, 54% of people had care plans but only 3% had been given a discharge date. Almost three-quarters (71%) of placements were outside the person's local area (McGill and Poynter 2012³).

Budget pressures

[The National Audit Office report Care Services for people with learning disabilities and challenging behaviour \(2015\)](#) states that around half of inpatients are funded directly by NHS England. It adds: 'There can be substantial extra costs to local health and care commissioners to meet

³ McGill P, Poynter J (2012) High cost residential placements for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 25(6): 584–7

discharged patients' community care needs when their hospital care was previously funded by NHS England'.

The report highlights that budget pressures have led clinical commissioning groups and local authorities to cut resources for mental health hospitals and community-based learning disability teams, including staffing. It says some 'specialist learning disabilities teams in the community have been run down, which has contributed to delays in introducing appropriate care packages. This has also increased the risk of hospital admissions, and readmissions, and the pressures on hospital resources'.

The implication is that reductions in community services are causing some people to remain in expensive hospital placements longer than is necessary. This is both bad for the person and a poor use of resources.

3.3 Policy, legislation, regulation and commissioning

Policy

The 2000 white paper [Valuing People: a new strategy for learning disability for the 21st century](#) signalled a new approach to the delivery of care for people with learning disabilities and their families. [Valuing People Now](#) (Department of Health) updated the original strategy and set out a 3-year strategy for implementing the change in approach it set out.

The Department of Health reports [Learning Disabilities Good Practice Project](#), [Improving health and care: the role of the outcomes frameworks](#) and [Valuing People Now: summary report March 2009 to September 2010 \(good practice examples\)](#) list several examples of innovative local practice.

This guideline will consider good practice examples, as well as drawing on the experience and knowledge of the guideline committee to review the effectiveness of different configurations of services and service models. It will also include the views and experiences of good practice from people using services, their families and carers and practitioners.

Legislation

The 2000 white paper [Valuing people: a new strategy for learning disability for the 21st century](#) set out 4 key principles underpinning the government's strategy: rights, independence, choice and inclusion. It states that everyone, including people with learning disabilities, has equal rights. This is supported by the [Human Rights Act 1998](#) and The [Equality Act 2010](#). The latter states that people with disabilities should not be discriminated against in: education, employment, exercise of public functions, goods, services, facilities and transport.

This guideline will make recommendations based on these principles.

Under the [Care Act 2014](#), local authorities have a duty to assess children and young people who are likely to have needs as adults, and their carers. If assessment shows they do have needs, the local authority has a duty to provide a care and support plan and offer them a personal budget to buy services. [The Carers and Disabled Children Act 2000](#) extends the provision of direct payments to carers and young people aged 16 and 17.

This guideline will examine evidence of the type of services that meet the needs of people with learning disabilities and behaviour that challenges, as children, young people and adults.

[The Children and Families Act 2014](#) requires that education, health and care plans reflect the views, interests and aspirations of children, young people and their parents and carers. It also requires that the assessment process is coordinated across education, health and care. Children and young people with learning disabilities or behaviour that challenges will probably need access to a range of organisations and professionals.

This guideline will examine the evidence on effective coordination of services across sectors for these children and young people.

People with learning disabilities and behaviour that challenge may sometimes need specialist mental health care in hospital. The rights of the person being admitted and the duties of healthcare professionals under these

circumstances are set out in the [Mental Health Act 1983 part II: compulsory admission to hospital and guardianship](#).

This Act is relevant to the services this guideline will look at, because people with learning disabilities are not to be detained for treatment for their learning disability alone and only in exceptional circumstances. For example, if their behaviour is 'abnormally aggressive or seriously irresponsible'.

Under the [Mental Capacity Act 2005](#), it is assumed that everyone aged 16 and over has the ability to make decisions about their own health and care, unless it is proven otherwise. So people should be supported in all ways possible to make their own decisions. This guideline will examine the most effective ways of achieving this.

Commissioning

The commissioning of services for people with learning disabilities and challenging behaviour involves local authorities, clinical commissioning groups and NHS England and can be fragmented. Provision is split between state-run and independent (mostly for profit) services. Often there is a lack of incentive to discharge and transfer people out of hospital or residential provision.

The Department of Health report [Services for people with learning disability and challenging behaviour or mental health needs](#) found that commissioning was 'too reactive', and there is evidence that this still applies. It was noted that decisions to buy services are often made 'on the basis of lowest cost in the short-term, without considering the long-term effects when things go wrong'.

Often, local services are still fragmented, disconnected and poorly designed and there is no consistent model for challenging behaviour services in England.

4 Further information

<p>This is the final scope, incorporating comments from registered stakeholders during consultation.</p>
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The expected publication date for this guideline is to be confirmed.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.