

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## SCOPE

### 1 Guideline title

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

#### 1.1 Short title

Challenging behaviour and learning disabilities

### 2 The remit

The Department of Health has asked NICE to prepare a clinical guideline on 'challenging behaviour in people with learning disability.'

### 3 Clinical need for the guideline

#### 3.1 Epidemiology

- a) Learning disabilities are heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood.
- b) 'Learning disabilities' is the widely used and accepted term in the UK. It is a term that has been used in Department of Health documents such as [Valuing people](#) (2001) and is well understood by health and social care professionals in the UK. It will therefore be used in this guideline, even though it is recognised that 'intellectual disabilities' is becoming the more widely accepted term internationally. The World Health Organisation's [International statistical classification of diseases and related health problems \(10<sup>th</sup> revised edition\)](#) (ICD-10) currently uses the term 'mental

retardation'. The group working on ICD-11, due to be published in 2015, has proposed that it amends this to 'intellectual developmental disorders'. [DSM-V](#), published in May 2013, replaced the DSM-IV term 'mental retardation' with 'intellectual disability'.

- c) [ICD-10](#) defines 4 degrees of learning disability: mild (an IQ of 50–69), moderate (an IQ of 35–49), severe (an IQ of 20–34) and profound (an IQ of less than 20). These categories have been criticised on the grounds that they omit any measure of social or adaptive functioning. In addition, it has been argued that in practice IQ scores are often uncertain in people with more severe learning disabilities. It is also widely recognised that IQ scores are not fixed throughout life, so provide only an approximate guide to intellectual ability. Accordingly, many health and social care professionals object to subdividing learning disabilities because such subdivisions create labels that are then used to describe people, often inaccurately. Moreover, there are numerous different ways of subdividing learning disabilities between and within countries (for example, in the UK 'mild' and 'moderate' learning disabilities/difficulties have different meanings in education services and in health services).
- d) Whatever subdivisions are used, a person with a milder degree of learning disability may need support in only some areas (for example, budgeting, planning and time management). The more severe a person's learning disability, the more likely the person is to have very limited communication skills and a very significantly reduced ability to learn new skills. Likewise, the more severe the learning disability, the more likely the person is to need support with daily activities such as dressing, washing, eating, and mobility. It is widely agreed that it is important to treat each person as an individual, with their own specific needs, and it is recognised that a broad and detailed assessment of needs is essential. This may

include assessment of communication skills, which may well be important when there is behaviour that challenges.

- e) Learning disabilities are pervasive and are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.
- f) Some people with learning disabilities display behaviour that challenges. 'Behaviour that challenges' describes actions that often result from the interaction between individual and environmental factors. It includes aggression toward others, self-injury, stereotypic behaviour (such as rocking or hand flapping), disruptive or destructive behaviour and withdrawn behaviour. It can also include violence, arson or sexual abuse, thereby bringing the person into contact with the criminal justice system. The most widely used definition of such behaviour is 'culturally abnormal behaviour(s) of such 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 use, or result in the person being denied access to, ordinary community facilities'<sup>1</sup>. Such behaviours increase the likelihood that restrictive and aversive management strategies will be used and can result in people being excluded from services and from ordinary community life.
- g) The terms 'challenging behaviour' and 'behaviour that challenges' are deliberately designed to remind professionals that the behaviour is a challenge to services, families and carers. Neither term is intended to be a diagnosis. The behaviour may appear in some environments and not others, and the same behaviour may be considered challenging in some settings or cultures but not in others. 'Challenging behaviour' or 'behaviour that challenges' can

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<sup>1</sup> Emerson C. (1995) Challenging Behaviour: Analysis and intervention in people with learning difficulties. Cambridge: Cambridge University Press.

therefore be seen as a socially constructed concept that is the product of individual and environmental factors interacting. In order for behaviour to be considered 'challenging', it is necessary to take account of the environment in which it is occurring, its impact on others, and the capability of the staff/carers to support the person in that environment. Nevertheless, if such behaviour has serious consequences for the person or for other people, it is likely to be considered challenging in most settings in which it occurs.

- h) Behaviour that challenges is relatively common among people with learning disabilities, although the criteria used to define it affect estimates of prevalence. Prevalence rates of 5–15% have been reported in people who are in contact with educational, health or social care services for people with learning disabilities. Substantially higher rates (30-40%) are found in people with learning disabilities who live in mental health hospitals than in those who live in the community.
- i) Behaviour that challenges has been found to correlate with severity of learning disabilities, with a general trend toward an increased prevalence of such behaviour in people with more severe learning disabilities. This is not to say that behaviour that challenges never occurs in people with mild learning disabilities, but is known to be less common among this group (although when it does occur it can bring the person into contact with the criminal justice system). People with profound and multiple learning disabilities, who often have serious physical disabilities, may not be physically able to show some behaviours that challenge but may still show self-injurious behaviour.
- j) Prevalence rates for behaviour that challenges in people with learning disabilities have also been found to be sensitive to age. The highest rates are observed during late adolescence (which may result from the difficulties experienced in transitions between services), falling to lower levels in later adulthood. Increases in the

number of people living longer who acquire dementia may affect this pattern in the future.

- k) There are likely to be a number of underlying factors that contribute to the likelihood of behaviour that challenges for people with learning disabilities, including communication difficulties, sensory impairments, sensory processing difficulties, physical or mental health problems, emotional difficulties, neuropsychiatric disorders, pervasive developmental disorders, phenotype-related behaviours, abuse, psychological trauma and attachment difficulties.
- l) Behaviour that challenges also results from environmental factors (including social, physical and emotional environmental factors). In particular, the social environment has a major effect on rates of behaviour that challenges, and if people are cared for in environments that are inadequate in some way (for example, that do not respond well to their needs because of staff knowledge, training, awareness or attitudes), behaviour that challenges is likely to develop. Carers or staff can influence the occurrence of behaviour that challenges by providing or removing social attention and by presenting or removing demands and physical objects. Many other aspects of the environment are also known to have a major effect on behaviour that challenges, for example: neglect, abuse, quality of social interaction, lack of meaningful occupation, lack of sensory input, lack of choice, excessive noise, and crowded, barren, unresponsive and unpredictable environments.
- m) The factors that contribute to the likelihood of behaviour that challenges for any one person are likely to be multiple and to involve physical, emotional and social environmental factors. Thorough assessments of the person and their environment are needed and functional analyses are likely to be useful to identify the relevant factors. Interventions are typically based on a formulation of the relevant factors for each person and may involve

intervening at multiple levels (including at the physical, emotional and social environmental levels).

- n) Behaviour that challenges affects the quality of life of the person and their family and carers. In the most extreme instances it may become difficult to take the person out of their home and into the community. This means the person may be living in a restrictive environment. Other people may be placed in restrictive environments to live, often for years at a time.

### **3.2 Current practice**

- a) Medication is the most common intervention used to manage behaviour that challenges. Although it may be effective for some people, it is considered by most professionals to be overused and there is a danger that it may simply sedate the person and lead to polypharmacy. A significant proportion of the antipsychotic medication given to people with learning disabilities is for the management of behaviour that challenges.
- b) Behavioural techniques (including applied behaviour analysis and positive behaviour support, as well as cognitive behavioural therapy) are the next most commonly used interventions to manage behaviour that challenges. Such interventions normally include communication assessments and intervention strategies. However, the research evidence shows that most people with learning disabilities do not receive evidence-based interventions for behaviour that challenges.
- c) Families provide the majority of support for most people with learning disabilities. Outside the families, the majority of support is funded by social services (for example, support for self-care, daily living, daytime activities and respite care, specialist equipment and adaptations). Most of this support is not directly provided by social services but by independent agencies (often not-for-profit agencies). Increasingly the support is provided through personal

budgets. In addition, children, young people and adults may receive education services (such as special needs education services in mainstream schools and colleges, services in special schools or classes in further education colleges). People whose behaviour challenges may also use additional specialist health services, which tend to be provided and organised by community teams. For children and young people these services are usually embedded in Child and Adolescent Mental Health Services teams, although many families report that services from these teams are variable. For adults, the specialist services are usually provided by Community Learning Disabilities Teams. The transition from child to adult services is often badly managed, as are other transitions (for example, to services for older people). Services are often lacking for adults with a mild learning disability who may have significant behaviour that challenges but are otherwise relatively able, because they may fall outside the Fair Access to Care Services criteria used by social services and the criteria used by the NHS.

- d) In terms of living situations, people with learning disabilities whose behaviour challenges may be supported at home with their families, in residential services of various kinds (including residential special schools and residential services for adults) or in homes with their own tenancies (when adults), sometimes with the support of specialist teams. Severe behaviour that challenges is a common reason for long-term placement in residential special schools, assessment and treatment units or other settings. These are often located outside the person's area, sometimes hundreds of miles away. Such services may be run by independent agencies or by the NHS.

## **4 The guideline**

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections.

## **4.1      *Population***

### **4.1.1    Groups that will be covered**

- a)       Children, young people and adults with mild, moderate, severe or profound learning disabilities and behaviour that challenges, and their families and carers.
  
- b)       Special consideration will be given with regard to a number of equality issues. Please see equality impact assessment form – scoping for further details.

## **4.2      *Care setting***

- a)       The guideline will cover the care and shared care provided or commissioned by health and social care, in whatever care setting the person resides.

## **4.3      *Management and support***

### **4.3.1    Key issues that will be covered**

- a)       Anticipating and preventing behaviour that challenges in children, young people and adults with learning disabilities, including:
  - identification of those at risk of developing behaviour that challenges
  - methods and tools for personal assessment (including assessment of sensory deficits, sensory processing disorders, physical health status, communication needs, emotional needs, mental health needs)

- assessment of environmental factors, including the physical environment, the social environment, parent, carers and staff attitudes, skills and staff competence
  - interventions to prevent the development of behaviour that challenges.
- b) Assessment of children, young people and adults with learning disabilities who have already developed behaviour that challenges, including:
- methods and tools for assessment including assessment of sensory deficits, sensory processing disorders, physical health status, communication needs, emotional needs and mental health needs, and individual and environmental risk factors
  - assessment of environmental factors, including the physical environment, the social environment, parent, carers and staff attitudes, skills and staff competence
  - functional assessment (including functional analysis) and formulation
  - assessment of staff/carer stress and attributes that contribute to their capacity to support the person.
- c) Interventions to reduce and manage behaviour that challenges, including:
- environmental changes (including physical and social environments)
  - psychosocial interventions (including a broad range of therapies, such as communication interventions, applied behaviour analysis, positive behaviour support and cognitive behavioural therapy) for the short- and long-term reduction and management of behaviour that challenges
  - pharmacological interventions for the short- and long-term reduction and management of behaviour that challenges
- Note that guideline recommendations will normally fall within*

*licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use a drug's summary of product characteristics to inform decisions made with individual service users.*

- interventions aimed at reducing health risks and increasing an individual's understanding of their physical illness or mental health problems, and thereby possibly reducing the contribution of untreated physical illness to the development and maintenance of behaviour that challenges
  - interventions aimed at potentially offending behaviour
  - reactive strategies, including safe and ethical use of restrictive interventions, such as physical restraint, mechanical restraint, confinement, containment and seclusion, and the alternatives to these.
- d) Training or education needed to allow health and social care professionals, paid carers and families to provide good-quality services and carry out all the above interventions if these are evidence based.
- e) Transitions between services
- f) Interventions and support for family and carers (including paid carers) which aim to improve the health and well-being of the family and carers
- g) Strategies to engage family and carers as a resource in the design, implementation and monitoring of interventions for the person with a learning disability.

#### **4.3.2 Issues that will not be covered**

- a) Management of coexisting conditions, unless these affect interventions, management or support for people with learning disabilities and behaviour that challenges.

#### **4.4 Main outcomes**

- a) Severity, frequency and duration of the targeted behaviour that challenges.
- b) Adaptive functioning, including communication skills.
- c) Mental and psychological health outcomes (such as mood and anxiety).
- d) Quality of life.
- e) Service user and carer satisfaction.
- f) Effects on carer stress and resilience.
- g) Adverse effects on other people with learning disabilities.
- h) Rates of seclusion.
- i) Rates of manual restraint.
- j) Use of psychoactive medication.
- k) Premature death.
- l) Rates of placement breakdown.
- m) Use of inpatient placements (including out-of-area placements).

#### **4.5 Economic aspects**

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY) but a different unit of effectiveness may be used depending on the availability of appropriate clinical and utility data for people with learning disability and behaviour that challenges. The costs considered will usually be only from an NHS and personal social

services (PSS) perspective, although economic analyses will attempt to incorporate wider costs associated with the care of people with learning disabilities and behaviour that challenges if appropriate cost data are available. Further detail on the methods can be found in 'The guidelines manual' (see 'Further information').

## **4.6 Status**

### **4.6.1 Scope**

This is the final scope.

### **4.6.2 Timing**

The development of the guideline recommendations will begin in July 2013.

## **5 Related NICE guidance**

- [Autism in adults](#). NICE clinical guideline 142 (2012).
- [The epilepsies](#). NICE clinical guideline 137 (2012).
- [Service user experience in adult mental health](#). NICE clinical guidance 136 (2011).
- [Self-harm: longer-term management](#). NICE clinical guideline 133 (2011).
- [Autism diagnosis in children and young people](#). NICE clinical guideline 128 (2011).
- [Dementia](#). NICE clinical guideline 42 (2006).
- [Self-harm](#). NICE clinical guideline 16 (2004).

### **5.1 Guidance under development**

NICE is currently developing the following related guidance (details available from the NICE website):

- Autism: the management and support of children and young people on the autism spectrum. NICE clinical guideline. Publication expected August 2013.
- Violence and aggression. NICE clinical guideline. Publication expected December 2014.

## 6 Further information

Information on the guideline development process is provided in the following documents, available from the NICE website:

- [‘How NICE clinical guidelines are developed: an overview for stakeholders the public and the NHS’](#)
- [‘The guidelines manual’](#).

Information on the progress of the guideline will also be available from the [NICE website](#).