

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 **Guideline title**

Challenging behaviour: prevention and interventions for people with learning disability and challenging behaviour

1.1 **Short title**

Challenging behaviour in people with a learning disability

2 **The remit**

The Department of Health has asked NICE: to prepare a clinical guideline regarding 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 three 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) The degree of learning disability is usually defined by the following IQ scores: mild=50–69, moderate=35–49, severe=20–34 and profound=under 20. A person with a mild or moderate learning disability may only need support in certain areas. However, a person with a severe or profound learning disability may have no speech or limited communication, a significantly reduced ability to learn new skills and need support with daily activities such as dressing and eating. In practice, exact IQ scores are often not

known for people with more severe learning disabilities. It is widely recognised that IQ scores differ on different tests and are not fixed throughout life, but that they do provide an approximate guide to intellectual ability. Learning disability is sometimes also called 'intellectual disability'.

- c) Learning disabilities are different from 'learning difficulties' like dyslexia, which do not affect intellectual ability.
- d) Diagnostic criteria are described and defined in the World Health Organization ICD-10 classification of mental and behavioural disorders and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), and both use the term 'mental retardation'. For the new version of the DSM (DSM-V, due to be published in May 2013), the working group proposes replacing mental retardation with intellectual disability. For the new version of the ICD (ICD-11, due to be published in 2015), the working group proposes intellectual developmental disorders. For this guideline we will use the term 'learning disability' as this is commonly used in the UK.
- e) Some people with learning disabilities display challenging behaviour. Challenging behaviour describes behaviour that often results from the interaction between individual and environmental factors. It includes anger, aggression, self-injury, stereotypic behaviour (such as rocking or hand flapping), and disruptive or destructive behaviour. The currently favoured definition of challenging 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'¹.

¹ Emerson, C. Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties. Cambridge: Cambridge University Press; 1995.

- f) Challenging behaviour is not a diagnosis. It 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. It is a socially constructed concept. Nevertheless, challenging behaviour that has serious consequences for the individual or for others is likely to be considered challenging in most settings it occurs in.
- g) Challenging behaviour is relatively common among people with learning disabilities, although the criteria used to define it substantially affect estimates of prevalence. Prevalence rates of 10–15% have been found in people who are in contact with educational, health or social care services for people with learning disabilities. Substantially higher rates are found in hospital settings than in community settings.
- h) Challenging behaviour has been found to correlate with severity of learning disability, with a general trend for an increased prevalence of problem behaviours in people with more severe learning disabilities, with the exception of aggression. An exception to this pattern has been found for people with profound and multiple learning disabilities (IQ of less than 20), because these people may also have serious physical disabilities that limit levels of challenging behaviour.
- i) Prevalence rates for challenging behaviour in people with learning disabilities have also been found to be sensitive to age. The highest rates are observed during late adolescence, falling to lower levels in later adulthood.
- j) There are likely to be a number of underlying individual causes to challenging behaviour in people with learning disabilities, including communication difficulties, sensory impairments, physical or mental health problems, neuropsychiatric disorders, pervasive

developmental disorders, phenotype-related behaviours, psychological trauma, and attachment difficulties.

- k) Challenging behaviour also results from environmental factors. In particular, the social environment has a major effect on rates of challenging behaviour. For example, carers or staff may alter challenging behaviour by providing or removing social attention, by presenting or removing demands, and by presenting or removing physical objects. Other aspects of the environment are also known to have a major effect on challenging behaviour: for example, loud noise and crowded, barren or unpredictable environments.
- l) The causes of challenging behaviour for any one person are likely to be multifactorial, and to involve physical, emotional and environmental factors. Functional analyses may be needed to identify the relevant factors for a person.
- m) Challenging behaviour affects the quality of life of the person and their family and carers. In the most extreme cases it may become difficult to take the person out of the house into the community. They may be sent to restrictive environments to live, often for years at a time.

3.2 *Current practice*

- a) Behavioural techniques (including cognitive behavioural therapy) are the most commonly used interventions to manage challenging behaviour, but most people with learning disabilities do not receive evidence-based psychosocial interventions for their challenging behaviour.
- b) A significant proportion of the antipsychotic medication given to people with learning disabilities is for the management of challenging behaviour.
- c) Most people with learning disabilities receive the majority of their support from social services (for example, for self-care, daily living,

daytime activities and respite care). Separately or in addition to this, they may receive education services (such as special needs educational services in mainstream schools and colleges, and services in special schools). People who have challenging behaviour usually also access additional specialist services for children and young people, which tend to be provided and organised in community learning disability teams. These services may include psychological therapy, speech therapy, occupational therapy, psychiatric and nursing input, as well as arts and other therapies (for example drama therapy, art therapy and music therapy). The transition from child to adult services is often badly managed, and services for adults with a mild learning disability who may have significant challenging behaviour but are otherwise relatively able are often poorly organised.

- d) In terms of living situations, people with challenging behaviour may be supported at home with their families or in residential services of various kinds, sometimes with the support of specialist teams. Severe challenging behaviour is a common reason for long-term residential placement.

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) Adults, children and young people with mild, moderate and severe or profound learning disabilities and challenging behaviour, and their families and carers.

4.2 Care setting

- a) The guideline will cover the care and shared care provided or commissioned by health and social care.

4.3 Management

4.3.1 Key issues that will be covered

- a) Anticipating and preventing challenging behaviour in people with learning disabilities, including:
- identification and assessment of people at risk of developing challenging behaviour
 - methods and tools for assessment (including assessment of sensory processing disorders and physical health status)
 - assessment of personal and environmental factors
 - interventions to prevent the development of challenging behaviour.
- b) Assessment of people with learning disabilities who have already developed challenging behaviour, including:
- methods and tools for assessment (including assessment of physical health) and risk assessment
 - assessment of environmental factors and functional analysis

- c) Interventions to reduce and manage challenging behaviour, including:
- environmental adaptations
 - psychosocial (including a broad range of therapies) and psychological interventions for the short- and long-term reduction and management of challenging behaviour
 - pharmacological interventions for the short- and long-term reduction and management of challenging behaviour.
- 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 patients*
- interventions aimed at potentially offending behaviour
 - restrictive interventions, such as physical restraint, mechanical restraint, and seclusion.
- d) Training or education needed to allow health and social care professionals and families to carry out the above interventions.
- e) Interventions and support for family and carers.

4.3.2 Issues that will not be covered

- a) Management of coexisting conditions, unless these affect interventions, management or support for challenging behaviour.

4.4 Main outcomes

- a) Severity, frequency and duration of the targeted challenging behaviour.
- b) Adaptive functioning.
- c) Quality of life

- d) Adverse effects.
- e) Rates of seclusion.
- f) Rates of manual restraint.
- g) Use of antipsychotic drugs.
- h) Premature death.
- i) Use of inpatient/residential 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), and the costs considered will usually be only from an NHS and personal social services (PSS) perspective. 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 consultation draft of the scope. The consultation dates are 7th May to 4th June 2013.

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).
- Self-harm: longer-term management. NICE clinical guideline 133 (2011).

- Service user experience in adult mental health. NICE clinical guidance 136 (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. NICE clinical guideline (update). 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](#).