

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 Guideline title

Mental health problems in people with learning disabilities: prevention, assessment and management of mental health problems in people with learning disabilities

1.1 *Short title*

Mental health problems in people with learning disabilities

2 The remit

The Department of Health has asked NICE to prepare a clinical guideline on 'mental health problems in people with learning disabilities'.

3 Need for the guideline

3.1 *Epidemiology*

- a) Learning disabilities are defined by 3 core criteria: low intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. There are many causes of learning disabilities and the cause is often unknown. People with learning disabilities have a diverse range of skills and needs.
- b) 'Learning disabilities' is the term that is widely used and accepted 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 practitioners in the UK. It will therefore be used in this guideline. It equates to the terms 'intellectual disabilities' which is widely accepted internationally. The World

Health Organization's revision of the [International statistical classification of diseases and related health problems](#) (ICD-11), due to be published in 2017, has proposed the term 'disorders of intellectual development'. [DSM-5](#), published in May 2013, uses the term 'intellectual disability (intellectual developmental disorder)'.

- c) Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect overall intellectual ability, and are not included in this guideline.
- d) People with milder learning disabilities will need support in some areas (for example, budgeting, planning, time management, and understanding complex information). Their needs may be less apparent to people who do not know them well. The more severe a person's learning disabilities, the more likely they are to have limited verbal communication skills and understanding of others, and a reduced ability to learn new skills. Likewise, the more severe the person's learning disabilities, the more likely they are to need support with daily activities such as dressing, washing, eating, and mobility. People with learning disabilities may also have physical and sensory disabilities and health or mental health problems that further affect the levels of support they need.
- e) It is important to respect each person as an individual, with their own specific skills and needs. It is recognised that a broad and detailed assessment of skills and needs is essential. This typically calls for a multidisciplinary, and person-centred approach.
- f) People with learning disabilities often experience mental health problems alongside other conditions such as epilepsy, physical health problems and sensory impairments. It is important to take these other problems into account when assessing, diagnosing and managing any mental health problems.
- g) The prevalence of mental health problems among people with learning disabilities varies depending on the populations sampled

and the definitions used. Population-based estimates suggest that 40% of adults with learning disabilities experience mental health problems (28% if problem behaviours are excluded). An estimated 36% of children and young people with learning disabilities experience mental health problems (24% if conduct disorders are excluded). These rates are much higher than for people who do not have learning disabilities. Psychosis, dementia, autism, attention deficit hyperactivity disorder, problem behaviours and conduct disorders are all more common than in the general population. Emotional disorders are at least as common as in the general population. Within learning disabilities some diagnoses are associated with particularly high levels of mental health problems (for example, Down's Syndrome) or particular presentations of symptoms (for example, obsessive compulsive symptoms in Prader-Willi syndrome and attentional problems in Fragile X Syndrome).

- h) There are many underlying factors that may contribute to people with learning disabilities developing mental health problems, including the severity of their learning disabilities; the cause of their learning disabilities (including behavioural phenotypes); other biological factors such as pain, physical ill health and taking multiple types of medication (polypharmacy); psychological factors such as attachment difficulties and trauma; social factors such as abuse and neglect, poverty, multiple co-occurring life events, poverty of social environment and social networks, stigma and hate crimes; developmental factors such as affect dysregulation and attentional control; and cultural and identity factors.
- i) Mental health problems are often overlooked in people with learning disabilities for a variety of reasons. For example, they may be unable to complain of or describe their distress; their carers may not recognise that their behaviour has changed (this depends on how long carers have known the person and how well information

is communicated within and across care teams); their symptoms may inadvertently be attributed to their learning disabilities; the more severe the learning disabilities, the more likely the person is to have unusual presentations of symptoms; symptoms may be attributed to side effects of medications or to other disorders such as complex partial epilepsy; and primary care services are typically designed to provide reactive rather than proactive health care. Diagnostic delay can compound problems over time, and influence outcomes.

- j) Mental health problems can cause significant distress for a person with learning disabilities, and restrict their opportunities for community participation and further development. They can also affect their family and paid carers, and place a stress on organisations and services.
- k) Race, ethnicity, gender, sexuality, social, cultural and religious factors and age may also influence the patterning of mental health problems and equity of access to services and supports.

3.2 *Current practice*

- a) The under recognition and/or misattribution of mental health problems in people with learning disabilities is a key issue, and can result in the person not being provided with effective interventions, or worse being given ineffective or harmful interventions.
- b) A further issue relates to access to services that offer prevention, treatment or support. Barriers can be present in accessing primary care services, secondary care, and social services. Variability in service provision across England and Wales may also contribute to access problems in some areas. Good practice in helping people access services often needs to take a 'whole system' approach including the person with learning disabilities, their family and paid carers and other key people in the person's life, as well as primary

care, secondary care, specialist learning disabilities health and social services. This needs good coordination and communication.

- c) Psychotropic medication is commonly prescribed for people with learning disabilities. About 50% of adults with learning disabilities are prescribed psychotropic drugs with 20–25% taking antipsychotics, and 12% antidepressants. A large proportion (about 25%) take mood stabilising drugs, although these are usually prescribed to manage epilepsy rather than mood disorders.
- d) The next most commonly used interventions for mental health problems in people with learning disabilities are psychosocial interventions. However, despite national guidance highlighting the importance of psychological therapies, many such therapies developed for the general population remain inaccessible for people with learning disabilities.
- e) Other approaches are also used, such as educational, occupational and developmental approaches, and promotion of healthy lifestyles.
- f) Families are an important source of help for many people with learning disabilities, so supporting them in their caring role is vital. Paid carer support is usually funded by social services (for example, support for self-care, daily living, daytime activities and respite care, specialist equipment and adaptations). This is frequently commissioned from independent agencies. Increasingly, support is provided through personal budgets. People with learning disabilities may also receive education support (such as support to meet special educational needs in mainstream schools and colleges, support in special schools or classes in further education colleges). There is a statutory duty to provide support in education to children with disabilities under the Children Act, 1989.
- g) People with learning disabilities and mental health problems may use general mental health services, and also 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 (CAMHS) 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. Transitions – for example from child to adult services or to services for older people – are often problematic, and need close coordination between services. Services are sometimes lacking for adults with mild learning disabilities who may have significant mental health problems but are otherwise relatively able. This is because they may fall outside of both local eligibility criteria established by social services and the criteria established by the local specialist health services.

- h) People with learning disabilities who have mental health problems live in a diverse range of environments. They may live at home with their families. They may hold their own individual or shared tenancy with paid carer support, or live in residential services of various kinds (including residential special schools, residential services for adults, or secure settings). Severe mental health problems are sometimes a reason for placement in residential special schools, or specialist services run by independent providers or the NHS, which may be located outside the person's area, sometimes hundreds of miles away, contrary to recent guidance.
- i) There is a statutory duty on services to make reasonable adjustments to accommodate the needs of people with disabilities (Equality Act, 2010). This may involve offering people with learning disabilities longer appointments and information written in an accessible way, and using different approaches to improve communication. The Mental Capacity Act, (2005), stipulates that people should get the support they need to make decisions, and that best interest decisions should be made in circumstances where a person does not have capacity to decide for themselves.

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 mental health problems, and their families and carers.
- b) People with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down's syndrome, Prader-Willi syndrome, Fragile X syndrome).
- c) Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.

4.2 Care setting

- a) The guideline will cover all settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.

4.3 *Management and support*

4.3.1 Key issues that will be covered

- a) Identifying people with learning disabilities who are at risk of developing mental health problems.
- b) Recognising mental health problems in people with learning disabilities.
- c) Diagnosing and assessing mental health problems in people with learning disabilities, including identifying contributory factors.
- d) Interventions to prevent, reduce and manage mental health problems, including:
 - psychological interventions
 - social and environmental interventions
 - personal and support strategies in community and residential settings
 - pharmacological interventions
 - dietary interventions
 - other multidisciplinary therapies
 - combined interventions
 - occupational interventions
 - community interventions (for example to reduce stigma or hate crimes).
- e) Accessibility of services for people with learning disabilities.
- f) Transitions between services.
- g) Coordination and communication with key people and services in the life of the person with learning disabilities.
- h) Strategies to engage, train and support family carers and paid carers in designing, implementing and monitoring interventions for the person with learning disabilities.

- i) Service structures, training and supervision to support practitioners in the effective delivery of interventions.
- j) Interventions, training, and support for family carers and paid carers that aim to improve their own health and wellbeing as well as that of the person with learning disabilities.
- k) The experience of care for service users and their carers.

4.3.2 Issues that will not be covered

- a) The specific care and management of behaviour that challenges in people with learning disabilities. This will be covered by another NICE guideline (see section 5, 'Related NICE guidance').

4.4 Main outcomes

- a) Mental health.
- b) Problem behaviours.
- c) Adaptive functioning.
- d) Quality of life.
- e) Service user and carer satisfaction.
- f) Carer health and quality of life.
- g) Adverse effects of interventions.
- h) Rates of placement breakdown.
- i) Psychiatric admissions.
- j) Out-of-area placements.
- k) Rates of seclusion.
- l) Rates of manual restraint.
- m) Use of psychoactive medication.

- n) Community participation.

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 disabilities and mental health problems. 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 mental health problems 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 October 2014.

5 Related NICE guidance

Related NICE guidelines include all those published on specific types of mental health problems for children and adults who do not have learning disabilities, such as:

- [Autism diagnosis in children and young people](#) NICE clinical guideline 128 (2011)
- [Autism: the management and support of children and young people on the autism spectrum](#) NICE clinical guideline 170 (2013)

- [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](#) NICE clinical guideline 16 (2004)
- [Self-harm: longer-term management](#) NICE clinical guideline 133 (2011)
- [Dementia](#) NICE clinical guideline 42 (2006)

5.1 Guidance under development

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

- [Challenging behaviour and learning disabilities](#) NICE clinical guideline. Publication expected May 2015.
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) NICE clinical guideline. Publication expected November 2015.
- [Transition from children's to adult services](#) NICE clinical guideline. Publication expected February 2016.
- [Transition between inpatient mental health settings and community and care home settings for people with social care needs](#) NICE clinical guideline. Publication expected August 2016.
- [Mental health of people in prison](#) NICE clinical guideline. Publication expected November 2016.

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](#).