

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

1 Guideline title

Mental health problems in people with learning disabilities: 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 Clinical 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 often the cause is unknown.
- 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. It equates to the terms 'intellectual disabilities' which is widely accepted internationally. The World Health Organisation's revision of the [International statistical classification of diseases and related health problems](#) for ICD-11,

due to be published in 2015, has proposed the term 'intellectual developmental disorders'. [DSM-V](#), published in May 2013, uses the term 'intellectual disability (intellectual developmental disorder)'.

- c) Persons with milder learning disabilities may need support in only some areas (for example, budgeting, planning and time management). The more severe a person's learning disabilities, the more likely the person is to have limited verbal communication skills and a reduced ability to learn new skills. Likewise, the more severe the learning disabilities, the more likely the person is to need support with daily activities such as dressing, washing, eating, and mobility. People with learning disabilities may also have accompanying physical disabilities and health or mental health problems that further impact upon the levels of support they require.
- d) However, It is important to treat each person as an individual, with their own specific skills and needs, and it is recognised that a broad and detailed assessment of skills and needs is essential. This typically requires a multi-disciplinary approach.
- e) Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect overall intellectual ability.
- f) Mental health problems are commonly experienced by people with learning disabilities, and are often comorbid with other mental health problems, epilepsy, other physical health problems, and sensory impairments. It can be important to consider these other problems in both the diagnosis and management of any mental health problems.
- g) The prevalence of mental health problems among people with learning disabilities varies depending upon the populations sampled and the definitions used. Population based estimates of mental health problems are 40% in adults and 36% in children and young people, compared with much lower rates in people who do

not have learning disabilities. Psychosis, dementia, autism, ADHD, and problem behaviours are all more common than in the general population. Emotional disorders are at least as common as in the general population.

- h) There are many underlying factors that may contribute to the development of mental health problems for people with learning disabilities, 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 polypharmacy; psychological factors such as abuse and neglect; social factors such as poverty, multiple co-occurring life events, poverty of social environment and social networks, stigma; and developmental factors such as affect dysregulation and attentional control.
- 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 they have changed in their behaviour, depending 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; they may have unusual presentations of symptoms the more severe their learning disabilities; symptoms may be attributed to side effects of medications or to other disorders such as complex partial epilepsy; and primary care services most typically are 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 impact upon their family and paid carers.

3.2 Current practice

- a) A major problem is the under recognition and/or misattribution of mental health problems in people with learning disabilities, and as a consequence, the failure to provide effective interventions, or worse the provision of ineffective or harmful interventions.
- b) A further issue relates to access to services; both preventative and treatment/supports. 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 often needs to include a “whole system” approach including family and paid carers, primary care, secondary care, specialist learning disabilities health services, social services, and other key people in the life of the person with learning disabilities, as well as the person with learning disabilities, This requires good coordination and communication.
- c) The most common intervention used to manage mental health problems in people with learning disabilities is psychotropic medication. About 50% of adults with learning disabilities are prescribed psychotropic drugs, 20-25% receive antipsychotics, and 12% antidepressants. A large proportion receive mood stabilising drugs (about 25%), although these are usually prescribed for the management of epilepsy, not mood disorders.
- d) The next most commonly used interventions to address mental health problems in people with learning disabilities are psychosocial interventions. However, some therapies developed for the general population are inaccessible for people with learning disabilities, and provision of effective interventions may vary across the country.
- e) Families are an important source of support for many people with learning disabilities. 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 often commissioned from independent agencies (often not-for-profit agencies). Increasingly, support is provided through personal budgets. In addition, children, young people and adults may receive education supports (such as supports to meet special educational needs in mainstream schools and colleges, support in special schools or classes in further education colleges). People with learning disabilities and mental health problems may use 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 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 problematic, as are other transitions, for example, to services for older people. Services are sometimes lacking for adults with mild learning disabilities who may have significant mental health problems 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.

- f) In terms of living situations, people with learning disabilities who have mental health problems are supported at home with their families, or hold their own individual or shared tenancy with paid carer support, or live in residential services of various kinds (including residential special schools and residential services for adults). 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.

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 paid carers.
- b) People with genetic conditions associated with learning disabilities and mental health problems, where some of their mental health problems and needs may differ from other people with learning disabilities,(for example, Prader Willi syndrome, fragile X)
- c) Special consideration will be given with regard to a number of equality issues.

4.2 *Care setting*

- a) The guideline will cover all settings in which care is provided, including health, social, educational, forensic and criminal justice services (where health interventions are provided).

4.3 *Management and support*

4.3.1 *Key issues that will be covered*

- a) Identification of people with learning disabilities at risk of developing mental health problems.

- b) Recognition of mental health problems in children, young people, and adults with learning disabilities.
- c) Diagnosis and assessment of mental health problems in children, young people, and adults with learning disabilities, including identification of 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.
- e) Accessibility of services to people with a learning disability.
- f) Transitions between services, due to age or relocation.
- g) Coordination and communication with key persons and services in the life of the person with learning disabilities.
- h) Strategies to engage family and carers as a resource in the design, implementation and monitoring of interventions for the person with a learning disability.
- i) Service structures to support effective delivery of interventions.
- j) Interventions, training, and support for family and paid carers which aim to improve the health and well-being of the family and carers, as well as the person with learning disabilities.

4.3.2 Issues that will not be covered

- a) The specific care and treatment of co-existing disorders that have already been well addressed for people with learning disabilities as part of another recent NICE guideline (e.g. autism).

4.4 Main outcomes

- a) Mental health
- b) Problem behaviours.
- c) Adaptive functioning.
- d) Quality of life.
- e) Community participation.
- f) Service user and carer satisfaction.
- g) Carer health.
- h) Adverse effects of interventions.
- i) Rates of placement breakdown.
- j) Psychiatric admissions.
- k) 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 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 draft 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/or adults who do not have learning disabilities. Some recent examples include:

- [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: 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):

- Challenging behaviour and learning disabilities. NICE clinical guideline. Publication expected May 2015.
- Mental health of people in prisons. NICE clinical guideline. Publication date tbc.
- Transition from Children to Adults NICE. Social Care guideline. Publication expected March 2016
- Transition from Health to Social Care. NICE Social Care guideline. Publication expected December 2015

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](#).