# General learning disability

## What is a learning disability?[1]

A learning disability is a reduced intellectual ability and difficulty with everyday activities, with onset in childhood. NICE states that: 'A learning disability is generally defined by three core criteria:

- Lower intellectual ability (usually an IQ of less than 70).
- Significant impairment of social or adaptive functioning.
- Onset in childhood.'

The World Health Organization (WHO) defines intellectual disability as: 'A condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, ie cognitive, language, motor and social abilities.'

Children with a general learning disability find it more difficult to learn, understand and do things compared with other children of the same age. Children and adults with intellectual disabilities have an increased prevalence of health problems and their health needs are often unrecognised and unmet. They are also more likely to experience abuse and less likely to access health and other support services successfully.[2] [3]

General learning disability differs from specific learning difficulty, where the person has difficulty in one area - such as in reading, writing or understanding - but has no problem with learning in other areas. Specific learning difficulties, such as dyslexia, do not affect intellectual ability.

Learning disability/intellectual impairment which arise in adulthood (eg, due to head injury) may raise similar health and social care issues but do not fall under the definition of generalised learning disabilities.

# Learning disability classification[3] [4]

Although the term 'intellectual disability' is becoming accepted internationally, 'learning disability' is the most widely used and accepted term in the UK.

The WHO classifies severity of an intellectual disability as:[1] [5]

- Mild (0.1-2.3 percentile): approximate IQ range of 50 to 69 (in adults, mental age from 9 to under 12 years). Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society.
- Moderate (0.003-0.1 percentile): approximate IQ range of 35 to 49 (in adults, mental age from 6 to under 9 years). Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.
- Severe (below 0.003 percentile): approximate IQ range of 20 to 34 (in adults, mental age from 3 to under 6 years). Likely to result in continuous need of support.
- Profound ((below 0.003 percentile): IQ under 20 (in adults, mental age below 3 years). Results in severe limitation in self-care, continence, communication and mobility.

However, this classification is only partially adequate, as the degree of intellectual impairment provides very little information about the person's social, educational and personal needs. It is important to treat each person as an individual, with specific strengths as well as needs. A broad and detailed assessment may be needed.

Generally it is the case that people with profound learning disabilities typically need support for long periods of time, whilst people with mild learning disabilities require a variable level and type of support, changing in response to changing circumstances.

Severe and profound intellectual disabilities are differentiated exclusively on the basis of adaptive behavioural differences because existing standardised tests of intelligence cannot reliably or validly distinguish intellectual functioning below the 0.003 percentile.

## How common are learning disabilities? (Epidemiology)[1]

- Public Health England (PHE) estimated that in England in 2015, there were almost 1.1 million people with learning disabilities, including 930,400 adults.
- In 2016-2017 data from over half of primary care practices in England suggested that 1 in 218 people (0.46% of the population) were recorded by their GP as having a learning disability.
- PHE also reported that in 2015, 70,065 children in England with a primary need associated with learning disabilities had a statement of special educational needs/education health and care plan. Of these, 44% were identified as having moderate learning difficulties, 41% severe learning difficulties, and 15% profound and multiple learning difficulties.

However data on the number of people with learning disability are poorly representative of the actual prevalence rate. This may lie partly in issues with terminology and coding.[6] Practice registers record only a proportion of those who are eligible, making it difficult to target improvements in their healthcare.[7] [8]

## Learning disability causes[1]

General learning disability is a presentation, not a diagnosis. It may result from many things. Risk factors for the development of a learning disability include:

- Chromosomal and genetic anomalies - eg, Down's syndrome, Williams' syndrome, Rett syndrome, fragile X syndrome.
- Some non-genetic congenital malformations - eg, some types of spina bifida, hydrocephalus, microcephaly.
- Prenatal exposures - eg, fetal alcohol syndrome, sodium valproate, congenital rubella infection, Zika virus.

- Birth complications resulting in hypoxic brain injury/cerebral palsy.
- Prematurity (usually less than 33 weeks of gestation).
- Childhood illness - eg, meningitis, encephalitis, measles.
- Childhood brain injury caused by accident/physical abuse.
- Childhood neglect and/or lack of stimulation in early life.

Neurodevelopmental disorders that may be associated with a learning disability include autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).

## Learning disability symptoms[3] [5]

This will depend on the cause. It would typically include:

- Poor performance on tasks such as learning, short-term memory and problem solving.
- Association with specific congenital syndromes - eg, Down's syndrome, fragile X syndrome.
- Challenging behaviour: this is commonly associated with learning disability and may be a presenting feature.

Assessment needs to be comprehensive when considering cause, and should include family history, birth history, functional disability and associated medical, psychological and social difficulties.

- People with mild intellectual disability often exhibit difficulties in the acquisition and comprehension of complex language concepts and academic skills. Most master basic self-care and domestic and practical activities. People affected by a mild disorder of intellectual development can generally achieve relatively independent living and employment as adults but may require appropriate support.
- Language and capacity for acquisition of academic skills of persons affected by a moderate disorder of intellectual development vary but are generally limited to basic skills. Some may master basic self-care and domestic and practical activities. Most require considerable and consistent support in order to achieve independent living and employment as adults.

- People with severe intellectual disability exhibit very limited language and capacity for acquisition of academic skills. They may also have motor impairments and typically require daily support in a supervised environment for adequate care, but may acquire basic self-care skills with intensive training.
- People with profound intellectual disability possess very limited communication abilities and capacity for acquisition of academic skills is restricted to basic concrete skills. They may also have co-occurring motor and sensory impairments and typically require daily support in a supervised environment for adequate care.

Severe and profound disorders of intellectual development are differentiated exclusively on the basis of adaptive behaviour differences

## Associated problems[2] [3]

General learning disability can affect any or every aspect of an individual's physical and psychological function. It also impacts on their ability to access and engage with help and support, their opportunity to realise their potential, the chance of their experiencing other causes of deprivation, the quality of service they receive from health and social care and their life expectancy. Problems are listed individually but clearly they will overlap with one another and may be present in many combinations and degrees.

**Physical**

- Motor and mobility problems.
- Abnormalities of movement.
- Speech, hearing and visual impairment.
- Epilepsy.
- Urinary and faecal incontinence.
- Increased risk of obesity, fractures.
- Poor oral health (including dental caries and loss of teeth).
- Poor diet, increased rates of constipation and gastro-oesophageal reflux disease.
- Lack of physical exercise.

- Sleep disorders.
- Increased risk of chronic obstructive pulmonary disease.
- More frequent physical disorders. The most common physical health problems are epilepsy, mobility problems and sensory problems.
- Disorders of vision and hearing - are also more frequent.

**Social**

- Adults with learning disability are more likely to smoke tobacco.
- Adults with learning disability are less likely to access health promotion activities.
- Adults with learning difficulty are more likely to be exposed to social determinants of poorer health (greater material hardship, greater neighbourhood deprivation, reduced community and social participation).

**Psychological**

The following are more common in patients with learning disabilities:

- Schizophrenia.
- Anxiety and depressive disorders.
- Personality disorder.
- Early-onset dementia.
- Autism.
- Hyperactivity and attention deficit hyperactivity disorder.
- Eating disorders, including rumination, food faddiness, anorexia nervosa and bulimia nervosa..

**Behavioural**

- Difficulty accessing care and support: the stigma associated with learning disabilities may lead to an unwillingness for those affected to use specialised services or self-identify as having learning difficulties:
    - This has probably been exacerbated by a decrease in surveillance by post-education health and social care services, and the increased 'tightening' of eligibility criteria to ration access to specialist support.
- Poor self-care, which may affect hygiene, diet, exercise, physical health and mental health.
- Lack of a supportive social network.
- Lack of regular employment.
- Lack of regular income.
- Boredom.
- Harmless behaviour interpreted as aggression by others.
- Temper tantrums.
- Criminal activity can occur, deliberately through challenging behaviour, or accidentally through misunderstanding.
- Challenging behaviour: this may include threatening themselves and others but is most often disruptive rather than dangerous. It is fairly common for people with a learning disability to develop behaviour that challenges, particularly where there is more severe disability. Prevalence rates are around 5-15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20s.
- People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

**Vulnerability to abuse**

- Children and adults with a learning disability are vulnerable to maltreatment and exploitation and to physical and sexual abuse and neglect. This can occur in both community and residential settings.
- In 2012-2013 there were over 20,000 referrals to local authorities regarding concerns about possible abuse of people with learning disabilities.

**Premature death**
People with learning disabilities have a lower life expectancy than the population as a whole.[9]

# Learning disability management

The National Institute for Health and Care Excellence (NICE) has published a guideline for dealing with the care of adults growing older with learning disability.[10]

As they grow older, people with learning disabilities have many of the same age-related health and social care needs as other people but they also face specific challenges associated with their learning disability. Many people with learning disabilities, especially those with milder disability, may not be known to health or social services, whereas others may find it difficult to express their needs and be heard.

Management of their needs will therefore be more complex than for other populations. This will create substantial pressure on services, which has not yet been fully quantified. This guideline advises specifically on annual health checks and screening for this group of people.

- Management includes multidisciplinary support for both the patient and the rest of their family. The person with general learning disability and their carer(s) and family need a great deal of physical and emotional support.
- Psychological, psychosocial, and educational interventions for deprived children with low IQ have been shown to have positive effects on behaviour, on overall adjustment and possibly also on IQ.
- Psychotropic drugs are often used but rarely produce significant benefits.

- Direct support and coaching of young people with learning disability are efficient ways to improve their integration into employment.
- If a person presents with challenging behaviour, assess for physical (for example, pain such as toothache, earache) and other sources of discomfort before treating the behaviour as psychiatric.[2]

## Communication[2]

- Focus on abilities and not disabilities. Talk respectfully, take time and explain what is happening.
- Always greet the person first, before addressing the accompanying person.
- Check if your patient has verbal capacity. There may be an imbalance between receptive and expressive language skills.
- Obtain the medical history as far as possible from the patient; otherwise, an accompanying person should complete it.
- Make it clear that, if the patient wants the accompanying person to leave at any moment during the consultation, he or she can indicate that.
- When communicating with people with learning disabilities:
    - Ensure that your communication is clear, with simple language and short sentences.
    - Explain any difficult or unfamiliar words.
    - Check that the person has understood - eg, ask them to tell you in their own words what you have just said.
    - Give the person time to respond.
    - Use gestures to emphasise your communication - eg, point to the part of the body you are talking about.
    - Use pictures or objects to demonstrate what you are going to do before you do it.
    - Be aware of any additional disabilities such as hearing or visual impairment.

- 'Total Communication' is about using a number of communication methods together to support people with complex needs. This may include a mixture of speech, gesture and accessible written information or pictures.

### Challenging behaviour

Challenging behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypical behaviour, withdrawal and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse and may bring the person into contact with the criminal justice system.

- Try to discover the reasons for the behaviours: they may produce a desired effect for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands or communicating with other people).
- Consider where the behaviour occurs. The behaviour may appear in only certain environments, or it may be considered challenging in some settings but not in others. Some care environments increase the likelihood of behaviour that challenges. This includes those with limited social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse and those where physical health needs and pain go unrecognised or are not managed.
- Multiple factors underlie behaviour that challenges. Interventions depend on the specific triggers for each person and may need to be delivered at multiple levels (including the environmental level). The aim should always be to improve the person's overall quality of life.
- Behavioural treatment methods for managing self-injury in learning disability are probably effective if used systematically by people who are well trained in such methods.
- Psychotropic drugs rarely produce significant benefits. It is of course always important to remember to treat the needs of the patient first, rather than those of the carer or institution, even though those may be the same.

### Annual health screening and GP care

- GPs should recognise people with learning disabilities on their practice list. Registered rates of learning disability vary considerably around the country, with 2013 figures of 3.3% in London but 5.9% in Durham, Darlington and Teeside.
- Health checks are a reasonable adjustment in the delivery of primary healthcare to help adjust for the fact that people with learning disabilities have more difficulty than others in recognising and managing health problems and in accessing help. There is considerable variation by geographical area in the delivery and uptake of such checks.
- Mental illness, chronic health problems, epilepsy and physical and sensory problems are more common and people with learning disabilities are less likely to receive regular health checks and access routine screening.

The Royal College of General Practitioners has published 'Health checks for people with learning disabilities toolkit'.[11]

- A recent randomised controlled trial on annual health screening in people with intellectual disabilities found an improvement in health in the intervention group.[2]
- Health management plans should be evaluated annually and should include case finding, appropriate monitoring of existing health needs, promotional activities and disease prevention.[2]

- As a minimum, the health check should include:
    - A review of physical and mental health with referral through the usual practice routes if health problems are identified:
        - Health promotion.
        - Chronic illness and systems enquiry.
        - Physical examination.
        - Epilepsy.
        - Behaviour and mental health specific syndrome check.
    - A check on the accuracy of prescribed medications.
    - A review of co-ordination arrangements with secondary care.
    - A review of transition arrangements where appropriate.
- One example of a form that can be used is the Cardiff Health Check for People with a Learning Disability.[12]

### Reducing premature death[9]

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) reviewed the deaths of 247 people with learning disabilities within five Primary Care Trusts in the South West of England. It also reviewed the deaths of 58 people without learning disabilities. The study, which revealed that the quality and effectiveness of health and social care given to people with learning disabilities were deficient in a number of ways, made a number of recommendations, some of which are directly relevant to primary care, including:

- Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.
- A named healthcare co-ordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
- Patient-held health records to be given to all patients with learning disabilities who have multiple health conditions.

- Standardisation of Annual Health Checks.
- Proactive referral to specialist learning disability services.
- Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.
- All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.

## Informed consent[2]

See also the separate Consent to Treatment (Mental Capacity and Mental Health Legislation) and Mental Capacity Act articles.

- There may be an incongruence between receptive and expressive verbal skills. It may take time to realise that, although a person is giving clear answers, he or she does not understand the question.
- Assessment of mental capacity is specific for each individual decision at any particular time. People are considered to lack capacity for a specific decision if they have an impairment that causes them to be unable to make that decision. In assessing mental capacity you must assess whether the person is able to understand, retain and weigh the information being provided and communicate their decision.

## Complications

- Behavioural problems and their consequences.
- Sexual problems: curiosity about other people's bodies may be misunderstood as sexual; inappropriate behaviour - eg, masturbation in public.
- Consequences of abuse including distress, increased mental health problems, pregnancy and sexually transmitted infection.
- Effects on the family: parental rejection, physical and emotional stress in caring for a child with learning disability, difficulty with family dynamics with other siblings, and increasing difficulty, as the child gets older, with isolation, contraception, etc.

# Prognosis

- Most adults with learning disability have very limited economic resources and limited opportunities to discover or fulfil their potential.
- Their chances of forming long-term, supportive relationships with their peers or with life partners are much lower than for the general population and are worse according to the degree of disability.
- People with severe learning disability have a particularly poor outlook. Those with mild learning disability and borderline intelligence also do poorly in terms of adaptive functioning.
- The median age at death for people with learning disabilities is significantly younger than for those who do not have learning disabilities.
- Although life expectancy is increasing, with people with mild learning disabilities approaching that of the general population, the mortality rates among people with moderate-to-severe learning disabilities are three times higher than in the general population.[11]
- Both the scope and pattern of disease mortality and cause-specific mortality tend to become increasingly similar to those of the general population after the age of 40 years.

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# Prevention

- Early and effective management of problems during the antenatal period and during intrapartum care.
- Early and effective management of problems in the neonatal period and early childhood.

***Dr Mary Lowth is an author or the original author of this leaflet.***

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# Further reading

- Mental health problems in people with learning disabilities: prevention, assessment and management; NICE Guidelines (September 2016)

- Learning disabilities: identifying and managing mental health problems; NICE Quality Standard, January 2017




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