**What is intellectual disability?**

Intellectual disability is the currently preferred term for the lifelong developmental disorder otherwise known in the United Kingdom as ‘learning disability’, and previously as ‘mental handicap’.

Modern definitions generally specify three criteria that must be present before a person may be said to have an intellectual disability:

- **a significant impairment of intelligence**, which includes abilities such as thinking rationally, understanding complex information, solving problems, learning quickly and learning from experience;

- **a significant impairment of social functioning**, which includes everyday living skills such as language and number skills, interpersonal and social skills, and work, safety and personal care skills; and

- **an age-of-onset before adulthood**.

The definition of intellectual disability used by the World Health Organization (2019) refers to all three of these criteria.

**How is intellectual disability determined?**

Health professionals assess a person in different ways to determine whether they meet the three essential criteria for intellectual disability.

**Intelligence** is generally assessed through ‘intelligence tests’. These allow for individuals to be compared against the population as a whole. They are based on the assumption that intelligence – just like many other human characteristics, such as the height of adult males or adult females – is ‘normally distributed’ throughout the population. This means that most people fall in and around the population average. The further you deviate in either direction from that average, the fewer people you would expect to find.

Intelligence tests are generally constructed so that the average intelligence quotient (IQ) of the population as a whole is 100; 50% have IQs between 90 and 110; fewer than 17% have IQs under 85, with a similar number above 115; and only 2–3% have IQs of less than 70 (with another 2–3% over 130).

A ‘significant impairment of intelligence’ is generally taken to equate to an IQ level of under 70 approximately. (There is some flexibility around this because IQ tests are not entirely error-free.)

**Social functioning** is usually determined through psychometric assessment measures – generally based on information provided by someone who knows the person concerned very well, such as a parent or other carer, rather than from the individual directly.

Modern measures yield social functioning ‘scores’ that are comparable to IQs. A ‘significant impairment of social functioning’ equates to a score that is amongst the lowest 2–3% of the population as a whole.

An **age of onset before adulthood** means that the impairments of intelligence and social functioning must both have been evident before the person reached the age of 18.
How common is intellectual disability?

Just over 2% of the population are believed to have impairments of intelligence and social functioning to the extent that they meet the definition of intellectual disability.

However, not everyone who fulfils the criteria is officially ‘diagnosed’ or receives specialist services. A significant number – especially from amongst those whose impairments are relatively mild – are able to function in their everyday lives, perhaps with the support of their families and others.

Are there different levels of intellectual disability?

It used to be common to think of four distinct levels of intellectual disability: profound, severe, moderate and mild. These would correspond to maximum development levels of approximately 3, 3–6, 6–9 and 9–12 years and to IQ ranges of <20/25, 20/25–35/40, 35/40–50/55 and 50/55–70.

Nowadays, it is more common to think of a single continuum of intellectual disability that ranges from mild to profound. By far the majority of people with intellectual disabilities fall towards the mild end, and a significant proportion of these are never formally identified. Progressively fewer people fall towards the profound end of the spectrum, but the disabilities and impairments of those who do tend to be both more severe and more numerous.

Many people with the mildest forms of intellectual disability may be virtually indistinguishable from the majority of the population, whereas those with more profound intellectual disabilities will require the support of others (including specialist services) in just about all aspects of their daily living.

People with mild intellectual disabilities tend to enjoy a ‘normal’ level of health and life expectancy; they may marry and have families (although any children they have are themselves more likely to have mild intellectual disabilities); they can usually communicate at least reasonably well; they will often have brothers or sisters with mild intellectual disabilities; and they can often lead relatively independent lives.

The more severe or profound a person’s intellectual disabilities, the more likely they are to have conditions or syndromes that make them look quite distinctive; to have defects with their brains and central nervous systems; to have one or more other serious health problems (for example, heart conditions, blindness, deafness or epilepsy); to have shorter life expectancies; to need additional lifetime supports; to have communication and educational difficulties; and not to marry or have children. (However, no one person – no matter how severe their intellectual disability – will necessarily display all of these features.)

What causes intellectual disability?

In at least one-third of cases no definite cause of a person’s intellectual disability is ever detected. As medical knowledge improves, this number will probably decrease.

Those causes that are known today may be broadly classified as genetic or environmental.

Genetic causes are linked to defects in a person’s chromosomes or genes. They include:

- chromosome abnormalities, such as Down syndrome (the single most common intellectual disability syndrome, where there is an extra chromosome number 21) and Edwards’ syndrome (where there is an additional chromosome number 18);
- single gene defects, for example the enzyme deficiency phenylketonuria (PKU); and
- multiple gene abnormalities, such as fragile X syndrome (believed to be the single most common inherited cause of intellectual disability).

It is likely that many of what are currently unknown causes of intellectual disability will be shown in the future to involve multiple genes.
Environmental causes relate to external factors that result in a child’s brain development being impaired. These can occur:

- **before the child is born**, for example if the mother contracts Rubella or consumes alcohol or other drugs during the pregnancy;
- **during the birth**, for example if the child is starved of oxygen for too long; or
- **after the birth**, for example if the child sustains a significant head injury or picks up an infection that causes meningitis or encephalitis.

**How does intellectual disability differ from other forms of mental disorder?**

As already indicated, intellectual disability can also be referred to as ‘learning disability’. These terms are sometimes confused with other terms that have different meanings.

**Learning difficulty** is a much broader term, used specifically in educational circles. A learning difficulty is any condition or impairment – for example blindness or dyslexia – that significantly impedes a child’s ability to learn through ordinary educational facilities. So, many children who have a learning difficulty will not have an intellectual (or learning) disability. However, all children who have an intellectual disability do also have a learning difficulty.

**Autism** has traditionally been viewed as a ‘triad’ of impairments in imagination, social interaction and social communication that is out of sync with a person’s overall level of development. It has been estimated that around half of those who have autism may also have an intellectual disability. However, intellectual disability is always associated with a low level of intelligence, whereas autism can affect people of any intelligence level. Indeed, Asperger Syndrome is a form of autism defined as the presence of autistic features in someone with a relatively high level of intelligence.

**Mental illness** can take a range of forms, including depression and schizophrenia. In many cases mental illness can be treated; it is not necessarily permanent. Like autism, all forms of mental illness can affect people of high as well as low levels of intelligence. People who have intellectual disabilities are much more likely to have mental illnesses than people who do not. However, not everyone with an intellectual disability will also have a mental illness.

**Has intellectual disability always existed?**

It is self-evident that most people down through the centuries will have fallen around the ‘average’ in terms of intelligence, and that some will have been relatively more able and others less so.

Although they may not always have been identified as such, those with the very lowest levels of ability at any point in time may presumably be said to have had an ‘intellectual disability’.

**Have attitudes to intellectual disability changed over the years?**

Before the industrial revolution, when work was mainly agricultural and manual, it is likely that most people with what we now consider ‘mild’ intellectual disability could have functioned adequately in their communities; only those with more severe intellectual disabilities would have been viewed as significantly different. It is also likely that very few babies with the severest forms of intellectual disability would have survived their births or, if they did, their childhood years.

The industrial revolution and more recent technologies have reduced the job opportunities for people with intellectual disabilities. This has led to more of those affected requiring specialist supports. Medical advances have also meant that many more babies survive who would not have survived in the past (although other changes, such as the option for parents to abort severely disabled foetuses, have limited the increase in numbers of children born with severe disabilities).
The 18th century began with great optimism over intellectual disability, with many believing that those affected could be educated and even cured. By the end of that century, however, it was recognised that cure was impossible, and intellectual disability came to be blamed for a whole range of society’s ills (including poverty, delinquency, etc.). Segregation (in specialist hospitals) and sterilisation were advocated and enacted, and it was only in the second half of the 20th century that the twin policies of ‘de-institutionalisation’ and ‘community care’ (that is, moving people out of the institutions and facilitating community placements) were promoted.

Recent decades have seen a move away from the ‘medical model’ of intellectual and other forms of disability, with its focus on reducing the impact on a person’s functioning of their individual impairments. Many people now prefer the ‘social model’, where the focus rather is on the need for society to remove the wide range of barriers that people with disabilities face, including those caused by inappropriate attitudes. The aim of both models is to enable people with disabilities to engage as fully and as meaningfully as possible in their respective communities.