

Intellectual disability: Information for health professionals

What is intellectual disability?

Intellectual disability (also known as intellectual developmental disorder and abbreviated as ID) involves impairment of general intellectual ability which begins during the developmental stage (birth to 18-25 years old).

It impacts significantly on the following areas of a person's adaptive functioning:

- **conceptual functioning** – language, reading or writing
- **social functioning** – empathy, interpersonal communication skills or social judgement
- **practical functioning** – personal care, self-management or lifestyle.

The severity of intellectual disability can be described clinically as mild, moderate, severe or profound.

People with intellectual disability have a wide range of skills, capabilities, interests, strengths and needs. It is important not to make assumptions about these. Each person with intellectual disability is unique, and an individualised approach is required to meet their healthcare needs.

How is intellectual disability different to brain injury?

Intellectual disability is sometimes confused with other conditions involving loss of cognitive and adaptive functions, such as acquired brain injury (ABI).

An ABI can affect a person's functional capacity and can be caused by an accident, abuse, stroke or drugs and alcohol. If this injury occurs during the developmental period and persists, the person is considered to have intellectual disability.

How is intellectual disability different to dementia?

Dementia is different from intellectual disability in that it is not a developmental disorder and it is usually characterised by progressive deterioration in cognitive function which impacts the person's ability to carry out daily tasks.

Sometimes dementia also affects people with intellectual disability. For example, this can occur with Down syndrome.

Is intellectual disability different to developmental disability and developmental delay?

Yes. Developmental delay describes when a child is slower to reach developmental milestones than other children (for example rolling over, sitting or talking). The delay could be temporary or permanent.

There are many things that can affect how a child develops. Some occur during pregnancy or during birth, others occur after the child is born. Medical conditions that may be associated with developmental delay include prematurity, inherited disorders, chronic illness (including epilepsy), infections and problems with hearing or vision.

When the developmental delay continues, it is often called developmental disability and can be a sign of more serious conditions such as cerebral palsy or a developmental disorder, like autism or intellectual disability.

How is intellectual disability assessed?

Assessment is usually based on the severity of deficits in adaptive functioning. This can be determined by clinical and standardised cognitive tools. Formal testing of intellectual ability will enhance the person's assessment.

Some people with intellectual disability enter adulthood without an assessment or a diagnosis. This could happen for a number of reasons, including:

- lack of access or awareness about diagnostic services
- a cultural background with a different concept of disability
- undiagnosed mental illness. People with intellectual disability are more likely to have a mental illness. This could mask their intellectual disability.

How does intellectual disability affect a person's health?

Common health conditions, such as gastro-oesophageal reflux, heart conditions, mental illness, autism, and sight and hearing difficulties, compound the impact of a person's intellectual disability on their functional capacity.

In all age groups, people with intellectual disability experience a higher prevalence of health conditions. These can either be associated with their disability (as part of a syndrome) or be direct or indirect consequences of the intellectual disability.

Factors that contribute to the complexity of health needs of people with intellectual disability include:

- having multiple disabilities
- severity of the intellectual disability
- mental illness
- severe, multiple or deteriorating health conditions
- behaviours involving harm to self or others
- alcohol and/or drug issues
- issues relating to past experience of trauma or neglect
- situational factors, such as socioeconomic disadvantage, lack of natural support, family/carer stress, breakdown in care arrangements, young people leaving care, involvement in the criminal justice system and multiagency involvement in provision of support.

A person's functional capacity may be affected by their health and other factors including:

- the specific characteristics and aetiology of their diagnosis
- related comorbidities (physical, mental or behavioural)
- family and community supports available
- access to health services (including specialised health services)
- understanding of and ability to act on preventive health advice
- housing
- financial situation
- educational and work opportunities
- challenging behaviours of concern
- other health conditions (diagnosed or undiagnosed).

What is diagnostic overshadowing?

Diagnostic overshadowing is when physical or mental illnesses are overlooked in people with intellectual disability or attributed to their intellectual disability.

For example, when a person with intellectual disability is self-harming, seeing the self-harm as part of their disability (instead of a treatable anxiety) is diagnostic overshadowing.

Can people with intellectual disability make choices about their lives?

People with intellectual disability have the right to make choices about their lives. In order to understand and communicate their choices and preferences, people with intellectual disability may require support.

Some people who have a more severe intellectual disability need support to make decisions or a guardian to make choices based on what they would want.

Health professionals may require expert and individualised support to understand the person's needs and choices and their role in the process.

How does intellectual disability affect the delivery of health services?

Cognitive and communication impairments mean people with intellectual disability often rely on carers or support workers to access healthcare.

People with complex support needs may encounter additional challenges to accessing timely and high quality healthcare. This is due in part to the need for health services to provide more accessible services and the need for skilled staff.

People with mild or borderline intellectual disability who live in the community and manage most areas of their life with minimal additional support are a vulnerable population at risk of being overlooked. Active outreach inclusive of people with intellectual disability helps them live healthier lives in the community.

A particular challenge for health services is ensuring that all people with intellectual disability, including those who have complex needs, are catered for by the mainstream system. This has implications for NSW Health in terms of the coordination of healthcare and the need to develop partnerships with the disability sector to support healthcare delivery and recognise the individual's need to navigate a range of healthcare specialties, and disability, educational and social services.

NSW Health is working to better support the healthcare needs of people with intellectual disability by focusing on:

- integrated care
- the engagement of primary care providers/networks
- partnerships between providers and people with intellectual disability, their families or support network.

Where do I get more information about intellectual disability?

More information and useful resources are available on the ACI Intellectual Disability Health Network [website](#).