

# What does your child having an intellectual disability mean?

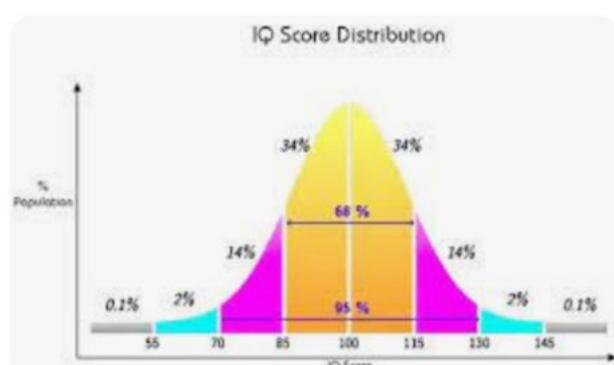
## Information patients and carers

For many parents, having a child diagnosed with an intellectual disability can be a confusing and worrying time. Intellectual disability used to be called 'learning disability' - people may use either of these terms.

Every child with an intellectual disability is an individual with their own strengths and needs, but they will have these three things in common:



1. Difficulties (functioning below 98% of people the same age) with everyday activities. This could be communication, daily living skills, self-care, socialising, or managing money. Psychologists often assess this using a questionnaire that parents/carers (and sometimes teachers) complete. This asks questions about how much help someone needs to meet the demands of daily life. The scores on this assessment can then be compared with other people of the same age. There are lots of reasons why someone might have more difficulty with everyday activities. These can include lack of opportunities or physical disabilities. It needs to be shown that these differences are due to difficulties with learning and thinking skills.
2. Difficulties with learning and thinking skills. Often a psychologist will assess these using an IQ test. They will be looking for difficulties in all or most areas and an IQ of around 70 or below (below 98% of people the same age)



IQ stands for intelligence quotient and is a measure of a person's thinking, understanding, learning, and remembering. An average IQ is 100.

There are different levels of intellectual disability which can be mild, moderate, severe, or profound. Current guidance is that these levels are based on the amount of support needed rather than IQ.

3. The difficulties are life long and start before 18 years of age.



As a parent, you can help your child by encouraging their strengths. Getting the right support to help them overcome the things they find difficult will help them lead fulfilling lives.

Here are some areas that may be difficult for them:

**Learning new information** tends to take longer. They may need support to develop new skills e.g. to do up a zip or use the toilet. New information or skills may need to be repeated many times.



**Applying learning to new situation.** For example, if a child is taught how to queue in the hall for lunch at school, they may find it hard to transfer the skill to queuing in a shop.

**Imagining ideas that are not visual or physical.** This could be time, feelings, emotions, and abstract or complex words such as 'later' and 'soon'.



**Communication** - they have difficulty understanding and thinking about what is being said and expressing their needs. Some children may use signs/symbols to communicate.

**Problem solving** - it can be hard to weigh up information and make informed decisions.



## What causes an intellectual disability?

For many children the cause remains unknown, although new genetic testing is improving our ability to diagnose conditions. Genetic causes are the most common (such as chromosomal differences e.g. Down syndrome, or changes within certain genes). Other causes include anything that can affect brain development before, during, or soon after birth. This could be an infection or exposure to alcohol, drugs, or other toxins, trauma during birth, inherited disorders of metabolism, accidents, seizures, or illness.

## Intellectual disability or learning difficulty?

**Intellectual disability** - a reduced ability to understand new or complex information and learn new skills. Also, a reduced ability to cope independently which started before adulthood.

**Learning difficulty** - used in schools to describe difficulties with an area of learning (e.g. reading, spelling, maths, or writing) that does not affect general intellect.

# Child development



Children with an intellectual disability will make progress and learn throughout their childhood, but at a slower rate. As a child grows and develops, they learn different skills, such as taking a first step, smiling for the first time, or waving goodbye. These skills are known as developmental milestones. A child with an intellectual disability will not reach every milestone at the same time as other children of the same

age. They may never reach some milestones fully. Many children with intellectual disability are given a label of ‘global developmental delay’ or ‘early developmental impairment’ in their preschool years.

## Common challenges

Emotional and behavioural difficulties are more common in children with an intellectual disability. Children or young people who have an intellectual disability

are still aware of what goes on around them. However, their ability to understand and communicate may be limited, and they can find it hard to express themselves. Speech problems can make it even harder to make other people understand their feelings and needs. Some children can become frustrated and upset. Transitions such as changing schools and puberty can both be very challenging times for children and families.



## Ways to help your child

What can help	Why
Use clear communication. Keep instructions and sentences short and clear. Use visual support such as photos, pictures, or draw things out where possible	To ensure messages can be easily understood and to prevent frustration
Encourage interests and areas where the young person is able to be most successful	To reinforce positive behaviour and to develop good self-esteem and positive mental health
Be realistic in expectations and demands (applies to home and school) and provide support so they can be successful	To reduce the frustration and stress they can experience if they don't have the skills to meet demands
Use a consistent approach, i.e. do things in the same way, wherever possible	To make life more predictable as this can reduce stress and improve learning of new skills
Use clear rules	To aid understanding with clear and consistent messages

## Websites and resources for support

### **Intellectual disabilities - child and adolescent mental health service (ID-CAMHS).**

A multi-disciplinary team that supports children 5-18 who have a diagnosed intellectual disability where there are also concerns around their mental health or significant challenging behaviour. Referrals can be accepted from any professional working with the child/young person, including a GP or school.

Tel: **01202 584353**

**[www.dorsethealthcare.nhs.uk/patients-and-visitors/our-services-hospitals/mental-health/child-and-adolescent-mental-health-camhs/intellectual-disabilities-camhs](http://www.dorsethealthcare.nhs.uk/patients-and-visitors/our-services-hospitals/mental-health/child-and-adolescent-mental-health-camhs/intellectual-disabilities-camhs)**

**Disabled children's social workers** coordinate assessments of need for children/young people, offer support to families, and signpost to other services. Dorset access via children's advice and duty service, BCP access via children's social care.

**Special educational needs and disabilities information, advice and support services (SENDIASS)** provide independent advice and support for those with special educational needs and disabilities (SEND)

**[www.sendiass4bcp.org/Home.aspx](http://www.sendiass4bcp.org/Home.aspx)**

**[www.dorsetsendiass.co.uk](http://www.dorsetsendiass.co.uk)**

**[www.bild.org.uk](http://www.bild.org.uk)**

**[www.mencap.org.uk](http://www.mencap.org.uk)**

**[www.mencap.org.uk/advice-and-support/learning-disability-helpline](http://www.mencap.org.uk/advice-and-support/learning-disability-helpline)**

**[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)**

**<https://cerebra.org.uk/> - lots of resources including their free book and toy library**

## **Parent Carers Together and Dorset Parent Carer Council**

This booklet has been created by professionals working in the Child Development Centre with the collaboration of Parent Carers Together and the Dorset Parent Carer Council. This is to ensure the booklet includes important information local SEND families need to know and we have proudly incorporated their contributions into the final version of this booklet.

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