Intellectual disability

What is intellectual disability?
A child with an intellectual disability learns and develops slower than other children. Intellectual disability affects two main areas:

- intellectual skills (this includes learning, reasoning, memory and problem solving)
- adaptive behaviour (this means activities that are part of everyday life, like talking, making friends, eating, dressing and using the toilet).

Some children with intellectual difficulties/disability have had delays in their development, including difficulties with thinking and learning, when they were young. They may have had Global Developmental Delay (a slow progress in developmental milestones). In others, difficulties are first noticed only when they start school and have trouble keeping up with the learning.

Intellectual disability is different for every child. There are four main levels:

- mild
- moderate
- severe
- profound

Sometimes, a level may not be used and the disability described as ‘unspecified intellectual disability.’

Intellectual disability also has different names in other countries. In Britain, for example, intellectual disability is called ‘learning disability.’

How is a child diagnosed with intellectual disability?
Children develop skills such as walking, talking and looking after themselves, at different rates. If you have any concerns about your child’s development, it is a good idea to have them seen early. Talk to your child and family health nurse, teacher, family doctor or paediatrician.

Intellectual disability is diagnosed using formal tests with your child. This is normally done by a school counsellor or a psychologist. They will gather information from parents, childcare or school teachers, therapists and doctors. They will also observe your child and do a series of activities called ‘formal’ tests or ‘cognitive assessments’. Formal tests might include activities such as naming and remembering pictures, completing puzzles and patterns, and answering questions. Your child’s independent and everyday living skills (i.e. adaptive behaviour) will also be checked.

What can be done to help?
Children with an intellectual disability will learn and develop new skills, but at their own pace. They will often need more time and practice than other children of the same age. Once a diagnosis of an intellectual disability is made, a child may get extra support at school and home to help them learn to their best potential. There are many options for education including additional support in a mainstream class, a specific unit in a mainstream school or a school especially designed for children with intellectual disabilities. Speech pathologists, occupational
Every child with an intellectual disability is different. Some will need support living independently in the community while others live independent lives with only some difficulties in the areas of reading and writing. Helping is always available. You can start by discussing your concerns and options with your family doctor and your child’s school.

All children have their own strengths and weaknesses. Building self-esteem is important for your child’s confidence in learning new skills.

What causes intellectual disability?

There are many possible causes for children having intellectual disabilities. Causes include:

- genetic conditions— for example Trisomy 21 (Down syndrome) or Fragile X Syndrome
- an injury to the head or brain
- an infection, such as meningitis
- problems around the time of birth

It is important that your child is assessed by your family doctor or paediatrician to identify related/further health concerns and discuss future steps to help your child and family.

Remember:

- Children with intellectual disability vary in their ability to learn and in their long term outcome. Other factors such as chronic illness, additional disabilities, the child’s own personality and social support also play an important role in how much a child is able to learn.
- The earlier a child is diagnosed with intellectual disability and supports put in place, the better the outcome for your child.
- It is important to find individual strengths and celebrate achievements.
- Many services are available to support people with disabilities and their families.

What support is there?

Many services can provide support and information to families:

- Your family doctor (GP) or paediatrician
- School/School Counsellor
- The National Disability Insurance Scheme (NDIS) supports children with a developmental delay or intellectual disability to get therapy and support. For children under 6 years old, this is through the NDIS early childhood early intervention (ECEI) approach. Early intervention (such as speech pathology, occupational therapy, physiotherapy) is the best way to support children to develop the skills they need to take part in daily activities and achieve the best possible outcomes throughout their lives. For children aged seven and above, a Local Area Coordinator (LAC) will work with the person with a disability and parents or carers and be your main contact point for the NDIS. Phone: 1800 800 110, website information: www.ndis.gov.au
- Multicultural Disability Advocacy Association (MDAA) Phone: 1800 629 072
- Carers NSW for carer information and support Phone: 9280 4744, website information: http://www.carersnsw.org.au
- Carer Gateway is a national online and phone service that provides practical information about services and support available to carers, provides emergency respite and free counselling services over the phone and connects you with other carers (through a community forum), Phone: 1800 422 737, website information: www.carergateway.gov.au
- Parent Line NSW a free telephone counselling and support service for parents and carers with children aged 0 to 18 who live in NSW, Phone: 1300 130 052, 9 am – 9 pm Monday to Friday and 4 pm – 9 pm on weekends.
- Resourcing Parents has information on services and support for families, including online webinars and courses, website information: http://www.resourcingparents.nsw.gov.au/Parents
- Relationships Australia provides relationship support services for individuals, families and communities which includes counselling for individuals, couples and families as well as parenting and relationship education, Phone: 1300 364 277, Website information: http://www.nsw.relationships.com.au
- Siblings Australia provides direct support to siblings and works with parents and service providers to better support siblings, Website information: http://siblingsaustralia.org.au