



n a m h i

promoting the rights  
of people with  
intellectual disability

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# *Intellectual Disability Causes and Prevention*

Your Questions Answered



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**Q. What is *\*intellectual disability*?**

**A.** Intellectual disability involves a greater than average difficulty in learning. A person is considered to have an intellectual disability when the following factors are present: general intellectual functioning is significantly below average; significant deficits exist in adaptive skills and the condition is present from childhood (eighteen years or less).

**Q. What is *general intellectual functioning*?**

**A.** General intellectual functioning is defined as an intelligence quotient (**IQ**) obtained by assessment with one or more of the individually administered standardised general intelligence tests. Significantly sub-average intellectual functioning is defined as an **IQ** of 70 or below on an individually administered test.

**Q. What are the *adaptive skills essential for daily functioning*?**

**A.** Adaptive skills are those everyday life skills needed to live, work and play in the community. They include communication, self-care, home living, social skills, health and safety, basic reading and writing, mathematical skills.

Adaptive skills are assessed in the person's typical environment across all aspects of an individual's life. A person with limits in general intellectual functioning who does not have limits in adaptive skills may not be diagnosed as having an intellectual disability.

\*The term mental handicap continues to be used by people in Ireland. However, in recent years the term learning disability has become increasingly popular. The term intellectual disability is recognised in international research circles and is used by the Department of Health & Children to describe the condition.

**Q. How many people are affected by intellectual disability in Ireland?**

**A.** Recent figures show that there are just under 27,000 people with intellectual disability registered on the National Intellectual Disability Database in Ireland. That is a prevalence rate of 7.38 per 1,000 of the total population. Of those registered on the database, approximately 41% are registered as having a mild intellectual disability, 36% as having a moderate intellectual disability, 15% as having a severe disability and 4% as having a profound disability. There are another 4% whose level of disability is not verified. Intellectual disability is one of the most common types of disability in Ireland. (Further information from Disability Database Division, Health Research Board, (01) 676 1176)

**Q. How does intellectual disability affect individuals?**

**A.** The effects of intellectual disability vary considerably among people just as the range of abilities varies considerably among people who do not have intellectual disability. About 87% will be mildly affected and will only be a little slower than average in learning new information and skills. As young children, their disability is not readily apparent and may not be identified even after they enter school, without formal testing. As adults, many will be able to lead independent lives in the community and will no longer be viewed as having an intellectual disability. Some will need guidance and support throughout their lives and others only at times of social and economic stress.

The remaining 13% of people with intellectual disability have serious limitations in functioning. Some may also have physical disabilities. However, with early intervention and with appropriate education and supports as adults, they can lead satisfying lives in the community, working in open, supported or sheltered employment. 1 or 2% of this group will require a highly structured environment, with one to one support from a caregiver, for optimal development.

## ***Q. How is intellectual disability diagnosed?***

- A.** The signs of intellectual disability are often evident by a child's first or second year. However, for some children diagnosed later as having a mild intellectual disability, the signs may not come to light until their school years when they have been formally tested. Children with intellectual disability lag behind their peers in developmental milestones such as sitting up, smiling, walking and talking. They demonstrate lower than normal levels of interest in the environment and in responsiveness to others. They are slower than other children in reacting to visual or auditory stimulation. By the time a child reaches the age of two or three, intellectual disability can often be determined using physical and psychological tests. Testing is important at this stage if a child shows signs of developmental delay.

Alternative causes such as impaired hearing may be found and treated. Diagnosis is highly dependent on a comprehensive personal and family medical history, a complete physical examination and a careful developmental assessment of the child.

## ***Q. Are people with intellectual disability mentally ill?***

- A.** Intellectual Disability is not the same as mental illness. Mental illness is characterised by severe disturbances of behaviour, mood and/or thought processes and/or social and interpersonal relationships.

In the distant past, emotional and psychiatric disorders and intellectual disability were viewed as the same. However, the two are now recognised as separate conditions, requiring separate services. People with intellectual disability can experience mental health problems. Due to diagnostic difficulties, mental illness can be missed in people with intellectual disability. It is thus recommended that people with intellectual disability whose behaviour changes and/or who present with difficult behaviours should have comprehensive multi-disciplinary (including psychiatric) assessment.

It is estimated that up to 40% of people with an intellectual disability will experience mental illness at one time or another. Rates of mental illness are much higher for adults with an intellectual disability than for children and higher rates are associated with mild intellectual disability versus severe intellectual disability.

**Q. What are the causes of intellectual disability?**

**A.** Intellectual disability can be caused by any condition that impairs the development of the brain before birth, during birth or in the childhood years. Many causes have been discovered, but in about one third of the people affected, the cause remains unknown.

***The following factors have been identified:***

- 1. Prenatal:** affecting the baby before birth e.g. alcohol and substance abuse by the pregnant mother (there are guidelines available on alcohol intake during pregnancy and mothers should discuss these with their doctors); bleeding during pregnancy and illness or injury of the mother during pregnancy. Recent research has implicated smoking for an increased risk of prematurity.
- 2. Perinatal:** affecting the baby at birth e.g. extreme prematurity, low birth weight and brain injury.
- 3. Postnatal:** affecting the baby after birth e.g. meningitis, encephalitis, measles, pertussis (whooping cough), head injuries and other traumas to young children.
- 4. Genetic/Inherited causes:** e.g. Down Syndrome, the most common genetic condition associated with intellectual disability or Fragile X Syndrome, the most common identifiable inherited cause of intellectual disability.
- 5. Environmental:** e.g. cultural deprivation and extreme poverty, which can result in malnutrition, inadequate medical care or environmental hazards.

**Q. Why is diagnosis of the causes of intellectual disability important?**

**A.** If the cause of a child's intellectual disability is established, a prognosis can be made for the future of the child. Social and educational interventions can be planned that will make the best of the abilities of the child. For example, if the child has a genetic inherited condition such as Fragile X Syndrome, specific interventions can be guided by what is known of the profile of other children with Fragile X syndrome. Families can also be advised on the risks of having another child who may have the same disability. In cases where the cause remains unknown, an early diagnosis means that programmes based on the needs of the child can be put in place.

**Q. Can intellectual disability be prevented?**

**A.** During the past 30 years, significant advances in research and medical services have prevented many cases of intellectual disability.

**Examples are:**

- Improved ante natal care
- Screening tests for newborn infants e.g. PKU (phenylketonuria): an inborn error of metabolism caused by a defective enzyme. Since the late 1960s all babies are tested for PKU after birth by doing a "heel prick" and any found positive can be treated by a special diet
- Increased level of care for newborn babies
- Use of vaccines e.g. MMR, which protects against measles encephalitis and congenital rubella syndrome, which are both recognised causes of intellectual disability, and Hib vaccine that prevents Hib meningitis, which was once the most common cause of intellectual disability
- Improved obstetric care
- Accident prevention e.g. child safety seats, bicycle helmets
- Follow up of high-risk infants with early intervention programmes

The risk of some conditions can be revealed by genetic studies, allowing counselling of couples to determine the risk of their having a baby with intellectual disability.

**Q. *Is there a cure for intellectual disability?***

**A.** There is no cure for intellectual disability once it has occurred. Treatment and education programmes are geared toward helping children reach their full potential. The sooner the diagnosis is made, the more the child can be helped. With infants, the treatment emphasis is on sensory-motor development, which can be stimulated by exercises and special type of play. Special pre-school education programmes are available for younger children. These programmes concentrate on essential self-care, feeding, dressing, toilet training and assistance with language and communication difficulties. As children reach school going age, education programmes geared towards their level of ability are available in both mainstream and special schools.

For adults, the emphasis is on encouraging as independent a life as possible and supporting the person in their own home or in an informal group or community home setting. Health and social services, including training and employment services are geared towards making this possible.

**namhi** is a national voluntary organisation working to promote the rights of people with intellectual disability in Ireland to ensure their full and equal participation in society. **namhi** was founded in 1961 and has become the co-ordinating body for over 160 organisations providing services and supports to almost 28,000 people with intellectual disability in Ireland.

## **USEFUL CONTACTS**

### **Dept of Health & Children**

Disability Section, Hawkins House, Hawkins St., Dublin 2.

T: (01) 635 4000, [www.doh.ie](http://www.doh.ie)

### **Health Research Board**

Disability Database Division, 73 Lower Baggot St., Dublin 2.

T: (01) 676 1176, [www.hrb.ie](http://www.hrb.ie)

### **Eastern Regional Health Authority**

Mill Lane, Palmerstown, Dublin 20.

T: (01) 620 1600, [www.erha.ie](http://www.erha.ie)

### **East Coast Area Health Board**

Disability Services, Southern Cross Business Park, Boghall Road, Bray, Co Wicklow.

T: (01) 276 5682, [www.ecahb.ie](http://www.ecahb.ie)

### **Northern Area Health Board**

Disability Services, Swords Business Campus, Balheary Road, Swords, Co. Dublin.

T: (01) 840 7446, [www.nahb.ie](http://www.nahb.ie)

### **South Western Area Health Board**

Disability Services, Leinster Mills, Osberstown, Naas, Co Kildare.

T: (045) 889 100, [www.swahb.ie](http://www.swahb.ie)

### **Mid Western Health Board**

Disability Services, 87 O'Connell Street, Limerick.

T: (061) 483 555, [www.mwhb.ie](http://www.mwhb.ie)

### **Midland Health Board, Disability Services**

APT-Kilcrutin Centre, Tullamore, Co Offaly.

T: (0506) 412 04, [www.mhb.ie](http://www.mhb.ie)

## **North Eastern Health Board**

Regional Disability Services Unit, Rooskey, Co Monaghan.

T: (047) 308 41, [www.nehb.ie](http://www.nehb.ie)

## **North Western Health Board**

Disability Services, Manorhamilton, Co Leitrim.

T: (072) 204 00, [www.nwhb.ie](http://www.nwhb.ie)

## **South Eastern Health Board**

Disability Services, Lacken, Dublin Road, Kilkenny.

T: (056) 204 00, [www.sehb.ie](http://www.sehb.ie)

## **Southern Health Board**

Disability Services, Quayside House, Princes St., Tralee, Co Kerry.

T: (066) 718 4511, [www.shb.ie](http://www.shb.ie)

## **Western Health Board**

Disability Services, Merlin Park Regional Hospital, Galway.

T: (091) 775 923, [www.whb.ie](http://www.whb.ie)

## **National Centre for Medical Genetics**

Our Lady's Hospital for Sick Children, Crumlin, Dublin 1.

T: (01) 409 6739.

## **Comhairle (Information on rights, entitlements, State services)**

Hume House, Ballsbridge, Dublin 4.

T: 01 605 9000, [www.comhairle.ie](http://www.comhairle.ie), [www.oasis.gov.ie](http://www.oasis.gov.ie)

## **National Disability Authority**

25 Clyde Road, Dublin 4.

T: (01) 608 0400, [www.nda.ie](http://www.nda.ie)

## **Attention Deficit Hyperactivity Disorder - HADD/ADHD,**

Stephanie Mahony, Carmichael Centre, North Brunswick St., Dublin 7.

T: (01) 874 8349

## **Birth Defects Foundation**

T: 00 44 87 007 070 20.

Email: [help@birthdefects.co.uk](mailto:help@birthdefects.co.uk), [www.birthdefects.co](http://www.birthdefects.co)

## **Borderline**

**(for families of persons with a mild intellectual disability),**

c/o Angela Carney, 38 Celtic Park Avenue, Whitehall, Dublin 9.

T: (01) 831 6924.

## **Contact A Family Northern Ireland**

Bridge Community Centre, 50 Railway Street, Lisburn BT28 1XP, NI.

T: 048 9262 7552, Email: [info@cafamily.org](mailto:info@cafamily.org) [www.cafamily.org](http://www.cafamily.org)

## **Cri du Chat Syndrome Support Group**

c/o David & Mary Lou Girvan, Audax, Saval Park Road, Dalkey.

T: (01) 235 3535, (086) 263 3090, Email: [david.girvan@indigo.ie](mailto:david.girvan@indigo.ie)

## **Down Syndrome Ireland**

30 Mary Street, Dublin 1.

T: (01) 873 0999, [www.dsi.ie](http://www.dsi.ie)

## **Irish Autism Alliance**

c/o Seamas Greene, 25 Hollybrook Grove Rear, Clontarf, Dublin 3.

T: (01) 853 1500, Email: [iaa@ireland.com](mailto:iaa@ireland.com)

## **Irish Fragile X Society**

c/o Mary Smyth, 24 Arden View, Tullamore, Co. Offaly.

T: (0506) 527 96, [www.fragilex-ireland.org](http://www.fragilex-ireland.org)

## **National Parents and Siblings Alliance**

c/o Karen Canning, 9 Whitecliff, Rathfarnham, Dublin 16.

T: (01) 493 5578.

## **Prader-Willi Syndrome Support Group**

Lena Lawlor, Kilmurray, Kilmacanogue, Co Wicklow.

T: (01) 286 8119.

## **Sotos Syndrome, c/o Sandra Pedreschi**

59 Hillview Estate, Ballinteer, Dublin 16.

T: (01) 296 0206, (086) 818 0713.

## **Support Organisation For Trisomy 13/18 (SOFT)**

Desie Boylan, Blackhall, Termonfeckin, Drogheda, Co Louth.

T: (041) 982 2419.

## **Tourette Syndrome Assoc.**

c/o Carmichael House, North Brunswick Street., Dublin 7.

T: (01) 872 5550.

## **Williams Syndrome**

Ann Breen, 13 Kilgarve Park, Ballinasloe, Co. Galway.

T: (0905) 43247.

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