

## Information

There is a lot of research and information available about different types of disabilities, life stages, and the financial and other assistance available.

The following can help:

**IHC:** advocates for the rights, inclusion and welfare of all people with an intellectual disability and supports them to live satisfying lives in the community.

**IHC Advocacy:** provides information and advice on the rights and entitlements of those with an intellectual disability. It also provides guidance on dealing with services and agencies such as schools, health professionals and government agencies.

Email: [advocacy@ihc.org.nz](mailto:advocacy@ihc.org.nz)

**IHC Library:** offers free access to a wide range of books, videos, journal articles, CDs and DVDs on all aspects of intellectual disability.

Email: [library@ihc.org.nz](mailto:library@ihc.org.nz)

Phone: 0800 IHC IHC (442 442)

Web: [www.ihc.org.nz](http://www.ihc.org.nz) – there is a section called Disabilities and Diagnoses which will link you to most of the websites in New Zealand and internationally about each specific condition.

IHC is on Facebook and Twitter.

**Kiwifamilies for passionate parents:** is a website giving practical parenting advice for parents in New Zealand. Here you can find what you need to know about raising children in New Zealand. [www.kiwifamilies.co.nz](http://www.kiwifamilies.co.nz)

**Weka:** “What everyone keeps asking” is New Zealand’s disability information website for people with a disability, their families, whanau and caregivers, health professionals and disability information providers. [www.weka.net.nz](http://www.weka.net.nz)

## Human Rights

The United Nations Convention on the Rights of the Child affirms that nations are to provide the necessary social programmes to support the child and their caregiver (article 18).

## Contact details

Please contact us for information or support.

IHC NZ

15th floor, 57 Willis Street

PO Box 6144

Wellington

Ph: 0800 442 442

Email: [advocacy@ihc.org.nz](mailto:advocacy@ihc.org.nz)



# What next?

*Practical advice for when  
a child is diagnosed with  
an intellectual disability*

## *When you receive news that your child has a disability – whether it's during pregnancy, after birth, during the early years or in later life.*

You and your extended family may experience a range of emotions and thoughts. The future may feel unsure. There is help and support for you and your family from a wide range of organisations.

This leaflet gives guidance on the steps you can take after you receive a diagnosis of a disability, and information about other support that is available when and if you need it.

### *Advice*

1. Ask questions. You need to learn all you can about the strengths and support needs that your child may have as a result of their disability.
2. Ask your GP for information about the relevant tests associated with your child's disability. Make appointments as quickly as possible as waiting lists can be long. You may want to take a support person with you so you can discuss this information later on.
3. Have your child's needs assessed to see what assistance you are entitled to from the Government – contact your local Needs Assessment and Service Coordination agency (NASC). You can find these details from the Ministry of Health at [www.moh.govt.nz](http://www.moh.govt.nz) or call **0800 DSD MOH (0800 373 664)**.
4. Open a bank account in your child's name and register your child with Inland Revenue to obtain an IRD number. This will be useful in applications for possible financial assistance over time.
5. Take time to learn everything you can about the disability and support programmes. It is important not to give up on any of your hopes and dreams for your child, but it is just as important that you understand what extra help and time your child may need.
6. If your child is going to school, make an appointment with your child's teacher and principal and discuss the impact that the disability will have on your child's learning needs.

### *Support*

It is important that you have people who you can talk to, especially those who can understand what you are going through. Here are some organisations you could contact for advice or support.

**Autism New Zealand:** provides support, resources and information on autism spectrum disorders to those affected, their families/whanau, caregivers and professionals working with them.

Phone: **0800 AUTISM (288 476)**

Email: [info@autismnz.org.nz](mailto:info@autismnz.org.nz)

**Barnardos:** is one of New Zealand's largest children's organisations. It provides child care services, family counselling, support, homes, parent education and a parent help line.

Phone: **(04) 385 7560**

**New Zealand Down Syndrome Association:** provides information and support for families/whanau whose lives are changed by Down syndrome.

Phone: **0800NZDSAI (693 724)**

Email: [national.coordinator@nzdsa.org.nz](mailto:national.coordinator@nzdsa.org.nz)

**Parent to Parent:** parents who provide information and emotional support to families who have a child with a disability, special needs or health impairment.

Phone: **0508 236 236**

Email: [national@parent2parent.org.nz](mailto:national@parent2parent.org.nz)

**Skylight:** provides support, counselling and information to children, young people and their families coping with change, loss and grief.

Phone: **0800 299 100**

Email: [info@skylight-trust.org.nz](mailto:info@skylight-trust.org.nz)

**Parent and Family Resource Centre:** supports parents and families of disabled children and young people.

Phone: **09 636 0351**

Email: [pfradmin@pfrc.org.nz](mailto:pfradmin@pfrc.org.nz)