



Advocacy Toolkit

For Supporters of People with an Intellectual Disability

Introduction

The IHC Advocacy Toolkit is designed to help families and supporters of people with an intellectual disability. The toolkit contains information sheets on topics and issues relevant to the lives of people with intellectual disability and their families.

More copies of toolkit resources and/or memory sticks can be ordered from IHC Advocacy or downloaded from ihc.org.nz.

IHC Advocacy welcomes your feedback about the contents of the toolkit and any suggestions you have for new information sheet topics or useful resources that can be added to the toolkit.

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When a family receives the news that their child has a disability, either during pregnancy, at birth, during the early years or later, a range of emotions and thoughts emerge and questions may arise.

It is important to:

- Ask questions, learn all you can about your child's disability and support programmes that are available. Connect with other parents who have experienced having a child with a disability
- Connect with organisations who have expertise with your situation
- Ask your GP and any medical specialists you are referred to about the relevant tests associated with your child's disability. Make appointments quickly as waiting lists can be long. This is a time when you can get overloaded with information, so consider taking a support person along with you so you can recall and discuss new information afterwards
- Contact your local Needs Assessment and Service Coordination (NASC) organisation to see what disability support you may be able to access.
Freephone 0800 693 342 to find your local NASC
- Read "A Guide for Carers" available from Work and Income
Freephone 0800 559 009
- If your child is attending an early childhood centre or school, make an appointment to meet with the Principal to discuss accessing support such as the Early Intervention Service to assist your child's learning and participation (see [Information Sheet 5](#))
- Join the IHC library and ask for assistance locating relevant and reliable information
- Making financial arrangements early can be very helpful later on. IHC recommends opening a bank account, enrolling your child in Kiwisaver and registering your child with Inland Revenue as soon as possible
- Contact WINZ regarding eligibility to the Child Disability Allowance (see [Information Sheet 3](#)).

Helpful information can also be found at:

Altogether Autism

altogetherautism.org.nz

0508 236 236

Autism New Zealand

info@autismnz.org.nz

0800 288 476

Carers New Zealand

info@carers.net.nz

0800 777 797

Complex Carers

complexcarers@xtra.co.nz

09 443 5786

Disability Information Centres

nzfdic.org.nz

0800 693 342

Fetal Alcohol Network

fan.org.nz

0800 442 442

IHC New Zealand

ihc.org.nz

0800 442 442

New Zealand Down Syndrome Association

national.coordinator@nzdsa.org.nz

0800 693 724

Disability Connect

disabilityconnect.org.nz

09 636 0351

Parent to Parent

national@parent2parent.org.nz

0508 236 235

Plunket

plunket.org.nz

0800 933 922

Prader-Willi

nationaldirector@pws.org.nz

0800 4 PWS HELP (0800 4 79743)

Rare Disorders

enquiries@nzord.org.nz

04 471 2226

Retts New Zealand

rett.info@nzord.org.nz

04 475 9265

Williams Syndrome

williams-syndrome.org.nz

Financial help is available for people with disabilities and their families.

Information about financial help available from Work and Income can be found at workandincome.govt.nz or Freephone 0800 559 009. Many benefits can be applied for online or you can ask for an appointment to see a case manager. The Work and Income website provides information about current benefit rates and limits. Some benefits and allowances are income tested.

If you are meeting with a Work and Income staff member for the first time you will need to take the following documents to your meeting:

- Birth certificate
- Personal identification such as a bank card, passport, driver's license, Real Me or 18+ card
- Bank account details
- A letter from Inland Revenue with your IRD number on it
- If you are applying for the Disability Allowance and/or the Child Disability Allowance, your doctor must fill in part of the application form. You will need to take this to the meeting with Work and Income
- If you are applying for the Disability Allowance you will need to provide your income details and verification of the additional costs incurred due to the disability

If you are concerned that Work and Income staff members do not understand your disability requirements ask for a Work and Income Disability Advisor to be involved.

Financial Need or Assistance	Supports	Contact
Income Support for Carers	Supported Living Payment	Work and Income
Help with the costs incurred when caring for a child	Working for Families Tax Credits	Inland Revenue
	Child Care or OSCAR subsidy	Work and Income
Recognition of the extra care required for children with a serious disability	Child Disability Allowance	Work and Income
Help with the additional on-going costs because of disability	Disability Allowance	Work and Income
Help with one-off hardship assistance	Assistance with Hardship	Work and Income
Help with medical costs for a person with a disability	Prescription Subsidy Card	Chemist
	High Use Health Card	General Practitioner
	Community Services Card	Work and Income
Transport Assistance for disabled people or if the person you support has difficulty getting around	National Travel Assistance	0800 281 222
	Total Mobility Scheme	nzta.govt.nz
	Mobility Parking Permits	mobilityparking.org.nz
Help with housing costs	Accommodation Supplement	Work and Income
	Rates Rebate Scheme	Local Council
Income support for people with a disability	Supported Living Payment	Work and Income
	Jobseeker Support	

Families tell IHC that it is difficult to navigate the Disability Support System. IHC recommends that families arm themselves with accurate information about what is available in your region. Supports available can vary across New Zealand.

The Ministry of Health (MOH) funds a range of disability support services for people who have a physical, intellectual or sensory disability, autism spectrum disorder or a combination of these that is likely to continue for at least six months and that limits the person's ability to function independently, so that ongoing disability support is required.

If a person requires support because of their disability, contact the local Needs Assessment and Service Coordination organisation (NASC) to discuss the person's needs. NASCs are organisations contracted by the MOH to:

- Determine the person's eligibility for MOH funded support services
- Identify the disabled person's strengths and support needs and allocate services (Needs Assessment)
- Advise what disability support services are available and make referrals (Service Coordination)
- Freephone 0800 693 342 for NASC contact details.

A NASC Needs Assessor will arrange to meet the disabled person to assess what supports are needed, what goals the person with a disability has and what things are important to them. When the needs assessment is completed a NASC Service Coordinator will discuss with the person with a disability what options are available to meet the needs and goals that were identified during the needs assessment.

Families and supporters of the person with a disability may be part of this process see

[Information Sheet 15](#).



The NASC will refer the person with a disability to a provider of the services identified as being able to meet their needs. There may be a choice of service provider but this will depend on the disability, the age of the person with a disability, what supports they are eligible for and what is available where they are living. It is a good idea to have a friend or family member or someone else you trust with you when you are meeting with the NASC and with disability support service providers as the process can be confusing and overwhelming.

The options suggested may be one or a number of services:

Disability Support Service Type	Description
Autism Spectrum Disorder Support	ASD specific services that are available are: <ul style="list-style-type: none"> • Disability Information and Advisory Services • Parent Education • Communication and Behaviour Support • Developmental Coordination
Behaviour Support	Services for people whose behaviour makes it difficult for them to engage in everyday routines, settings, activities and relationships. Support services will work with the person and their support network. A plan will be developed and implemented to reduce the impact of the person's behaviours.
Child Development Service	A multi disciplinary, community based service that provides: <ul style="list-style-type: none"> • specialised assessment • intervention and management services • works with other agencies to ensure integrated support
Choice in Community Living	A trial of an alternative to Community Residential Support for people with significant disabilities in Auckland and Waikato.
Community Day Services	The MOH funds day services for people who were deinstitutionalised under a formal deinstitutionalisation plan and for some people with high and complex needs. The Ministry of Social Development funds community participation programmes for other adults with disabilities.
Community Residential Support	These services provide support for up to 24 hours a day in small or large homes or in groups of small homes or flats. People will usually be living with other adults with disabilities.
Hearing and Vision Services	Financial support with the cost of children's spectacles. Help with the costs of contact lenses, hearing aids and cochlear implants.

Disability Support Service Type	Description
Equipment and Modification Services	Equipment or modifications may be provided to assist people with disabilities to manage or access everyday activities e.g. wheelchairs, walking frames, communication devices, ramps, handrails and door widening, van hoists and wheelchair carriers.
Funded Family Care	Funding for people over the age of 18 with high or very high support needs to pay the people they live with to help with personal care and / or household tasks. People cannot employ their husband, wife or partner.
Home and Community Support	These services assist people live in their own home. Services may include help with: <ul style="list-style-type: none"> • meal preparation • laundry • house cleaning • eating and drinking • dressing and undressing • getting up in the morning or going to bed • showering and toileting • getting around the home
Individualised Funding	A way of paying for Home and Community and Respite support that lets the person directly manage their allocated support, for example directly employing a support worker of their choice (not husband, wife or partner).
Enhanced Individualised Funding	This allows people with disabilities to use their budget to purchase disability support and is currently available in some regions.
Local Area Coordination	Coordinators assist people with disabilities to plan for a good life. Check for availability in your region.
Respite	Respite services are community based services designed to enable carers of a person with a disability to have a short break.
Carer Support	Carer Support provides reimbursement of some of the costs of employing a person to provide support while the carer takes some time out for themselves.
Supported Living	Assists people with disabilities to live independently with support in areas of their life such as: shopping, budgeting, cooking, dealing with banks, Work and Income or accessing community facilities.
Enabling Good Lives	An across government project (Ministries of Health, Social Development and Education) looking at new ways of supporting people with disabilities and their families. See the Office of Disability Issues website for information odi.govt.nz .

All teacher-led early childhood education services, Kōhanga Reo and Playcentres are able to offer 20 hours per week of government funded early childhood education to all three, four and five year old children.

There are a variety of Early Childhood Education services operating in New Zealand, including Kindergartens, Kōhanga Reo, A'oga 'Amata and other Pacific childcare centres, early childhood education and care centres, home-based education and care centres and playcentres. It is best to look around your area for a service before you actually need one, because many Early Childhood Education services will have waiting lists.

As with all children, it is important that planning begins early, so that any supports needed are in place when the child starts attending. Visiting a variety of centres to discuss how children with disabilities are included and asking other parents of children with disabilities about their experiences will help with planning.



Available Support

The Ministry of Education, Special Education is responsible for providing support for children with special education needs attending early childhood education, primary and secondary school.

Parents with a pre-schooler with a disability can talk to their family doctor, Paediatrician, Plunket nurse, Parents as First Teachers educator, Iwi Health Authority or early childhood education centre about making a referral to the local Ministry of Education, Special Education. Parents can also contact the Special Education office directly.

The Early Intervention Service provides specialist support for children whose disability significantly impacts on their ability to participate and learn. Early Intervention staff can work with your child at home, at their early childhood education service or elsewhere from soon after they are born, or from when their needs are identified, until they start school, if necessary.

Ministry of Education specialist support can be provided from speech language therapists, early intervention teachers, psychologists, advisers on deaf children and Māori cultural advisors.

The Ministry of Health can provide support for audiologists, physiotherapists, paediatricians, dieticians and occupational therapists. These supports should be discussed with the local DHB Child Development team or your paediatrician.

Children with disabilities:

- Have the right to be enrolled and included at their local school
- Have the same rights, freedoms and responsibilities as other students of the same age
- Have the right to have their individual learning and development needs met and appropriate accommodations made so they can access the school curriculum and participate in school life
- Have the right to seamless education from when their needs are identified until they leave the education system.

Some pre-school children with disabilities will have had their needs assessed by Ministry of Education Early Intervention staff and services should therefore be in place for them when they start school. Sometimes a child's learning and development needs will be identified at the B4 School Check and some may not be identified until after they start school.

B4 School Checks

The B4 School Check is a nationwide programme offering a free health and development check for 4-year-olds. The B4 School Check aims to identify and address any health, behavioural, social, or developmental concerns that could affect a child's ability to get the most benefit from school, such as a hearing problem or communication difficulty.

Information about this service can be found at moh.govt.nz.

Enrolling a child with a disability

Despite all children having the right to be enrolled and included at their local school, IHC frequently hears reports of children not being welcome at their local school.

Once parents decide which school they wish their child to attend, an appointment should be made to meet the Principal. It is important that planning begins early so that support is in place when your child starts school.

Ask the school:

- How they will make sure your child is included in all aspects of school life?
- Which staff member is likely to be teaching your child and who should parents talk to about progress?
- Will your child have an Individualised Education Plan (IEP) and who will attend those meetings?
- Does the school have experience in developing and monitoring IEPs?
- Does the school have experience in making applications to the Ongoing Resourcing Scheme (ORS)?
- How is the school's Special Education Grant (SEG) spent to support students with special education needs and how does your child access that support?
- Where the Resource Teacher: Learning and Behaviour (RTL) is based, what other schools they work with, and how might they be involved in supporting your child's learning?
- Who will supervise the child in the playground, if required?
- What will happen when the teacher aide is not able to be at school?
- What will happen with school outings, sports events and school camps?

The Education Act 1989 provides for:

- Free education in any state school from age five until the end of the year in which the student turns 19
- The same rights to enrol and receive education for students who have special educational needs as those who do not
- Education from age five until the end of the year in which the student turns 21 for those students who are funded by the Ongoing Resourcing Scheme (ORS)
- Students who are not ORS funded can remain at school beyond the end of the year in which they turn 19 ([Section 9 of the Education Act](#)), if their continued enrolment is agreed to by the Secretary of Education.

A child with a disability's right to education is protected by law and international human rights conventions. Schools have obligations to children with disabilities and their families based on legislation, policies, strategies and international law. Many parents of children with disabilities have reported to IHC examples of difficulties and discrimination in schools, including:

- Children with disabilities discouraged or denied enrolment at their local school
- Exclusion (being sent home) from school for part of the school day
- Difficulties in getting specialist support or families paying privately for these services
- Classroom teachers lacking confidence, skills or knowledge to teach a child with a disability
- Children with disabilities' potential as learners not recognised and developed
- The learning and achievements of children with disabilities not monitored or reported in the same way as other children
- Children with disabilities being excluded from participating in usual classroom activities
- Inadequate response to complaints of abuse, bullying and harassment of children with disabilities

- Children with disabilities being excluded from activities such as music, school outings, school camps and sport
- Children with disabilities being stood down, suspended or excluded from school despite their behaviours being related to their disability
- Children with disabilities being unable to participate in all school activities unless families provide support or pay for teacher aide support.

Schools have an obligation to ensure the learning needs of all students are met. If this involves modifying property or making specialist services available, the school should work with the Ministry of Education or other agencies to meet these needs. Special Education 2000, the special education policy framework, aims for clear, consistent and predictable allocation of resources for children with disabilities. These resources are to be allocated fairly, irrespective of school setting or geographic location. Special Education Policy Guidelines affirm the right of every student to learn in accordance with the principles and values of the National Education Guidelines and in accordance with the 1989 Education Act.

The Ministry of Education folder "*Services and support for children and young people with special education needs*", contains information about educating children with special needs, contact Special Education 0800 622 222 to request a copy.

If there are difficulties in enrolment and accessing support (see [Information Sheet 8](#)) for your child with a disability that cannot be resolved by going through the school's complaints policy and procedures, contact the local Ministry of Education office (see [Information Sheet 9](#)).

If these avenues are unsuccessful contact Youthlaw 09 250 2670 or IHC Advocacy 0800 442 442.

Research shows that inclusive education is the building block for inclusive communities.

Types of support available

Children and young people with disabilities should receive the support and services (reasonable accommodation) they require from the school they attend, but if additional services and resourcing are required, the school should make a referral to Special Education who will assess the child's learning needs. An Individual Education Plan (IEP) should be put in place for all children with special education needs. Children with moderate special needs should be supported by their school through:

- The school's operational funding
- The Special Education Grant
- Resource Teachers for Learning and Behaviour, Vision or Hearing Impairment

If your child is recognised as having high needs, school staff should organise and coordinate extra services from Special Education or another agency that receives Government funding for this purpose. The Ministry of Education is responsible for supporting children with high needs through:

- Ongoing Resourcing Scheme (ORS) (see [Information Sheet 9](#))
- School High Health Needs Fund
- Severe Behaviour Service
- Communication Service
- Transport Assistance
- Assistive technology
- School Property Modifications
- Intensive Wraparound Service

Assessment

Assessment is the responsibility of the class teacher and school staff, and specialists from appropriate agencies. Information gathered from the assessment will form the basis of the child's IEP.

Developing an Individual Education Plan

An IEP meeting should include the parents, classroom teacher, child and specialists as appropriate, to set short and long-term goals for the child's development and learning. The IEP should be reviewed at least twice a year in a meeting with parents, and the team that developed the plan. For more information see the [IHC Pocket Sized Guide](#) to Individual Education Plans.

Other support available from the Ministry of Education may include:

- Traumatic incident management
- Cultural support
- Positive Behaviour for Learning
- Outreach service - provides an itinerant specialist teaching service for students on ORS who are enrolled in their local schools.

If a child's needs are not being met at school, you can:

- Talk with the class teacher or Principal as soon as any problems arise
- Gather information, such as a copy of the school's charter or strategic plan and talk through issues with people you trust such as other parents of children with disabilities, support groups or specialists who know your child and their needs
- Arrange a meeting with the Principal to discuss your concerns
- Identify what supports are needed
- When you have come to an agreement, write it down and develop a plan
- If you fail to reach an agreement, discuss your options
- Write a letter of complaint to the school's Board of Trustees outlining your concerns.

Parents can ask questions and challenge decisions made about special educational support services for their child. Parents may apply to the Ministry of Education (MinEdu) for formal reconsideration under s10 of the Education Act 1989 of any decision made regarding either enrolment in a special school, or the provision of education or help from a special service, i.e. the Ongoing Resourcing Scheme (ORS). Decisions about ORS funding are also subject to the formal process under s10. Requests for reconsideration must be made in writing to the Secretary for Education within one month of the decision or direction the parent does not agree with. [MOE Leadership Team](#). Contact Youthlaw or IHC Advocacy for support to lodge a s10 appeal.

For decisions or directions that do not involve enrolment or the provision of education or help from ORS there is generally no formal means of redress. This does not mean that parents should not complain about the decision. Complaints can be made to the Principal, the Board of Trustees (BOT), the Ministry of Education, the Minister of Education, the Education Review Office and / or the Office of the Ombudsmen. The Ministry of Education commenced work in 2011 on developing a mediation and complaints resolution service. Parents wishing to make a complaint could enquire if the service has commenced operation.

Stand-downs, suspensions, exclusions and expulsions

Children with disabilities are over-represented in the numbers of children who experience stand-downs, suspensions, exclusions and expulsions. Children with disabilities should not be subject to these processes where the concerning behaviours are related to their disability.

There is a clearly defined process for stand-downs, suspensions and exclusions that schools must adhere to. [Ministry of Education Guidelines](#)

- The stand-down period is up to five school days in any term and no more than 10 school days in a year
- Stood-down or suspended students may attend school in certain circumstances and must be provided with appropriate guidance or counselling
- Students and their parents must be provided with a report from the Principal setting out the reasons for the suspension
- Students have the right to speak and be represented at suspension meetings
- Suspended students are to be provided with an educational programme
- The Board of Trustees (BOT) must arrange a suspension meeting before the close of the seventh school day after the suspension or the tenth day after the suspension if the suspension occurs within seven days of the end of term
- The BOT can extend suspensions with conditions aimed at bringing the student back to school
- The BOT may exclude students from their school
- Principals have 10 school days in which to find another school for an excluded student and if they haven't they must inform the Ministry of Education
- Expulsion is the formal removal of a student aged 16 or over from school. The Principal and Ministry do not have to help an expelled student find a new school.

Getting Help

It is against the law to be discriminated against in education. Contact the Human Rights Commission 0800 496 877 for information about how to make a discrimination complaint.

If you think your child is experiencing an unfair disciplinary process seek support. Youthlaw 09 309 6967 and Parents Legal Information Line (PLINFO) 0800 499 488 can provide advice and assistance on school issues.

Youthlaw: is a specialist nationwide community law centre for children and young people under the age of 25. They have particular expertise in education law ranging from school enrolment, and discipline, to special educational needs. Youthlaw has extensive experience in attending disciplinary meetings at schools and providing advocacy for student issues, assisting clients with complaints to the Human Rights Commission and providing advocacy and assistance in accessing special educational support and assistance. Youthlaw staff solicitors are unique specialist practitioners being some of the only lawyers practicing in the field of education law and having the ability to assist with appeals of ORS funding under [Section 10 of the Education Act](#).



All young people leaving school require support making decisions. Support will involve finding out information and helping them to make decisions about work, further education, getting involved in community activities or adult disability support services. It is about planning for a balanced, enjoyable and rewarding adult life, including making time for recreation and fun and learning how to develop and keep relationships. This is commonly called transition planning. Transition planning works best where a team of supporters gets involved. The team can include the young person, their family, friends, school staff, adult service providers and any other community support staff. The team should work together to develop a transition plan that meets the student's needs and wishes, in a range of areas that may include:

- employment or vocational options (see [Information Sheet 12](#))
- income and financial arrangements
- living arrangements (see [Information Sheet 13](#))
- cultural and religious supports
- further education options
- recreation and leisure options
- advocacy arrangements
- friendships, sexuality and relationships
- transport and community access
- disability support services

Transition planning for young people with disabilities should begin around age 14 and become more specific and focused as the young person moves towards leaving school. Transition services funded by the Ministry of Social Development (MSD) are available for all Ongoing Resourcing Scheme (ORS) funded students who are in their last year of school. Funding is for up to 12 months.

ORS funding ends when a young person leaves school. For some young people with very high needs additional support may be required to enable them to attend a MSD funded

service during the week. Contact the National Contracts team at MSD 04 916 330 to find out what is available in your area. The transition service, the Needs Assessment and Service Coordination (NASC) organisation and the service provider should work together to ensure all the necessary supports are available.

Supporting the young person preparing to leave school

Young people with disabilities preparing to leave school should have access to all the programmes and supports available to all secondary students:

- Develop a plan that sets clear goals for where they would like to be
- Plan for any support and ongoing education if needed with literacy and numeracy
- Plan for getting around the community and learning any new skills required
- Identify key people in areas where support may be needed
- Identify skills needed to become as independent as possible
- If they have equipment provided by the Ministry of Education that they will need to use after leaving school discuss with their lead worker from Special Education
- Get an IRD number, a Work and Income number and an 18+ or Real Me card
- Discuss the transition plan with the NASC.

Social and recreational activities

- Contact the local city council, community centre, Disability Information Centre or NASC for information about suitable social, recreational and community groups
- [Enabling Good Lives](#) aims to develop new ways of supporting people with disabilities and their families. Check availability in your region with the NASC.
- Local self advocacy groups such as People First may have useful information
- If suitable find out what Special Olympic sports are available in your area.

In 2008 the New Zealand government ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Article 12 of the Convention requires a shift from substitute decision-making to having laws, policies and processes that support people with disabilities to make their own decisions. Article 12 states that people with disabilities are equal under the law and that the necessary support be provided so they can exercise their legal capacity. It requires safeguards to be put in place to prevent abuse if substitute decision-makers have been appointed.

Make a Plan

Support your family member to lead the creation of a vision for the future, as early as possible. Support them to invite others to be involved in building a plan and putting it into action. Encourage them to think about where they want to live, work and spend leisure time in the future (see [Information Sheet 13](#)). Make a plan and support the making of decisions about how the vision will be achieved.

Good Support

People with an intellectual disabilities have the right to be supported to make decisions in the way that suits them best. The support they need may change with each decision being made. [Supported Decision-Making A Guide for Supporters of People with an Intellectual Disability](#) is an online resource developed by [IHC Advocacy](#). The guide is designed for family, whanau, friends, staff, workmates, volunteers - anyone who may have a role in supporting people with intellectual disabilities to make decisions.

Getting the Right People Involved

A useful approach is to support the person with a team of people. This is often called a circle of support. Ideally, the team will include people who have similar values and beliefs, are strategic thinkers, are passionate and committed and have a strong personal philosophy towards full inclusion of all people in the community. *Believing in Better* is a workbook that provides families with tools and encouragement to take the steps needed towards a positive future and supports the development of a circle of support. *Believing in Better* is available free to families of young adults (13 -24) from the [IHC Library](#).

Supporting a person with a disability to make their own decisions involves:

- Knowing and understanding the person who is being supported
- Using the person's preferred communication style
- Having the right people involved
- Providing easy to understand information
- Exploring options
- Supporting the person to tell others their decisions
- Supporting the person to make the next steps work
- Reviewing the plan regularly



Resources about Supporting Decision-Making

[Supported Decision-Making A Guide for Supporters of People with an Intellectual Disability](#)

is available online from the IHC website.

Believing in Better is available free to families of young adults (13 -24) from the [IHC Library](#).

A leaflet is also available from the [IHC Library](#), which lists some excellent resources that can be borrowed by people who want to know more about how to support decision-making. The library catalogue can be accessed online at: ihc.org.nz/resources/our-library or phone 0800 442 442 to discuss your particular requirements with a librarian.

Financial and Property Matters

As with all young people, legal guardianship of a young person with a disability ends when the child turns 18.

Most adults with an intellectual disability can be supported to manage their affairs by family, friends, members of a circle of support, and/or by disability provider support staff. Support can range from informal day-to-day support to more formal support such as the appointment of an agent to assist with money matters.

Sometimes families are advised that adult guardianship arrangements (Welfare Guardianship and Property Management) need to be put in place to support adults with disabilities with financial, health and legal matters. Increasingly families are finding that alternative arrangements can be made and work well.

Examples Include

The appointment of an agent or nominated person to support people in their dealings with Work and Income and Inland Revenue. Forms for these can be found online, workandincome.govt.nz and ird.govt.nz.

There are a number of other ways to support a person with their day-to-day banking arrangements without involving court processes, for example by becoming an account signatory or by operating a joint bank account.

Sometimes a person may indicate they want a trusted person to be a signatory on their account or with Work and Income but due to their disability are unable to physically sign the forms. Consider using a declaration similar to this (adapt to your circumstances): “*XXX has indicated they wish XXX to be a signatory/ agent. Due to their impairment they are unable to sign this form*”.

See [Information Sheet 15](#) for information about supporting people to give consent for health procedures.

People with disabilities have the same right to take part in community life including employment and tertiary education as everyone else. Many people with intellectual disabilities find it difficult to gain employment. Employment of people with intellectual disabilities can be facilitated in several ways.

Employment and Participation and Inclusion Services funding

The Ministry of Social Development (MSD) funds a range of services to support people with disabilities to gain and maintain employment. This includes the range of services available to every job seeker on a benefit, and some specialist services for people with disabilities.

Career planning and employment

- Discuss career planning with a school guidance counsellor or school careers advisor
- Tertiary providers will have a contact person or a support service for people with disabilities; contact the tertiary provider directly for specific details
- Develop a plan to gain work skills and work place experiences
- Contact youth transition or career services for assistance with career planning, CV development and job searching
- Look in local newspapers to explore job vacancies or approach local businesses
- Contact the local Work and Income office to discuss employment and services and supports available to assist with finding employment
- Supported employment agencies provide help with job searching and ongoing support such as job coaches and work brokering. Contact the NZ Disability Support Network for details of supported employment agencies in your area. nzdsn.org.nz
- Contact Inclusive NZ comms@inclusivenz.org.nz to find out about vocational services in your area
- In some regions support may be available from Enabling Good Lives navigators or Local Area Coordinators. Ask your Needs Assessment and Service Coordination organisation (NASC) about whether these services are available in your region.

Employment Agreement

People First New Zealand Inc Ngā Tāngata Tuatahi in conjunction with IHC developed an Easy Read Employment Agreement, which is able to be downloaded from their website peoplefirst.org.nz. This agreement complies with New Zealand employment law and can be used to assist people to understand their employment rights and responsibilities.



As young people become adults, decisions about their living arrangements will need to be made. Some will want to leave home and others may choose to remain living in the family home. Encourage and provide opportunities for talking with people their own age about where they want to live. Leaving home is a major change for all young people. Support and assistance with planning the move is essential. The plan should include where the person will call home in the future and their vocational aspirations.

Living in the Community

The United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) Article 19, states: “People have the right to live in the community with choices equal to others so they have:

- The opportunity to choose where and who they live with
- The support needed to make decisions
- Access to a range of in home and community based supports
- Access to the same community services and facilities as others and these are responsive to their needs.”

Questions to consider:

- Where does the person want to live?
- What will suit your family circumstances, culture, and community?
- Do they want to live alone or with other people?
- How will they access their friends, family, work, community and own home?
- The type of house that will suit their needs?
- What natural networks are available to support them to live as independently as possible?
- What financial supports are available from Work and Income?
- Will appropriate transport be readily available?
- Are money management supports needed?
- Is support needed around sexuality and relationships?
- Are there any safeguards that need to be put in place?
- Are there technologies available to assist with personal and home safety?

Funded supports are available to assist people with intellectual disabilities to live as independently as possible in the community. Meet with the local Needs Assessment and Service Coordination (NASC) organisation to discuss what support options are available in your region. Freephone 0800 693 342 for NASC contact details. Availability varies across New Zealand, but all or some of the following support options for people leaving home may be available: Individualised Funding, Supported Living, Choices in Community Living, Contract Board, and Residential Services (see [Information Sheet 4](#) for information about these). Access to funded support services is via the NASC. There are several options to be considered, and a community residential group home operated by a service provider is one option. In the past options were limited but now there is an increasing range of options being developed and becoming available in several regions.

The following ideas may assist:

- Families build or move to a property that has a detached or semi-detached space to be used as a step towards moving out
- Families, or a group of families have family-governance arrangements, working in partnership with a service provider or setting up an independent service
- Your family member flats independently or with friends, with formal and/or informal support
- Your family member lives in a home owned by a disability service provider with support from that provider
- The family moves out of the family home and the family member stays there
- The person uses their Kiwisaver contributions as a deposit on a home
- Contact the NASC for more information if household modifications are required.

For young people with high or very high needs who remain living at home Funded Family Care (FFC) could be considered. FFC allows eligible people with disabilities to employ family members to provide their supports for activities such as showering, eating, cooking and cleaning. Find out more about [FFC](#) and how it can be used from the Ministry of Health website.

Work and Income provides financial support to people who are not in paid employment. Depending on the person's circumstances they may qualify for The Supported Living Payment (SLP), previously called the Invalids Benefit or Jobseekers Support (JS) previously known as the Unemployment or Sickness Benefit. Both benefits provide financial support while also allowing the person to receive support to seek suitable work.

Jobseeker Support is a temporary benefit paid while a person is looking for work. The Supported Living Payment provides income support for people with a permanent and severe health condition or disability. Most people with an intellectual disability will meet the criteria for Supported Living Payment.

An application for the Supported Living Payment can be made by a person who is 16 years or older, whether or not the person is attending school or tertiary education. The payment of the Child Disability Allowance (an allowance to assist with the extra care required for a child with a serious disability) will discontinue if the Supported Living Payment is granted or when the young person turns 18. As part of the application for Supported Living Payment information about the person's disability and the impact it has on their ability to work is required.

Work and Income policies and procedures are intended to be supportive of people with disabilities who want to work and provide assistance to find suitable employment. Many people with intellectual disabilities will want and be able to work full or part-time. People who are working part-time must declare their earnings. People can earn or receive extra money and still be entitled to a benefit. The income test for the Supported Living Payment is based on annual earnings. The first \$5,200 in addition to \$20 per week earned from the person's own efforts does not affect the benefit. The next \$5,200 reduces the benefit by 30 cents in the dollar, that is, if \$10,400 is earned after the deduction of \$20 per week in which the money is earned, \$1,560 will be deducted. After \$10,400 the abatement rate increases to 70 cents in the dollar.

Exemption of all or part of income 'as incentive to personal effort'

Work and Income can use their discretion to decide if all or part of the income of a person with a significant impairment can be disregarded 'as an incentive to personal effort'. The exemption is not just to provide a person with more money. Its primary focus is to increase participation in the community by exempting all or part of the person's income that is earned by the person's own efforts. The discretion is aimed at recognising and encouraging personal endeavour. The exemption is not limited to offsetting the extra costs associated with employment that a person with a disability may face.

The Supported Living Payment (SLP) can be paid for up to 26 weeks on a trial basis to a person working 15 hours a week or more in open employment

A person on SLP can continue to receive the benefit for up to 26 weeks after starting work in 'open employment' for 15 or more hours a week. This gives people an opportunity to see whether working in 'open employment' is a good option.

Some people starting work may qualify for the Work Bonus or Transition to Work Grant, which helps people with the costs of moving into a job.

Review and Appeal Processes

Any decision made by Work and Income about benefit entitlement can be appealed. There is a review and appeal process that people can use to ensure decisions are correct. The website workandincome.govt.nz can provide more information. If you are concerned you may have received inaccurate or insufficient information or poor advice, ask for the matter to be referred to a Work and Income Disability Advisor.

People with intellectual disabilities experience inequalities in health outcomes and inequity of health access. They experience lower life expectancy and a greater prevalence of health problems when compared to the general population. Often the health conditions of people with intellectual disabilities are under recognised or inadequately managed. Preventative health care and health promotion programmes often fail to target people with intellectual disabilities.

Annual Health Checks

IHC supports comprehensive annual checks as being the most effective strategy for health and wellbeing.

Health Passports

A Health Passport is a booklet that can be used for all medical appointments. The Health Passport contains information about the best ways to communicate with and support the person with a disability. Several DHBs have fully integrated Health Passports use into their hospitals and as a key tool for patient care. Find out more about [health passports](#) from the Health and Disability Commissioner's website.

Care Coordination Centres

When people with intellectual disabilities become unwell or have an accident they have the same right as anyone else to access supports, in addition to their disability supports. The NASC, or in some regions a Care Coordination Centre, should work with all the support agencies involved to ensure that appropriate and well-coordinated services are arranged.

Code of Health and Disability Services Consumers Rights

All New Zealanders enjoy the same rights under the code, hdc.org.nz. Two important rights for people with intellectual disabilities are often not recognised and responded to.

Right 7 (4) c (ii)

Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where - if the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and are available to advise the provider.

Right 8

Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed.

Advocacy

Where rights under the code have been breached, it is best to talk or write to the health provider concerned. Keep a copy of any correspondence. Support for making a complaint can be accessed from the free and independent Health and Disability Advocacy Service, advocacy.hdc.org.nz. You can also [complain](#) to the Health and Disability Commissioner, who can respond in a number of ways.

The intent of the Protection of Personal and Property Rights Act was to protect a person with a disability by appointing people to assist with decisions relating to their welfare and financial matters. The provisions of the Act are all aimed at protection, not control.

If, after consideration (see [Information Sheets 11](#) and [21](#)), you think that personal orders are appropriate for your situation you can download information and application forms about welfare guardianship, property management and property administration justice.govt.nz.

It is important for welfare guardians and property managers to know and understand the serious obligations and significant responsibilities of their appointment.

Roles and Responsibilities of Welfare Guardians and Property Managers

Welfare Guardians must:

- Promote and protect the incapacitated person's welfare and best interests
- Encourage the person to develop and use whatever capacity they do have
- Encourage the person to act on their own behalf wherever possible
- Help the person to be, as much as possible, part of the community
- Consult with the person and with other people the welfare guardian thinks can give competent advice about the person's care and welfare
- Consult with the person's property manager if there is one appointed.

A Welfare Guardian cannot:

- Make decisions about marriage or adoption
- Refuse consent to medical treatment
- Consent to ECT, surgery involving the brain or medical experiments.

Property Managers administer property for people who are partly or completely unable to manage their own property affairs. Property Managers must:

- Act in the person's best interests
- Enable and encourage capacity and intervene as little as possible
- Consult with the person and other interested parties
- File annual financial statements, including detailed statements of receipts and payments to the court, which are then examined by the Public Trust. There is a fee charged for this, but an application can be made to the court for this to be waived.

Property Administration may be an appropriate and less onerous way to support the management of a person's property, income or benefit. Property Administration orders can be made by the Family Court for items of property worth less than \$5000, and/or an income or benefit less than \$20,000 per annum. Property Administration orders do not require annual financial statements to be prepared for the court.

Having a will ensures that the people that matter most to you are provided for when you die. A will sets out your wishes so nothing is left to chance. If you die without a will the law will determine how your estate is divided, this could be very different to what you want. Making a will that specifically provides for a family member with an intellectual disability ensures that their future financial needs are provided for. Wills should be revised regularly. Any bequests or trusts set out in your will do not come into effect until you die, so can be changed by you at any time.

Letters of Intent

A letter of intent is a document that can be attached to your will. It sets out your ideas and wishes about the future care of your family member with an intellectual disability. Letters of intent are not legally binding but can be very useful. They should be updated regularly. Make sure the letter is flexible so that other people don't feel locked into arrangements that cannot be adhered to at a later date. Include the contact details for people who are included in the letter. Let family, friends and caregivers know that you have attached a letter of intent to your will and where your will is filed. The letter of intent could contain information such as:

- Social and personal family history
- Health history
- Financial information
- Statements about your values and your wishes and about how life decisions should be approached
- Property
- Any other important information you wish to include, e.g. funeral arrangements
- A photo of your son or daughter.

Setting up a trust for your family member with an intellectual disability could enhance the quality of their life, while at the same time allowing them to receive existing funding from the government. A trust can be designed to help with lifelong advocacy and the administration of money and other assets

Trusts

A trust is able to own, buy, sell and manage assets. Its terms and powers are contained in a trust document. You may wish to write a Letter or Memorandum of Wishes and attach this to the Trust Documents. In the Letter or Memorandum you can inform the Trustees on how you want the Trust run after you are gone. You can include anything in it, for example, specifying what is to happen if there are no beneficiaries surviving. The document is not legally binding but is morally persuasive. Setting up a trust can assist parents and their family member with an intellectual disability by:

- Helping with the day to day administration of their affairs
- Investing surplus capital through the trust in a way that the capital remains as a family asset
- Leaving your assets to the trust when you die, but on the death of your family member with an intellectual disability, the assets can go to other members of your family
- Assisting a family member with an intellectual disability into their own home.

Support for future planning

IHC has several resources to assist future planning including, *Preparing for the Future and Living Well*, and *Thinking and Planning for the end of your life*. Call 0800 442 442, to request these.

Being well prepared for retirement, old age and dying makes our final years less stressful.

IHC suggests that families consider the following ways to support people with an intellectual disability to prepare for retirement and beyond.

Kiwisaver: Enrolment in Kiwisaver at an early stage can be beneficial.

kiwisaver.govt.nz has information about how being enrolled in Kiwisaver can assist with homeownership, how to apply for a contribution exemption if necessary and taxation implications.

Pre paid funerals: There are several commercial products available that encourage people to contribute regularly towards the cost of their funeral.

Planning a funeral service: The IHC resource, *Living Well – Thinking and planning for the end of your life*; contains a section to assist people to think about the sort of funeral they would like. Contact IHC 0800 442 442 to request a copy of this resource.

Successful Ageing Project: IDEA Services as a priority, supports people so they can age in their home if they wish. Talk to your local IDEA Services Area Manager to discuss options and support available for your older family member.

Making a Will: Having an intellectual disability does not prevent many people from making their own will. Support people with intellectual disabilities to think about making a will. Your local Community Law Centre or the Public Trust will be able to provide the necessary information.

Intestacy: When a person dies without making a will the rules of intestacy will apply. The law provides a code that sets out an order of priority for people to receive the deceased person's property and in what proportion. All the people are family members. Who gets what depends on which family members exist.

The basic order of priority is:

- spouse, civil union partner or de facto partner, then:
- children,
- parents,
- brothers and sisters,
- grandparents,
- uncles and aunts.

Advocacy is to do with rights. The main goal of advocacy is to ensure that a person's 'voice' is heard and their rights are recognised and realised.

Disability Advocacy ensures the human and legal rights of people with disabilities are promoted and protected so that people with intellectual disabilities are valued and they can enjoy satisfying lives.

Self-Advocacy means advocating for one's self, standing up for one's rights with the support needed. An advocate supporting and/or working with people with intellectual disabilities will ensure that their right to advocate for themselves is upheld. An advocate will support a person with an intellectual disability to make decisions and to speak up for themselves. This may include providing information and advice to assist them to advocate for themselves and others with intellectual disabilities.

Individual Advocacy is when a person is assisted by an advocate who, with their permission, advocates on their behalf. You always need to get a person's permission to be their advocate. For informal situations such as supporting someone at a meeting, verbal permission may be sufficient. If, however, you are requesting personal information from organisations or advocating on a person's behalf, it is advisable to get written consent. If at any time you think you may have a conflict of interest, you need to declare it, and discuss whether you are still the best person to act as the advocate.

Systemic Advocacy is about social change. It addresses laws, systems or structures that adversely affect people with intellectual disabilities and their families by advocating for change. Systemic advocacy includes lobbying politicians, campaigning and the raising of public awareness.

An Advocate:

- Listens carefully – this means finding out what the individual or group is actually saying, not what you think they should be saying
- Communicates clearly and often
- Is creative and tries different approaches – don't give up if your first idea doesn't bring a solution
- Is assertive – takes a firm stand and sticks to it without getting angry or going on the attack
- Is persistent – some issues take a long time to resolve. A good advocate must be willing to 'hang in there' until the issue is resolved and not back off if it becomes difficult or time-consuming.

Advocacy Processes

A strategic approach to advocacy delivers the best results. Identify and focus on "the bit" that is broken.

- Define the issue – the presenting problem is not always the real one
- Identify who the issue affects
- Find out when the problem started and how long it has been happening
- Try to identify the cause of the issue
- Agree on the desired outcome.

You may have concerns about the services received from a government funded agency, organisation or service. Government funded organisations are required to have a complaints process. The [service specifications](#) for Ministry of Health funded disability support services can be read online. Service Specifications explain what the Ministry of Health expects from disability support service providers.

When you have concerns about a service it is helpful to be well prepared before you raise the issue or make a complaint.

- Write down the details of what happened, as soon as possible, including any dates, times and names you can recall (you may need to refer to this later). Stick to the facts
- Approach the organisation directly and ask for a copy of their complaints process
- Take your concerns directly to the organisation. You may choose to do this in writing so you have a record
- If you meet with the organisation, ask a family member or friend to accompany you for support
- After a face-to-face meeting or phone conversation note down any decisions made or agreements reached and confirm these in writing with the people you met with
- If the organisation is a health or disability organisation you can seek the support of an Advocate from the Health and Disability Advocacy Service Freephone 0800 555 050
- If you are unable to resolve an issue with a government funded organisation consider approaching the government department responsible for their funding
- See [Information Sheet 9](#) for how to challenge education support decisions.

Official Information

Official Information is any information held by the Government, Ministers of the Crown, government departments and organisations, educational institutions, Boards of Trustees and public hospitals. A full list of the organisations that you can request information from can be found in the Directory of Official Information, which is published by the Ministry of Justice every two years. The Directory is available on the Ministry of Justice website justice.govt.nz. The principles of the Official Information Act 1982 mean that information must be made available unless a good reason exists under the Act for withholding it.

Making an information request is simple. Contact the organisation concerned and ask for the information. Be as specific as you can about what you are wanting. It is best to make the request in writing. You can ask for: reasons for decisions made about you, internal policies, principles, rules or guidelines; and meeting agendas and minutes of public bodies, including those not open to the public. If you are requesting personal information about someone other than yourself this is covered by the Official Information Act. If you are asking for personal information about yourself, the request is covered by the Privacy Act 1993.

You can complain to the Ombudsman if; you are refused access to any information, the person handling your request does not reply to you within 20 working days, you are not happy with the length of an extended time limit, you believe that you have been charged an unreasonable amount for the information, you are not happy with the way the information has been made available or are unhappy with any conditions placed on the use of the information.

People of all ages with intellectual disabilities can be vulnerable to abuse. Abuse can take many forms e.g. sexual or financial abuse, violence, rough handling, neglect, bullying, intimidation, manipulation, withholding medication or overdosing, name-calling and teasing.

Recent New Zealand research highlights high rates of abuse of people with disabilities, much of which is hidden, and confirms that current systems do not always keep people safe, protect them from abuse or ensure that perpetrators of abuse are held to account. People with intellectual disabilities find it difficult, or may be unable to report abuse and there is frequently a failure to respond to, or investigate allegations of abuse and neglect.

[Hidden Abuse of Disabled People](#)

After recent publicity about the abuse of people with intellectual disabilities living in government funded residential services, the Ministry of Health conducted a review that resulted in the report [Putting People First](#) and a subsequent Ministry of Health led project plan.

Keeping Safe

When people with intellectual disabilities have ongoing access to learning about their human rights and how to speak up, particularly, when they have a complaint and when they are trained alongside their support staff, then the likelihood of abuse and neglect is reduced. Safe disability support services are more likely when support services are welcoming of families and other supporters. People with intellectual disabilities need a range of paid and unpaid people in their lives. They need someone who they can speak to, who they can trust and who will believe them. Priority needs to be given to supporting the development of effective circles of support for people with intellectual disabilities as these can both assist in preventing abuse and also provide ongoing support should abuse occur. Excellent information about establishing a Circle of Support can be found in the *Believing in Better* workbook. A personal copy of the workbook to keep is available free for families of young adults (up to 24 years of age), or can be borrowed from the library. To access the free book offer or to borrow email Librarian@ihc.org.nz or phone 0800 442 442.

Support to develop friendships in the community through programmes such as [IHC Volunteering](#), [Citizens Advocacy Auckland](#) and the [Dunedin Friendlink Trust](#) are also ways to increase the number of people involved in a person's life.

Reporting Abuse

The Crimes Act makes it an offence to stay silent when it is known that a child or vulnerable adult is at risk of death, grievous bodily harm or sexual assault. The Act requires family and community members to report concerns about the safety of children and vulnerable adults.

If you think that someone is in immediate danger, call the Police. If you have concerns about the safety of a child, call Child, Youth and Family, 0508 FAMILY (0508 326 459). If the social worker thinks the child is in immediate danger they will act on it within 24 hours.

While there are a number of organisations that can receive complaints about abuse or neglect of vulnerable adults; the Police, the Health and Disability Commissioner Freephone 0800 496 877, the Ministry of Health Freephone 0800 373 664 or the New Zealand Disability Support Network 04 473 4678, there is no single organisation responsible for investigating abuse. Adults with intellectual disabilities will often fit the criteria of vulnerable because they are often unable to remove themselves from the care or charge of another person or speak up about abuse.

Anyone over the age of 18 who is aware that abuse of a child or vulnerable adult is occurring in the household they are living in or a household they are a member of (whether or not they are living there) must take reasonable steps to protect them from abuse.

Likewise support staff must ensure that the people they support are not being abused. If a staff member is aware a person is being abused in a residential or respite service, hospital or aged care facility or similar, they must take reasonable steps to protect them and report their concerns.

Failure to speak out and take reasonable steps to protect a child or vulnerable adult may result in charges with a maximum penalty of 10 years imprisonment.

Protection under the Domestic Violence Act

The Family Court can issue a protection order to protect any adult from further abuse by someone they are in a domestic relationship with. The court may allow a representative to apply for a protection order on behalf of an abused adult if they are unable to do so themselves due to lack of capacity or fear of harm.

People who are living in a group home fall outside of the definition of living in a domestic relationship.

Personal Orders

Sometimes a vulnerable adult may be making decisions that are putting them or others at risk, for example medication refusal, or being in situations where they are being taken advantage of.

Personal Orders can be made for people who are unable completely or partly to understand decisions about their personal care and welfare and to foresee the consequences of those decisions. An application can be made under The Protection of Personal and Property Rights Act 1988 to the Family Court for a Personal Order.

The Family Court can make a personal order that makes arrangements for the person's care, about medical and other services, or appoints someone to manage the person's affairs or to represent them. The Family Court can make an interim personal order in urgent cases for example for urgent medical treatment. Interim orders last for up to six months.

A personal order ends 12 months after the order is made or when all the things that are stated in the order have been done. Welfare Guardianship, Property Management and Property Administration are types of Personal Orders. More information about these can be found in [Information Sheet 16](#).

A basic knowledge of relevant policy and legislation will help you to prepare and implement an advocacy plan. The New Zealand Legislation website legislation.govt.nz provides free public access to unofficial versions of New Zealand statutes (Public, Local, and Private Acts) and statutory regulations.

The New Zealand Disability Strategy

The Strategy recognises that people with disabilities have the same rights as all other citizens. The Minister for Disability Issues is required to report annually to Parliament on progress made by government departments in implementing the Strategy.

New Zealand Law

- Human Rights Act 1993 (and amendments)
- New Zealand Bill of Rights Act 1990
- Privacy Act 1993
- Official Information Act 1982
- Education Act 1989
- Protection of Personal and Property Rights Act 1988
- Children, Young Persons and their Families Act 1989
- Care of Children Act 2004
- Employment Relations Act 2000
- Health and Disability Commissioner Act 1994
- The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996

International Law

New Zealand has signed and ratified a number of international human rights treaties and conventions that place obligations on our Government. When a government ratifies a treaty or convention it is agreeing to do its best to implement and enforce rights in the treaty or convention.

- Universal Declaration of Human Rights
- United Nations Convention on the Rights of the Child (UNCROC)
- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The United Nations Convention on the Rights of Persons with Disabilities

The Convention aims to promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by all people with disabilities. New Zealand signed the Convention in 2007 and ratified in 2008. The full text of the convention is available at odi.govt.nz.

Office for Disability Issues

The Office is responsible for promoting and monitoring implementation of the Disability Strategy and the UN Convention on the Rights of Persons with Disabilities. Alongside government monitoring the Office uses an independent reporting mechanism for monitoring the implementation of the Convention that involves the Human Rights Commission, the Office of the Ombudsman, and the Convention Coalition of Disabled People's Organisations. The Office has responsibility for the development and implementation of the [Disability Action Plan](#), which sets out New Zealand's priorities to advance implementation of the United Nations Convention on the Rights of Persons with Disabilities and the New Zealand Disability Strategy.

Ideally everyone with an intellectual disability has a person in their life that is able to support them to advocate for themselves or to advocate on their behalf if needed.

Auckland Disability Law

Free Auckland based service that helps disabled people access legal services.

aucklanddisabilitylaw.org.nz

09 257 5140

Banking Ombudsman

Free, external and independent processes to help people sort out their unresolved problems with banks.

bankomb.org.nz

0800 805 950:

CCS Disability Action

Works with people with disabilities and communities.

ccsdisabilityaction.org.nz

0800 227 2255

Children's Commissioner

Makes inquiries and reports on matters that relate to the rights, welfare or interests of children.

occ.org.nz

0800 22 44 53

Citizen Advocacy Auckland

Promotes one-to-one relationships between people who have intellectual disabilities (protégés) and committed citizens (advocates).

caauckland.org.nz

09 366 4545

Community Law Centres

Provide community legal services including free legal advice.

communitylaw.org.nz

Dunedin Friend-Link Trust

Assists people with intellectual disabilities to make friends and participate more fully in community life.

friendlink.org.nz

03 474 1335

Health and Disability Advocacy Service

Free, confidential, and independent. Advocates assist people with making sure their rights are respected. They help consumers to resolve complaints about health or disability services.

advocacy.hdc.org.nz

0800 555 050

Health and Disability Commissioner

Enforces the Health and Disability Consumers Code of Rights and provides an independent health and disability advocacy service.

hdc.org.nz

0800 11 22 33

Human Rights Commission

Facilitates resolution of disputes about discrimination.

hrc.co.nz

0800 496 877

IHC New Zealand

Advocates for the rights, inclusion and welfare of all people with intellectual disabilities.

ihc.org.nz

0800 442 442

IHC Volunteers

Help people with intellectual disabilities to be part of their community, to learn new things and to form friendships.

ihc.org.nz/get-involved/volunteering

0800 442 442

Inclusive Education Action Group

Supports the rights of all to an inclusive education.

ieag.org.nz

New Zealand Disability Support Network

An association of disability support service providers.

nzdsn.org.nz

04 473 4678

Office of the Ombudsmen

Investigates complaints about central and local government agencies.

ombudsman.parliament.nz

0800 802 602

YouthLaw

Specialist nationwide community law centre for children and young people with particular expertise in education law.

youthlaw.co.nz

09 250 2670

Parent to Parent New Zealand

Has advocates in some areas who are parents of children and young people with disabilities.

parent2parent.org.nz

0508 236 236

People First

Advocacy for and with people with learning disabilities.

peoplefirst.org.nz

0800 20 60 70

Privacy Commissioner

Investigates complaints about breaches of privacy.

privacy.org.nz

0800 803 909

Submissions are a way to contribute to the decision-making processes of government, councils, District Health Boards, government departments and other agencies. Submissions take time, energy and good information gathering skills. In a submission you can provide information, make comment or raise an issue. Your submission can support or oppose what is proposed, or may provide information you want considered.

Identify the issues:

- What is being proposed
- Think about what you agree with, as well as the parts you don't
- Discuss with others who may also be concerned
- Support people with intellectual disabilities to be involved in discussions.

Work out your response:

- Work out exactly what you want and how it differs from the proposal. Identify the elements of the proposal you feel most strongly about.

Work out your reasons and alternatives:

- Make suggestions of what would be better than the proposals. Back up your suggestions with reasons and show how and why your ideas would be better.

Write a draft:

- Support people with intellectual disabilities to write their own submissions
- Support people with intellectual disabilities to contribute to your submission, include quotes of what they say
- Thank the organisation for the opportunity to present a submission

- Write a paragraph about who you are and your connection to the issue
- Summarise your submission at the beginning of the document
- Briefly outline the parts of the proposal you agree with
- Then list your concerns by number and in detail
- Using the same layout, address those concerns with some of your own solutions
- Sign-off with names and titles. If this is a group submission, or if it goes out under someone else's signature, you may wish to add a contact name as well
- Print the first page on letterhead if you have one
- Formally request to present your submission orally or to speak in support of it at a meeting. State the names and titles of the people in your group who will attend.

Last important details

- Have the draft checked carefully by everyone who will be a signatory
- Check the accuracy of any evidence you may have referred to
- Check grammar, spelling and formatting
- Submissions to Parliamentary Select Committees are now made online
- Make sure your submission will get in on time
- If hard copies are required, write a letter to accompany your submission.

Oral Submissions

- Advise the names and positions of the people who will present the submission
- Support self-advocates to present
- Allow time beforehand to practice your presentations and to be familiar with the setting and the process.

Facebook, Twitter, Pinterest, Instagram, Tumblr, Blogs and message boards such as those on Trade Me can all be effective advocacy tools.

Social Media

- Be genuine: stay credible
- Stay focused: ensure you are always polite, reasoned and trustworthy
- Be reliable: share quality content, post regularly, be seen as a credible spokesperson
- Get social: social media is about a conversation. People tire of fanatics. Manners are important.

Facebook

- Keep posts short and conversational
- Include an image whenever possible
- Include links to the source of what you are discussing
- If you are developing your own page, post regularly and ask people to share your content
- Friend, Like and follow people of influence and potential allies
- Spelling and grammar matter to most people
- You may achieve wider coverage if you raise your concerns via an established page e.g. [facebook.com/ihcnewzealand](https://www.facebook.com/ihcnewzealand).

Twitter

- Share links and images and other information in less than 140 characters
- Tweet directly to members of the media, bloggers and potential allies encouraging them to cover your efforts.

Letters to the Editor

Letters to the editor give an opportunity to respond, correct or give your perspective on community issues and are a well read part of most newspapers. A letter to the editor will be more powerful if it is the voice of a person with an intellectual disability or includes their point of view in a quote. Support a person with an intellectual disability to share their views and opinions.

- If you are responding to an editorial or an article that has been printed, respond within two or three days of publication. Don't be afraid to show your passion. State the argument you're rebutting, or responding to, briefly, in the letter's introduction
- Be aware of length. Short, concise letters are more likely to be published
- Organise your letter logically. After recapping the argument, follow with a statement of your own position and then present your evidence. Close with a short restatement of your position or a strong comment
- Use facts, figures and expert testimony whenever possible
- Proof-read your letter carefully. An error free letter is more likely to be published
- View the letter from the reader's perspective. Will your letter make sense to someone who doesn't know the background?
- Include your name, address, day-time phone number and signature. This information will not be published, but may be used to verify that you wrote the letter
- Don't be discouraged if your letter isn't published. The editor may have received more responses on the issue than the publication can handle.