

An introduction to future planning

There are many ways that families can plan with their daughter/son with an intellectual disability for the future.

It may be helpful to think of planning for the future in terms of building a web of support, with as many strands as possible. Some of the strands will be legal or financial, others will be about relationships, and others based on formal service providers. The most important ones will involve people.

An act of courage

*Planning for the future when you have a son or daughter with a disability means planning to let go.
That's what makes it so hard. - Al Etmanski*

Building a vision

For many parents, the fears and concerns they have about the future are overwhelming, and can prevent them from taking steps to plan.

Building a clear vision to guide your choices and decisions will help you to plan for the quality of life you expect for your daughter/son. Many families find that having a clear vision helps change the way they think about their present situation. Support your daughter/son to lead the creation of the vision and ask who they would like to be involved. Siblings, friends and cousins can provide a different perspective to you.

Begin by thinking about where your daughter/son may want to live, work and spend leisure time in the future. Look ahead and imagine what your daughter/son will enjoy doing and who her/his friends will be. Don't limit your vision to what other people with similar disabilities are doing, or what people tell you is possible or likely to happen.

Create a plan

An imperfect plan is better than no plan at all.

Once you've built a vision, the next step is to think about what skills and supports might be needed and to create a plan of short-term goals that lead toward the vision.

Person-centred planning tools can be a useful way to develop a vision and set goals for the future. Consider involving siblings, friends and cousins in the planning. Many parents do not discuss future plans with their disabled daughter/son or other family members, despite the fact that they are often likely to play a significant role in the life of their relative.

Undertaking future planning can be a balancing act between honouring choices and safety concerns. Planning puts concerns out in open for discussion and action and reduces worry over the long term. Involving other people in the planning can give you a different perspective on where the balance between empowerment and safety should lie.

Personal networks

A personal network is a team of people who voluntarily commit to support a person. Through their relationships with the person with the disability and their family they offer support, advocacy and friendship.

The team of people can include family members, friends, former teachers or teacher aids, former support staff, neighbours and leaders and members of faith, sport and recreation groups. Ideally the team includes people who have similar values and beliefs as your daughter/son and are committed and care about their future.

Networks change and adjust over time but it is important to start with an understanding that network members are prepared to make a long-term commitment to the individual and their family. Networks usually cannot replace all paid service provision but strengthen the long term support around your daughter/son and their connection to the community.

Advocacy and decision-making

A personal network is usually a strong voice of advocacy for the individual. Other options include linking with an organisation that can offer friendship-based relationships or provide specific advocacy for example the IHC Volunteer Programme or The Personal Advocacy Trust.

Encouraging your daughter/son's ability to advocate and make decisions will also assist them in their future life and independence. Self advocacy organisations such as People First provide opportunities to increase advocacy skills. For information on supported decision-making see the IHC Advocacy Toolkit.

The Protection of Personal and Property Rights Act 1988 provides a mechanism for the Family Court to make a decision about an issue or to appoint a person to act on behalf of another through the use of personal orders, welfare guardians, property managers or enduring powers of attorney. For more information go to www.justice.govt.nz or contact your local Community Law Centre.

Creating a home

Your vision and plan will likely include where your daughter/son will live and call home in the future. Before you put lots of effort into researching what options are available it helps to build a picture of what a home for your daughter/son would look and feel like.

Questions to consider:

- Where does your daughter/son want to live?
- What will suit your family circumstances, culture, community?
- Does your daughter/son want to live alone or with other people?
- How will your daughter/son access their friends, family, work, community and own home?
- What sort of house will suit your daughter/son's needs?

Encourage and provide opportunities for your daughter/son to talk with people his or her own age about where they live or want to live.

Here are some ideas for housing options to consider:

- the family moves out of their family home and your daughter/son stays there
- families have family-governed arrangements, working in partnership with a service provider or setting up an independent service
- your daughter/son flats independently or with friends, with formal or informal support
- families build or move to a property that has a detached or semi-detached space for their daughter/son to use as a step to moving out
- your daughter/son lives in a home owned by a disability service provider with support from that provider

Funding may be available for household modifications, contact your NASC for more information. Housing New Zealand provides rental accommodation and offers home ownership services to help people on low incomes become home owners.

People who have been saving through KiwiSaver for at least three years may be entitled to a one-off deposit subsidy towards their first home. Your daughter/son does not have to be in work to contribute to KiwiSaver. Some KiwiSaver providers also allow a percentage of contributions to be diverted towards mortgage payments.

Options for support

Creating a home cannot be done in isolation from considerations of support. Some of the options for support are:

Informal support – includes family, friends and personal networks.

Formal disability support services – allocated through a Needs Assessment and Service Coordination Agency (NASC), these can include:

- individualised funding packages
- supported independent living
- residential services
- contract board

Independent arrangements for support can also be arranged by the family.

To get disability support services you must have a needs assessment. It is free and is carried out by a NASC. Decide a vision before the needs assessment takes place. This means everyone is clear about what support is needed to achieve the vision.

If your daughter/son will be accessing support from a service provider, everyone will need to work together to ensure a smooth transition from home.

Money matters

Talk to Work and Income or a beneficiary advocacy service to ensure your daughter/son is receiving all the benefits they are eligible for. You can also use wills, insurance and family trusts as tools to secure the financial security of your daughter/son.

The Total Mobility Scheme provides subsidised taxi trips and is administered by your local council.

Achieving your daughter/son's vision may not cost as much as you think. Sorted www.sorted.org.nz is a free independent money guide to help manage personal finances and has useful information about accessing independent financial advice. A budget advisory service can also provide assistance with money management.

Trusts

A trust is able to own, buy, sell and manage assets. Its terms and powers are contained in a trust document.

Setting up a trust can assist you and your daughter/son:

- it can help with the day to day the administration of their affairs
- if you have some surplus capital it can be invested through the trust but in a way that the capital remains as a family asset
- on your death your assets can be left to the trust but once again on your son or daughter's death, the assets can go to other members of your family
- it can be used as a vehicle to get your son or daughter into their own home

All of the above could enhance the quality of life for your daughter/son while at the same time continuing to receive existing funding from the Government.

For more information on setting up a family trust, see the Family Trust Kit included in the IHC Advocacy Toolkit or contact The Disability Trustee Ltd.

Wills

Your will is a legally binding and important record of your wishes that will directly affect those close to you. It is the only way you can ensure that your assets are distributed as you want them to be when you die. If you do not make a will the Court will decide how your assets will be distributed according to the law.

Making a will that specifically provides for the child or adult with an intellectual disability is another tool to ensure that their financial needs are provided for. Don't try to think too far ahead, wills should be revised regularly and alterations made to reflect changing circumstances and the age of the will maker. 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.

While wills can be written by you, it is far easier and safer to take your ideas to a solicitor and have your will drawn up professionally. Home-made wills can easily be challenged.

Letters of intent

A letter of intent is a document you devise and leave with your will, setting out your ideas and wishes about the future care of your daughter/son with an intellectual disability. Letters of intent are not legally binding.

It is important that any such letter is updated regularly and that the letter is flexible so that other people don't feel locked into arrangements that can't 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 should contain information such as:

- social and personal family history
- health history
- financial information
- your statements about your values and your wishes about how life decisions should be approached
- property
- any other important information you wish to include, eg funeral arrangements
- review and update reminder
- a photo of your son or daughter

Support for future planning

Parent and Family Resource Centre can provide information and support on future planning. Call 09 636 0351 or go to www.parentandfamily.org.nz

Standards Plus promotes and holds training on person-centred approaches, developing Circles of Support and family governance. Email StandardsPlus@imaginebetter.co.nz or go to www.imaginebetter.co.nz

The IHC Library has information on person-centred planning, developing personal networks and planning for the future. Call 0800 442 442 or go to www.ihc.org.nz

The New Zealand law society has information on property law and a list of property lawyers at www.propertylawyers.org.nz

The Disability Trustee Limited specialise in family trusts where a family member has a disability. Contact Tony Banks, Solicitor Ph: 07 856 8525 Email: bankst@ihug.co.nz

Citizens Advice Bureau helps you find a local budget advice or beneficiaries advocacy service. Call 0800 367 222

With thanks to the Planned Lifetime Advocacy Network www.plan.ca

