

**Care Matters**

Learning & Wellbeing

# Planning for the future

If you have a disabled child or care for a disabled family member, future planning—sometimes referred to as succession planning—is important. It can assist in securing a positive future for your loved one, ensuring necessary support is available throughout their lifetime.



# Planning...

- > Provides an opportunity **to think about the future life of the disabled person**, especially as their primary caregivers age and are no longer able to provide support. For example, where will they live and who will support them? What will their day-to-day life look like?
- > Will be **unique to each individual and their family** as each disabled person has unique strengths, interests, support needs, goals and family circumstances.
- > Should **involve the disabled person and focus on their needs and preferences** as much as possible, while still considering the needs of other family members.
- > Is often initiated and led by the parents of a disabled child, but in some cases may also be initiated by other family members/trusted friends (for example, if the parents are unable or reluctant to do so themselves).
- > Can include family discussions, researching options, seeking advice informally and formally, compiling notes and ideas into a document, and formalising plans with the guidance of a professional such as a lawyer or accountant. **The process varies for each family—there is no right or wrong way to do this!**



I'm learning about the supports that may be available to her, if she needs them. I research online, follow Facebook pages and just generally keep an ear out for what is happening in the disability sector, and how other autistic adults manage. I just want to know that she is going to be okay and can live independently when the time comes."



## Start early!

Planning can happen at any time or stage of life, but the sooner you start planning, the better. Why?

- > You will have more time to research options and make informed decisions in advance, reducing the need to make decisions at short notice or in an emergency.
- > **You** will be the person driving the planning process—rather than someone else having to do it, if you are unable to. You know your loved one best, and therefore, you are the best person to put in place plans for a good life for them.
- > You can plan at a pace that everyone is comfortable with—allowing time to prepare for any changes and a better chance of smoother transitions. You can prioritise what is applicable now and leave other decisions until later.
- > You can hopefully resolve any feelings of concern or anxiety that you, your loved one, or others may be feeling about the future—the earlier any issues can be discussed and worked through, the better.

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**We had to confront the reality that we wouldn't live forever. We didn't want to leave it till the last minute and then have her face the trauma of adjusting to living in a new and strange home after living all her life with us."**

**"We didn't want the full responsibility to fall on the shoulders of her siblings—we wanted to get some plans in place ourselves."**

## Have a vision

- > Think about the vision that you and your loved one have for their life. **What does a good life look like for them?** How do they spend their days? What are their hobbies and interests? Where do they live? What people are involved in their life?
- > Having a vision, and keeping that vision in mind, can help keep you on track as you make decisions and plan for the future. Consider the steps and goals necessary to work towards that vision, while balancing your own needs and those of other family members.

You can read more about vision planning here:

<https://parent2parent.org.nz/resource-hub/vision-planning-a-guide-for-parents-carers/>



## Talk to others – seek support and advice

> **Talk to your family, friends and support network.** Think about the people who are part of your life and consider asking for their input as you plan for the future.

- Some people may be a sounding board for you to discuss ideas with or offer a different perspective or opinion; others may be willing to get more involved or take on some responsibilities.
- Don't make assumptions about whether people will or won't want to be involved—talk to them to find out.

> **Seek professional advice if needed.** This will depend on your unique circumstances. If you do need professional advice (e.g. from a lawyer, accountant or financial advisor) it may be helpful to:

- Work with a professional who has experience with disability-related issues.
- Ask for a quote for any work upfront, so that you are clear on the costs involved.

> **Connect with others who are in a similar situation.** While everyone's circumstances are unique, talking things through and sharing ideas with others can be helpful. If you don't know anyone in a similar situation, some ideas to connect with others include:

- Attend your local Parent to Parent Support Group:  
<https://parent2parent.org.nz/how-we-help/local-support-groups/>
- Request a phone call with one of Parent to Parent's volunteer Support Parents:  
<https://parent2parent.org.nz/how-we-help/support-parent-network/>
- Attend Disability Connect's Zoom Parents Support Group:  
<https://disabilityconnect.org.nz/parents-zoom-support-group/>



## Be flexible and realistic

- > Future planning is an ongoing process—you will need to update your plan over time as your circumstances and those of your family change.

For example, planning for the future when your child/loved one is still at school and living at home will look quite different from planning when they are in their twenties or thirties and may already be living independently. A change in the preferences and support needs of your loved one may also necessitate a change in the plan, as might a change in your own (or other family members') health or financial circumstances.

- > Planning is important, but not always easy and may bring up difficult or confronting emotions. Some parents have told us that they find the process challenging as they confront the reality that they will not be around forever to support their child; others worry about 'imposing' additional responsibility onto their other adult children.



**Things changed when Dad died. We had to step up and support Mum more with decision-making around my sister's care. Attending meetings, bouncing ideas around with Mum, writing emails etc. It was a bit of a transition process, taking on that extra info and new responsibility."**

# Topics to consider as part of your planning

Although planning for the future will be unique for each family and their circumstances, we have listed below some topics that may be helpful to consider as part of your planning process.

As you plan, remember to keep in mind the overall vision for your loved one's life!

## Decision-making in adulthood

- > Once people turn 18, they become legally responsible for their own decisions. Their parents are no longer their guardians and cannot make decisions on their behalf, or give/refuse consent, nor do they have the legal right to any information on that person.
- > The Protection of Personal and Property Rights Act 1988 (PPPR Act) provides a way to legally assist people who do not have the capacity to manage their affairs once they turn 18.
- > If you believe that your child/loved one doesn't have the capacity to understand the nature and consequences of their decisions and is unable to communicate them, then you may wish to consider applying to the Family Court under the PPPR Act for legal authority to make decisions on their behalf. You can apply for:
  - Welfare Guardianship – which, if granted, and subject to certain conditions, enables you to legally make decisions in relation to their personal and medical needs (i.e. where they will live or decisions around standard medical care).
  - An order to Appoint a Property Manager or Administer Property – which, if granted, and subject to certain conditions, enables you to legally make decisions in relation to their property and financial affairs (i.e. decisions around bank accounts, KiwiSaver, or other assets they own).

> You should also consider who will support your loved one with decision-making in the future when you are no longer able to.

> To learn more about this topic, you can:

- Read this article: <https://parent2parent.org.nz/resource-hub/welfare-guardianship-under-the-pppr-act/>
- Check Disability Connect’s website to see if they are running one of their “Planning for Adulthood” seminars: <https://disabilityconnect.org.nz/information/>
- Contact Community Law to see if they can offer any support or information: <https://communitylaw.org.nz/free-legal-help/>, or engage the services of a trusted lawyer who is experienced in this area (remember to ask for a quote first).

## Finances

> Consider your loved one’s financial situation. Can they financially support themselves during adulthood (e.g. through employment or government benefits) or is extra support needed?

Financial support from the government may be available for disabled adults through Work and Income New Zealand (WINZ). Contact your local WINZ office or check their website

(<https://www.workandincome.govt.nz>) for further information.

Depending on individual circumstances, options to consider include:

- Supported Living Payment
- Jobseeker Support
- Disability Allowance
- Accommodation Supplement
- Residential Support Subsidy
- Community Services Card

In seeking support from WINZ, an ‘agent’ who is often the parent of a disabled person can be appointed to act on a person’s behalf. You can read more here: <https://www.workandincome.govt.nz/on-a-benefit/your-rights-and-responsibilities/having-someone-act-on-your-behalf>



> If you intend to provide financial support to your loved one, think about the best way to provide these funds, both now and in the future, and seek professional advice as needed. For example, consider:

- Will you gift money or other assets directly to your loved one for them to manage themselves, or will the assets be managed by another person or legal entity (such as a family trust) on their behalf? Is your loved one likely to be at risk from financial predators?
- How will any financial support you provide affect your loved one's income streams from other sources, such as benefits from WINZ?
- Do you have a will and is it up to date? Consider the implications of any inheritance your loved one may receive.

> You may also wish to consider retirement and end-of-life planning/funeral costs. For example, you may want to set up a KiwiSaver account for your loved one and ensure they have a will.



**I've set up an automatic payment of \$5 per week into a KiwiSaver account for her. It's not a lot, but it will hopefully be enough to cover some extra costs in her old age, and the costs of her funeral one day. I don't want the financial burden to fall on my other children once I'm gone."**

## Living arrangements

➤ Think about where your loved one will live as they (and you) get older, what support they will need, and how this will be funded. Are they eligible for government-funded disability support services? If your loved one lives at home with you, is there a plan in place for when you can no longer support them? If your loved one has already left home, will their current living situation be suitable for the long term?

➤ Depending on your loved one's preferences, support needs and financial situation, along with your own and other family members' needs, some housing options to consider include:

- Accommodation options that already have support services attached to them, such as Community Residential Services or Supported Living.
- Accommodation options that do not have support services attached, with arrangements for external/additional support where needed. For example:
  - Continuing to live at home during adulthood with parents/caregivers.
  - Living in a rental property.
  - Living in a privately-owned/family-owned house.

You can read more about housing options in this resource here:

<https://carematters.org.nz/adulthood-19/>

➤ Consider whether your loved one is eligible for any of the support services regarding housing/independent living for disabled people funded by Whaikaha-Ministry of Disabled People. There are a variety of support options available, depending on a person's circumstances and support needs, find out more here: <https://www.whaikaha.govt.nz/support-and-services/housing-and-transport/living-at-home-and-in-a-community-residence>.

To find out if you are eligible for any of these support services, contact your local Needs Assessment Service Coordination (NASC) service. You can read more about this process here:

<https://parent2parent.org.nz/resource-hub/3556/>

## Friends and support networks

> Consider your loved one's support network—what connections do they have with friends, family members, and other people in the community? Think about how these friendships and connections can be maintained and strengthened into the future. A trusted support network can provide a sense of wellbeing, acceptance, and safety—the more people involved in their life and 'keeping an eye out,' the better.

> If your loved one needs help to develop and/or maintain their support network, here are some tips to consider:

- Organise social outings with their friends/extended family members or invite them to your house for celebration events.
- Support them to use technology (i.e. Messenger, Facetime) to stay connected with people.
- Ask paid support staff to help support their friendships.

Some families find using the 'Circle of Support' method useful to develop and expand their loved one's support network. You can read more about this here: <https://carematters.org.nz/wp-content/uploads/2017/12/Talking-About-Surrounding-Yourself-with-Support.pdf>



I was asked to be part of a circle of support for one of my disabled daughter's friends, and I was happy to join and contribute in a small way. I'm part of the WhatsApp group to keep communication lines with the young lady open, and I take her out to have our nails done at the mall every now and then—something that we both enjoy."





## Medical and support needs

- > It can be helpful to collate all information relating to your loved one's health and day-to-day support needs. Include the names and contact details of all specialists/health professionals/paid support staff that are involved in their life. Consider sharing a copy of this information with another family member, trusted friend, or professional so it is easily available for others if something were to happen to you.

The following templates may be helpful to complete, or you can create your own documentation that better suits your family:

- Carers New Zealand – Care planning tools:  
<https://carers.net.nz/information/care-planning-tools/>
- HDC – My Health Passport:  
<https://www.hdc.org.nz/media/b2vfqh1p/hdc-mhp-a4-2023.pdf>

### References:

Acraman, E. (2021). Caring for a disabled family member: The importance of succession planning. Parent to Parent. <https://parent2parent.org.nz/resource-hub/caring-for-a-disabled-family-member-the-importance-of-succession-planning/>

The Arc. Where to Start? <https://futureplanning.thearc.org/pages/learn/where-to-start>

Towers, C. Thinking ahead: a planning guide for families. Together Matters. <https://www.togethermatters.org.uk/downloads/thinking-ahead-planning-guide-rewriteable>

### Disclaimer:

*The information in this document is for general information purposes only. It is not intended as a thorough and complete guide to an individual's specific situation. Reasonable care has been taken to ensure the accuracy of the information in this document, which is reviewed regularly. If you have any questions, please contact:*

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