



Future planning:

A guide for parents and carers.

Leap in!



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Future planning.

It can be difficult to look to the future when you care for someone with a disability. Everyday responsibilities can feel overwhelming, leaving little time to consider what the future might hold. Thinking about the future can also be emotionally challenging, causing fear and anxiety.

This Leap in! ebook has been developed to guide parents and carers through some of the key topics, important considerations and difficult decisions associated with future planning when you care for someone with a disability.

You'll find valuable tips on caring for yourself and preparing for an emergency including how to develop an emergency care plan. There's helpful information on goal setting and transition planning including preparing for independent living.

We also delve into some of the more difficult topics such as planning for progressive conditions, what happens when you can no longer fulfill the role of carer and how to navigate the complex legal and financial considerations.

You may also want to check out the supporting resources:

- [Emergency Plan Template](#)
- [Emergency Cards.](#)



Part 1

Caring for yourself when you care for someone with a disability.

Looking after yourself can often be the last thing on your mind when you have multiple responsibilities. If you care for someone with a disability, taking time out for you can bring about feelings of guilt, especially if you are also juggling work or other family commitments.

However, the importance of looking after your mental and physical health is that it will improve your overall wellbeing and make it easier to look after others.

Health and wellbeing.

Try to incorporate the following four aspects of a healthy lifestyle into your regular routine.



Be active: Try to undertake some physical activity or exercise you enjoy every day. Take advantage of some of the free exercise classes on YouTube, take a walk around the block, visit the park with your pet or join a free community exercise program.



Eat well: It's easy to fall into the habit of skipping meals, snacking or overeating when you are on the go, but your body runs on the fuel it gets from the food you eat.

Takeaway and fast foods are super tempting because they are quick and easy but they're ineffective at providing long-term energy. The first step to eating well is to be aware of your habits and target any areas you'd like to change. This could be eating a more balanced diet or reducing processed foods, sugar or alcohol.



Get enough sleep: It's easy to underestimate the importance of sleeping well for energy and maintaining good health.

Take the time to relax before bed with a hot shower, a cup of chamomile tea, read a book or magazine, or do some stretching. Make sure your room is the right temperature, minimise screen time and dial down the brightness of your mobile screen if you use it before bed. If you haven't been sleeping well for a period of time, speak to a professional who can recommend options specifically for you.



Get outside: Research shows that being in nature can reduce stress and fear, decrease blood pressure and lift your spirits. Spend time in a green space (a park, a forest or a community garden), go for a walk or treat yourself to a takeaway coffee.

Mental health.

We don't often think of mental health as something we need to manage but looking after your mind is as important as eating healthy food and getting enough sleep. Caring for someone can be stressful and emotionally demanding which makes it even more important to look after your own emotional health.

Useful mental health strategies.

Support networks.

Build a support network of caring family and friends you can talk to and have fun with. Try to build social activity such as meeting a friend for a coffee into your regular routine.

Online groups.

Join an online community such as a Facebook group which you can find by using the search function and filtering by "groups".

Many support groups have private Facebook groups based on a specific disability that you can request to join. For example, a search for 'Parents' + 'Autism' will display a list of public and private groups as well as articles, videos, events and relevant posts from your Facebook friends. .

Build networks.

Find a support group in your community so you can connect with others who are going through the same thing. Google is a great place to start. If your first search provides an exceptionally long list of options, trying refining your search by adding more relevant terms.

Practice mindfulness or meditation.

Free apps such as *Smiling Mind*, *Calm*, *Headspace* and *Mindfulness* offer short exercises that you can do anywhere, anytime.

Seek professional help.

Being able to turn to a professional counsellor or psychologist can really make a difference when you are feeling overwhelmed, stressed or depressed. Many people are reluctant to share their feelings with family or friends so having an outside person to talk to can help you feel less overwhelmed and support you to develop effective coping strategies.

Your GP can also assist with a Mental Health Care Plan which offers up to 10 subsidised visits to a psychologist or social worker. Find out more [here](#).



Respite.

Taking a break from caring is key to looking after yourself and ensuring you can maintain a caring role for the long-term.

Respite can be provided informally by friends or family. Formal respite care is also available as a paid in-home service or a centre based service. Planned breaks or respite can be for a few hours, a day, night, weekend or longer.

The benefits of respite care.

- Reduces stress for you and your family, often leading to greater levels of patience
- Relieves feelings of frustration and exhaustion, increasing wellbeing
- Allows you time to interact with family, friends and the wider community
- Improves the relationship between you and the person you are caring for
- Allows the person you are caring for to have valuable interactions with other people.

While it may feel like you have to do everything yourself, you are only human and it's ok to feel vulnerable, ask for help or seek out formal support options like respite.

Both respite care and emergency care can be covered by the NDIS. It is important that any NDIS Plan includes funding for both ongoing and short-term overnight care needs and takes into consideration any planned absences by regular caregivers.

This is something you can discuss at an NDIS Plan or Plan Review meeting. Respite care will appear as *Short term accommodation and assistance (incl Respite)* in the *NDIS Core supports – Assistance with Daily Life budget*.

For more information, check out [Respite and the NDIS](#).



Part 2

Being prepared for an emergency situation.

It can be hard to think clearly during an emergency. When you care for someone with a disability, planning ahead can reduce the stress associated with an emergency situation.

If you get sick and require emergency treatment, or are called away unexpectedly, having a plan provides confidence that the needs and preferences of the person you care for will be considered.

Proactive planning also assists you to act swiftly if there is a sudden change in the condition of the person you care for.

Why plan ahead?

- It's easier for someone else to take over at short notice
- Provides a chance to think through what is best for the person in advance
- The person you care for is more likely to be looked after according to their needs
- Helps reduce the stress of unexpected situations.

Developing an emergency plan.

An emergency plan is a document that outlines important contacts, care needs and medical information that become a point of reference in an emergency. An Emergency Plan Template can be found [here](#).

The first step is to identify an emergency contact person who is willing and able to take your place if something unexpected happens. It's important to ask the person first and ensure they are comfortable with the tasks required before nominating them as a contact on your emergency plan.

What to include in an emergency plan.

Name and contact details of:

- Parent/s or primary carer/s
- Person who the plan has been created for
- Emergency contact details (i.e. phone, email).

Details about the person's illness or primary disability.

Care needs including:

- Things they need help with
- Any special equipment used
- Behavioural challenges and strategies.

Contact details for organisations providing regular care, and a brief description of the care provided.

If the person is an NDIS participant, it is helpful to include a copy of their current NDIS Plan and any current Service Agreements.

Medical information

- Allergies to medication as well as any other allergies
- Medicines taken, dosage and timing
- Health information including Medicare number and health fund information
- Contact details for doctors and specialists.

It's also a good idea to include the following details about who to contact for emergency respite:

- *Emergency respite: Call the Commonwealth Respite and Carelink Centre on 1800 052 222 during business hours or 1800 059 059 outside business hours.*

Emergency plans should be signed and dated. Remember to update the plan if something changes (like obtaining new care providers or changing medications).



Involve the person you care for.

Where possible, it's important to include the person you care for in discussions about what might take place in case of an emergency. Find out if they have any special needs or concerns. Also consider how they may be able to assist.

Once the plan is finalised, talk through it together so they know what to expect and can ask questions.

Where to keep an emergency plan.

Keep your emergency plan in a place that is safe and visible, like on the fridge or a family noticeboard.

Carry a copy with you when travelling with the person you care for. Ensure your doctor and emergency contacts have a copy too.

Emergency cards.

Emergency cards help other people to help you, regardless of whether you are a carer or a person with a disability. They can be carried in a wallet or mobile phone case so you always have them when out and about.

"I am a carer" cards include your name, the name of the person you care for and your relationship to them. They also include contact details of the person in the emergency plan.

"I have a carer" cards include the person's name, condition or disability, a brief outline of the care required and the carer's name and contact details.

Download Emergency Card Templates that can be completed and printed [here](#).

Adding emergency details to your phone.

It's a good idea to add emergency contact details to your phone. If a child or other person you care for has their own phone, ensure the emergency contact function is enabled so you can easily be contacted in case of an emergency.

iPhone

How to add an emergency contact to your phone.

1. Click on the **Health** app (look for the red heart on a white background)
2. Go to *Update your medical ID*
3. Add medical conditions, allergies, medications, blood type, weight and height



4. Add emergency contact information
5. Turn on “Show when locked” under *Emergency Access*.

Your emergency contact will show even if the screen is locked. This also enables your emergency contact to receive a message saying that you have called emergency services if you use Emergency SOS (see below).

How to make an emergency call (calls police when your phone is locked).

1. Hold down any volume button and the power button at the same time.
2. You will then see a little slider pop up that says “Emergency SOS”. If you slide that across, it will call the police.

Android

How to add an emergency contact to your phone.

1. Open the phone’s **Contacts** app
2. Search for *Groups > ICE Emergency Contacts*
3. Select *Edit > Add members* and follow the instructions to add emergency contacts to your phone
4. To enable the calling of emergency contacts from your locked screen, ensure the screen is locked and access the lock screen but don’t unlock it
5. Hold the phone icon and drag it to the centre of the screen. Select the **Emergency** button and add your emergency contacts by selecting + to add each new contact
6. Your emergency contacts will now appear on the locked screen.

How to make an emergency call (calls police when your phone is locked).

1. Go to the password unlock screen
2. Press the emergency call button.

These instructions may be slightly different from Android to Android, so if in doubt, check with your manufacturer.



Part 3

Goals and milestones.

It can be difficult to think ahead when you're juggling present-day demands and challenges. It can also be a big step emotionally to ask yourself questions about what the future may hold.

Setting goals can help you take charge of the future. They can also give you and the person you care for a sense of purpose as you work towards those goals together. For example, moving into a shared house with help from a Supported Independent Living package from the NDIS. For more information, check out the Leap in! ebook [*Supported Independent Living: Achieving your goal to live independently.*](#)

We tend to think of life in stages, with milestones that mark certain events or achievements, like starting school or getting your first job.

Milestones are different for everyone and so are the paths that we tread to achieve them. This is where goals can come in handy. A **goal** is something a person wants to learn, develop or achieve. A **milestone** is a goal that has been reached or achieved.

Goals and the NDIS.

Setting goals not only offers a roadmap for achieving a particular milestone, it can assist a person with a disability to obtain NDIS funding to help achieve that goal.

The NDIS splits goals into two categories.

Short-term goals.

- Can be achieved in less than one year
- May only require one step or a small number of steps to achieve
- Are based on more immediate needs or plans that can be achieved in less than 12 months – such as learning how to cook a meal.

Medium or long-term goals (or milestones).

- Take several years or longer
- Usually take more steps or a series of short-term goals to achieve
- Are an important aspect of meeting future needs and aspirations.

There are three steps to setting goals:

- 1. What is important?** Think about what is important and explore how to articulate that. For example “I want to improve how I communicate.”
- 2. Define your goals.** Once you decide what is important, think about where you might like to improve in relation to that. For example, for someone who wants to improve how they communicate, a goal might be: “To improve my ability to speak clearly.”
- 3. Outline the steps.** What is needed to reach those goals? This may include support from other people or learning new skills. If we use the same example, the steps might be: “To work with a speech pathologist to improve the way I speak and practise with family and friends every day.”

The NDIS is designed to support a person with a disability throughout their lifetime. That includes providing the supports and services needed to help them achieve their goals and lead a fulfilling life.

Participants can request NDIS Plan durations of up to three years. Longer plans are suitable for participants with stable and consistent support needs who are confident in using their funding to achieve their goals. They're also ideal for people who are focused on achieving long-term goals.

Where major life changes or milestones are likely to be achieved over the next three years, a shorter NDIS Plan is recommended. Such changes include:

- Leaving school
- Starting work
- Changes in a living situation.

The Plan Review process happens at the end of each NDIS Plan and means supports can be added or removed as the person's needs and goals change over time, providing the support is considered "reasonable and necessary" for their individual needs.

Check out [How to set and achieve your goals](#) to find out more about setting, tracking and managing goals and why these are an important part of getting an NDIS Plan approved.

The Leap in! app can help.

There's a special section in the Leap in! app designed to assist with preparing for an NDIS Plan meeting including goal setting. If you don't know where to start with setting goals, it has hundreds of suggestions!

Transitioning from ECEI to NDIS.

Early Childhood Early Intervention (ECEI) supports children aged 0–6 who have a disability or developmental delay and their families and/or carers.

When a child turns 7, they are no longer eligible for ECEI funding. There is no automated process for the child to receive support from the NDIS and different eligibility criteria apply (see [NDIS eligibility checklist](#)). A separate application process is required, called an Access Request (see [Providing evidence of disability for children](#)).

It is important to plan ahead for this change with your Early Childhood Partner to ensure continuity of care and supports.



Part 4

Planning for progressive conditions and long-term care.

Progressive conditions.

The NDIS is designed to provide supports for people who have impairments that are likely to be lifelong. Some disabilities or conditions are progressive or degenerative, meaning they can worsen over time.

While it can be hard to confront the reality of a changing condition, it is helpful to understand the prognosis and possible future changes.

Questions to consider with your health care practitioner:

- How is this condition likely to change in the future?
- What are the treatment options?
- Where are these treatments available? Can they be obtained in the local area?
- How are the person's independence and/or care needs likely to change?
- What additional supports or services may be needed?
- What capacity building skills can be learnt now to assist with future needs?

It's important to talk about these issues together and ensure that the wishes and preferences of the person you care for are taken into consideration each step of the way.

Thinking about long term care.

There are many reasons that a person may need to enter a longer-term care arrangement such as moving to supported accommodation. Two of the most common reasons are changes to their condition and changes in the health or circumstances of people who are responsible for their care.

Part of the process of planning ahead is to consider what longer term needs may arise and thinking in advance about things such as:

- The person's likely long-term care needs
- Their long-term goals and aspirations
- Lifestyle and care preferences
- Whether a transition phase is likely to be required
- The medical or allied health professionals who can provide guidance and/or support
- The options for care in your local area
- If Supported Independent Living (SIL) is a realistic option
- The financial implications and any financial support available.

Changing circumstances and the NDIS.

If you or a person you care for is an NDIS participant and circumstances change, it is important to let the NDIS know. This includes changes to:

- The level of care provided by family or friends
- Living arrangements
- Health and wellbeing (such as the worsening of a condition).

While a review of an existing NDIS Plan is not always required when something changes, if the changes mean additional supports are required, an NDIS Plan Review may be undertaken.

Find out more in [My circumstances have changed: What next?](#)



5 future thought-starters.

Working through the following list one item at a time is a good way to think about and structure forward planning without it becoming overwhelming.

1. **Future living arrangements:** such as where you will live, the type of home you will need to live in and who you live with.
2. **Employment:** how the changes may affect your ability to work or earn income as well as the types of financial support that may be available if you can't work.
3. **Other responsibilities:** such as other family members, ageing parents and children in your care and how these might change over time.
4. **Future support needs:** including likely home or vehicle modifications.
5. **Changing care needs:** such as obtaining more support at home, respite options or new services.

With the right care and support, many people with progressive conditions live full and satisfying lives. Planning ahead can help equip them (and you) with the tools and skills to adapt and manage.



Part 5

Transitioning to adulthood.

Moving through the teen years into adulthood can be a challenging time for young people, as well as parents or carers. It can be hard to know when to offer support and when to step back.

You're not alone if you're concerned or anxious about:

- Talking to children and teenagers about their bodies, boundaries and sexuality
- Risky activities and behaviour
- Using drugs or drinking alcohol
- Extreme emotions or emotional swings
- Self-esteem and social interactions
- Social media, bullying and societal pressures
- Future education or work.

The transition to adulthood can be particularly difficult for people with a disability and their families as they navigate a changing landscape of emotions, relationships, decisions and desire for independence.

Research indicates that “youth with disabilities have reported that they have similar aspirations to their counterparts without disabilities, but there are more obstacles during the transition to adult life”¹

Early transition planning and clear communication are valuable strategies for managing this rite of passage and supporting your teen to become more responsible and independent.

The 6 steps in transition planning.

A transition plan can be a simple document that sets out the steps that support a transition. It not only gives you and your family an agreed plan of action, it can also be a valuable document to refer to when completing an NDIS Plan.

Step 1

Write down your child's strengths, skills, interest and abilities.

Step 2

Work together to develop some short and long-term goals.

Step 3

Write down the skills/qualifications, practical requirements and/or support needs associated with achieving those goals.

Step 4

Identify which skills your child needs to develop or practice to reach their goals. The NDIS usually refers to learning new skills that increase independence as "capacity building".

Step 5

Talk with people who might be able to provide advice or support such as teachers, support workers, allied health professionals, doctors, government agencies, family members and friends. Research the funding available (through the NDIS or other programs).

Step 6

Review the plan regularly and adjust as goals and aspirations change.

It is recommended that a transition plan cover the following four areas of life. Include those that are relevant for the person you care for:

- Education
- Employment
- Independent living
- Social or community participation.

Types of transitions.

School to further education.

With many courses now available online, there are more options for further education than ever before. However, there are often additional barriers for people with a disability to overcome, which is why prior planning is important. Barriers may include the availability of suitable courses, accessible course structures and financial constraints.

The good news is that more people with a disability than ever are attending university, with enrolments increasing by 73.2% from 2007 to 2014². Most universities and TAFE colleges have Equity and Diversity offices that promote inclusion and accessibility as well as provide student support. Government funding is available to educational institutions for disability-related supports such as sign language interpreters, notetakers and screen reading software.

Tips for further education planning.

- What steps can be taken to improve the chances of securing a place? For example, grades, prior study, Recognition of Prior Learning, industry experience.
- Research courses available and how they are delivered. Find a course that suits your requirements.
- Check out campus facilities and access – it helps to visit in person.
- Is online study a more flexible, accessible option?
- Get in touch with the Equity and Diversity Office and see what supports will be available.
- Explore financial assistance options including equity scholarships, bursaries and HECS-HELP or FEE-HELP loans.

Check out [Attending university: How the NDIS can help](#) for guidance on what the NDIS can cover when it comes to higher education.

How can the NDIS support further education?

While the NDIS generally doesn't cover course fees, it can fund reasonable and necessary supports that help participants achieve their education-related goals. For example, the NDIS might fund a support person to help with transitions or personal care.

School or further education to work.

Working can help build confidence, skills, independence and social networks. But finding a job if you have a disability can be tough and requires dedication and patience.

As a parent or carer, it can be challenging to watch a person you love go through setbacks but it's important to encourage them to talk to someone they trust and ensure emotional support is in place throughout their journey to employment.

Adequate research and transition planning during high school years can help you both be more prepared for the next step into employment.

Leap in! has developed a range of handy resources to help:

- [Thinking about finding a job?](#)
- [5 tips for getting job ready](#)
- [Resources to help you find a job](#)

Independent living.

“My child has flown the nest” is a fairly common refrain of parents whose kids have moved out of home. Transitioning your child or adult with a disability to independent living can be an emotional time.

See [Part 7](#) on *Preparing for independence* and [Part 8](#) on *Options for independent living* for more information.

Social or community participation.

Being involved in the community can be fulfilling, build confidence, develop skills and contribute to an overall sense of wellbeing.

Social isolation is common among people with a disability, particularly for people on the autism spectrum or people with an intellectual disability.

For this reason, it's important to set social and community participation goals and ensure the steps to achieving them are appropriate to the individual.

The NDIS can assist in two ways:

- 1. Increased Social and Community Participation** – Capacity Building budget category covers development and training to increase skills to participate in community, social and recreational activities.
- 2. Assistance with Social and Community Participation** – Core supports budget category may fund a support worker to assist an NDIS participant to take part in social and community activities. For example, driving the person to and from the activity if they are unable to drive themselves or catch public transport.



Part 6

Planning for the future together.

Some people are more comfortable talking about the future than others. But they're important conversations to have. By talking together about what the future might look like, you have a better chance of creating a future that fulfils the aspirations and meets the needs of the person you care for. It can also take a lot of pressure off you.

This section covers the considerations for decision making, planning for a good life and the different types of goals.

Independent decision making.

Every person has the right to make decisions about their own life.

“Respect for the freedom to make choices should be accorded to all persons with disabilities, no matter how much support they need,” says Theresia Degener from the UN Committee on the Rights of Persons with Disabilities.³

It is important to approach future planning and associated decision-making with an understanding of the rights of people with a disability. People with a disability have the right to:

1. Make their own decisions about every aspect of their lives
2. Have help to make decisions
3. Say what they want to do
4. Take risks.⁴

If a person with a disability is able to make their own decisions independently, they have the right to do so. In this case, the role of a parent or carer can take on the role of a sounding board or guide.

Supported decision making.

Some people with a disability may require support when it comes to making decisions. “Supported decision making” is the term used when a person makes a decision by themselves with support or assistance from others. Supported decision making provides an opportunity for the person to learn and build their decision-making capabilities.⁵

Types of support.

Supported decision making can take many forms and the role you’ll play will depend on the experience and abilities of the person you care for as well as the complexity of the decision being made.

Examples of the ways you may be able to support the person include:

- Providing information about the options available
- Describing the pros and cons of each option, or exploring them together
- Using tools or visual aids to improve understanding
- Supporting the person to try out different options
- Identifying other people to talk to or researching additional information to aid the decision.

Tips for talking together.

It is important to set aside enough time for each conversation and to find a quiet place where you both feel safe and will not be interrupted.

- Check if the person would like someone else to be there to help them communicate their views (for example a speech pathologist)
- Ensure any communication aids they use are available
- Talk about one topic at a time
- Have some information prepared in advance
- Give the person time to think about things and ask questions
- Allow the person to finish what they are saying
- Write a list of questions for further research and between you, allocate who is going to do the research
- Discuss a time for a follow up.

Planning for a good life.

An important question to consider in the future planning process is “*What does a good life look like?*”

What a good life looks like will be different for each person. But most people would agree that having a home to live in, social connectivity, an opportunity to make a meaningful contribution to society and the ability to learn and grow are some of the important aspects of living a good life.

This can be a valuable guiding question for future planning that helps to ensure the person you care for is at the centre of decisions about their future. For people with a disability who have the capability to be actively involved in decisions about their future, understanding what they perceive as a good life can guide both decisions and goal setting. It’s also an important part of the NDIS planning process.

Some of the things you might like to explore together are listed below.

Home sweet home.

- What are the person’s goals and aspirations when it comes to their home environment? Do they want to move out of the family home, live with friends, buy their own home?
- What are the main considerations for their home environment? For example, safety, support needs, equipment, accessibility, proximity to services, family and friends etc. Are these likely to change over time?
- Other things that are significant such as space to pursue hobbies, privacy and location.

- What options for funding and financial support are available? Is there a financial plan that needs to be implemented now to accommodate these goals later? (See page 8 for more information on Options for Independent Living.)

Making a contribution.

Regardless of your ability, having the opportunity to make a meaningful contribution to society through employment, volunteer work or other pursuits has countless benefits including generating self-confidence, developing skills and building friendships.

- What are the person's work goals?
- How can their interests and abilities be developed to provide a pathway to that goal?
- What training or education opportunities might help?
- Are there people or organisations that can assist?

Learning and development.

Known as “capacity building”, this is all about building skills to become more independent and helping the person reach their long-term goals. Think of it as the steps that can be taken along the way.

- What are the skills the person can learn in the short-term that will help them reach longer-term goals?
- What support might be needed?
- What are the goals associated with learning and development that can be included in the person's NDIS Plan and be supported by funding from the Capacity Building budget category?

Meaningful relationships and social interactions.

- What are the person's goals when it comes to family connections, friendships and relationships?
- What programs, supports or community activities might be able to help?
- How can opportunities for building friendships and being connected with people in the community be incorporated into regular activities or routines?
- Identify any barriers to meaningful relationships such as a lack of confidence, poor communication skills or challenging behaviours. Talk about how to overcome barriers or challenges.

Making decisions on another person's behalf.

Sometimes, circumstances require another person to make a decision on behalf of a person with a disability. Such decisions can be considered a denial of the person's rights and should be treated with consideration, caution and with reference to appropriate laws.

Under Australian law, parents are able to make decisions for their children until they turn 18. When someone turns 18, they are considered an adult and legally allowed to make their own decisions. This law applies to everyone, regardless of ability.

Many families implement informal decision-making processes to support a person with a disability after they turn 18. These often work well and eliminate the need for a formal approach.

National Disability Services (NDS) is Australia's peak body for non-government disability services and outlines the two decision-making processes in its [Supported Decision Making Guide for NDIS providers](#), which is outlined below.

Informal decisions.

In situations where a person with a disability aged 18 or over is unable to make a decision for themselves, a family member or long-term carer or even a close friend may make informal decisions on their behalf. Informal decisions can be made when:

- "They reflect the person's wishes and preference, where known
- And the person seems willing to go along with the decision
- And there is a shared view among the significant people in the person's life that this should happen
- And it's not a decision that requires a formally appointed decision-maker."⁶

Informal decisions cannot be made by providers or staff.

Formal decisions.

A formal legal process is usually required to appoint a decision maker for an adult 18 years and over who, because of a disability, is unable to make their own reasoned decisions. This may include:

- Where there are conflicting views about what is best for the person
- When a bank or financial institution wants to see formal authority
- When the person objects to the proposed decision (verbally or through their actions)
- For decisions affected by legislation
- When the parent or main carer becomes unwell and can no longer provide adequate care or support.

(See Appointing a Guardian or Administrator on page 39 for details)



Part 7

Preparing for independence.

What independence means is different for each person. In any case, it is a journey that can involve quite a few steps along the way.

For a person with a disability, becoming more independent might look like:

- Being able to dress themselves
- Becoming responsible for their own shopping, cooking and food preparation
- Commencing study or getting a job
- Taking control of their own finances
- Moving out of home.

For parents, families and carers, there can often be mixed feelings about the shift to greater independence. It is natural to feel concern for the person's welfare and whether they will be able to manage a new situation.

Having to "let go" can also evoke a wide range of emotions – from fear and anxiety to frustration and grief. Changes in the family unit can affect everyone, including siblings. In cases where a person with high care needs is moving out of the family home, it is common for families and carers to experience a degree of guilt that they are no longer primary caregivers as well as a deep sense of loss.

10 tips for supporting independence.

1. Start early and build from there
2. Begin with easy, day-to-day decisions and activities
3. Encourage interactions with others, especially friends or community members outside the family unit
4. Let them choose their friends and who they spend time with
5. Work on developing a healthy lifestyle including eating well and exercising where possible
6. Take the time to talk about sexual health including what sexual abuse looks like and how to speak up if something is not right
7. Set goals and use the NDIS Capacity Building budget category to build skills
8. Develop a core network of health professionals and providers that can support you both on the journey
9. Talk about what the future might look like and work together to address issues, concerns or questions along the way
10. Be informed and research supports and funding available so you can provide guidance as necessary.

Trialling different options.

On the journey to independence, it can help to have a transition period which involves trialling several different options. Depending on the goal, this could take place over a number of years.

Example: Goal – Independent living.

If the person's goal is to live independently, you might like to trial longer periods of respite where they are away from their usual place of residence.

It may also be worthwhile to find out their preferred living arrangements via a trial. Are they happiest living with another person with a disability? Do they prefer to live with someone their own age or gender? Refer to the home environment related questions in the *What does a good life look like?* section on page 24 for guidance. For non-verbal adults, these trials can help assure you that the final choices align with the person's preferences.

What is capacity building and how can the NDIS help?

Capacity building and independence are closely linked. The Capacity Building budget category is all about developing and improving the skills needed for living more independently.

This may include support to:

- Find and maintain an appropriate place to live
- Improve skills to participate in community, social and recreational activities
- Access training or therapy to increase skills such as learning how to cook or improving communication skills
- Find employment-related support, training and assessments for the person find and keep a job
- Improve relationships through positive behaviours and interactions with others
- Obtain training, advice and help for transitioning from school to further education such as university or TAFE.

For more information, check out [What is capacity building \(and how can it help build independence\)?](#)



Part 8

Options for independent living.

With a few exceptions, people with a disability are required to find their own housing. If the person is able to manage their own money and make decisions for themselves, this can usually be achieved with a range of supports available. There are also a number of NDIS-related options for people with higher care needs to live independently.

However, ensuring the person you care for has a safe and suitable place to live when you are no longer around can be a real source of stress for family members and carers. What can you do to future-proof housing to ensure changing needs are adequately accommodated?

This question is particularly concerning for parents or carers who are ageing or ill, and even more worrying for people on low incomes without existing property assets.

The Australian Government recommends that families make arrangements for accommodation proactively and early to ensure a plan is in place to provide appropriate accommodation for family members with a disability⁷. In this section, we explore some of the options for independent living and the assistance available.

Independent living options.

Private rental market.

Private rentals may be ideal for people with a disability who are able to manage their own finances and decision-making. However, housing in the private rental market may be too inflexible to provide for long-term needs or unsuitable for a person with high care needs. Changes to circumstances or ownership may result in the person having to move elsewhere, sometimes at short notice.

Social housing (also called public or community housing).

An option for longer term housing could be social housing, with many community housing agreements offering long-term security and affordable terms. The opportunity may also arise to purchase the home in the future. Eligibility criteria apply and there are wait lists in many areas.

Private ownership.

Not every family can afford to purchase a separate property but for those that can, private ownership offers a secure home for the person to live in perpetuity. Legal arrangements can be made in your will for the person to continue living in the property.

Some families choose to establish a Special Disability Trust, making the person a beneficiary of property such as a house or apartment where they can live indefinitely (see section on Special Disability Trusts on page 37 for more details).

Custom arrangements.

With a lack of long-term and suitable accommodation for people with a disability across most of Australia, some families and communities are developing innovative solutions to meet current and future needs. A range of examples exist including people with a disability pooling their resources and investing in properties with friends, as well as small-scale community-based housing solutions.

Private disability accommodation.

A number of independent housing cooperatives or organisations are popping up, offering a range of purpose-built investment opportunities and rental accommodation. While they are mostly connected with Specialist Disability Accommodation (SDA), options may be available that do not require SDA funding.

Specialist Disability Accommodation (SDA).

SDA is a new program that builds or modifies accommodation for people with extreme functional impairment or very high support needs who require specialist housing solutions. Funding is available through the NDIS for the development of specialised homes for a small number of people (approximately 6% of NDIS participants) who meet strict eligibility criteria.

Eligible NDIS participants receive funding in their NDIS Plan that can be used to approach the market and find or develop a registered dwelling that meets their needs. SDA supports the concept of a “home for life” where needs can be met for the long-term and people with a disability can “age in place”, with the supports they need.

Other considerations.

Some of the other things that you might need to think about when considering independent living options include:

- Ongoing care expenses
- Location suitability
- Ability to accommodate changing future needs
- Strategies for overcoming loneliness and isolation
- Continued skill development and capacity building
- Consideration of continuity of supports as the person moves from one location to another, such as maintaining the same doctor and allied health professionals
- Ability to accommodate support worker preferences.

Assistance with independent living.

1. Supported Independent Living (SIL).

Supported Independent Living (SIL) was established by the NDIS to provide assistance with or supervision of daily tasks, as well as skill development, to help an individual to live as independently as possible. As SIL is designed to aid independence, it is worthwhile considering whether SIL could be part of your future planning strategy.

SIL may be available when informal supports, such as the care of family or friends, is unable to meet the needs of the person and they are living in an independent environment such as a rental property, share house or Specialist Disability Accommodation. It may be appropriate in shared living environments with 2–7 participants.

The types of things that may be covered by SIL include:

- 24/7 care
- Assistance with personal care needs such as getting into and out of bed
- Support for household tasks like preparing meals
- Participating in household activities like shopping
- Managing challenging behaviours.

Note: Living expenses such as rent and day-to-day costs such as food are not covered.

Broadly, there are three support level groups:

1. **Lower needs:** where the participant requires regular supervision of living arrangements.
2. **Standard needs:** where more active, 24-hour assistance is required.
3. **Higher needs:** where continual, complex active assistance is required.

SIL is most likely to be included in an NDIS Plan where the person has set a goal to live independently and has been working towards this goal for some time.

Important points about SIL.

- Living expenses such as rent and day-to-day costs such as food are not covered by the NDIS under SIL
- It does not include items covered under other NDIS budgets such as transport or consumables
- SIL providers do not have to be registered, but they generally are and all non-government providers must provide a quote
- Individual and shared supports may be provided
- SIL appears under *Core supports – Assistance in Shared Living Arrangements* in an NDIS Plan. Approved funds are stated and can only be used for SIL. They are not flexible like other Core supports.
- SIL funding can only be used for the purpose of Supported Independent Living through a registered provider.

For more information, check out the Leap in!'s [Supported Independent Living ebook](#).

2. Individual Living Options (ILO).

Individual Living Options are new support options, funded by the NDIS. They focus on the individual and are designed to support NDIS participants living in a range of situations. They are often a more suitable alternative to a shared home and offer a degree of flexibility in terms of living arrangements.

ILO is a person-centred arrangement that can be implemented in the mainstream housing market, such as through renting a private property alone or with friends.

- **Co-residency:** support resides full-time in the person's home
- **Host arrangements:** participant resides full-time in the home of a non-related host who provides support
- **Living alone:** support is provided in the home of the participant
- **Living together:** the person lives with other people – who may or may not be NDIS participants – and receives support. This could include family.

A provider works with the participant to develop a customised support plan that suits their individual needs, that is implemented in stages and refined over time. It can include both primary and supplementary supports.

3. Other types of financial support.

Some of the below financial supports may be available if eligibility criteria are met:

- Disability Support Pension
- Newstart Allowance
- Mobility Allowance
- Essential Medical Equipment Payment
- Continence Aids Payment Scheme

For more information, check out the Centrelink [payment and service finder](#).

Note: The NDIS does not provide income support.



Part 9

Legal and financial considerations.

A significant source of distress and concern for many parents and carers is how the person they care for will be supported when they are no longer able to provide care themselves. This may be especially true for parents of children or adults with high care needs or progressive conditions.

Many parents and carers feel overwhelmed trying to manage the current, everyday responsibilities and administration associated with having a child with a disability and say they don't have the brain space to deal with future planning.

But concern about what may or may not happen in the future is never far from their thoughts. A common fear expressed by parents is that no one else really knows or understands the personality and needs of their son or daughter so how could anyone else take on the role of carer? Also, the legal and financial aspects of planning ahead can be daunting, so many people put it in the "too hard" basket.

If you care for someone with high care needs, it's important to take the time to make formal arrangements that can be implemented in your absence. On the following pages, we'll demystify the common terms used and talk about some of the options available.

Peace of mind.

The advantage of spending time on legal and financial planning now is peace of mind that your son, daughter or the person in your care is at the centre of any decisions about their future.

While it's difficult to foresee what might happen in the future, it's important to consider changes in circumstances while you are still alive (such as you becoming ill), as well as after your death.

During this process, it is helpful to think back to the information on What does a good life look like? (see page 24) provided earlier in this booklet. This can be a valuable exercise when making future provisions.

When a formal arrangement might be necessary.

In situations where the person is able to make their own decisions, special arrangements are less likely to be required.

More control and formal arrangements might be required in the following situations:

- Where a disability affects mental capacity
- Where the person needs assistance with money management
- To maintain control of family assets such as the portion of your estate that goes to each child
- Where there are no obvious options for future informal care-givers
- If there are likely to be disagreements about the person's future care.

Making a will.

Making a will may be the most important thing you can do to plan for your family's future. A **will** is a **legal document expressing a person's wishes about how their property is to be distributed upon their death**. This can include personal and business assets, property such as a home or investment property, cash, investments, shares and personal belongings.

What happens if I don't have a will?

If you die without a valid legal will, or the will fails to properly dispose of all of your assets, you will be said to have died "intestate". This creates a complicated situation where an administrator must be appointed to manage things like your funeral, collecting assets and distributing them after any debts are paid.

If you die intestate, your assets will then be distributed to certain relatives according to a formula set by law. Your wishes are not taken into account.

How do I make a will?

The Public Trustee in most states offers a free will-making service. However, due to the complicated nature of future planning for children with a disability, we recommend having your will drawn up by a solicitor. Some community based legal centres can also provide guidance.

Can I use my will to provide for my child with a disability?

Yes. Your will can be used to make special provisions for accommodation, physical needs, support needs etc. regardless of your child's age. Some examples of things you might like to include in your will are:

- Leaving your child money or property
- Allowing your child to live in a designated property such as the family home
- Establishing a trust fund to support your child.

You may also like to consider what might happen if circumstances change and, if appropriate, provide funds for managing future care needs.

Of course, providing for a child with a disability may only be one aspect of your will, especially if you have several children. Every family is different and what you decide to include in your will is your own decision. You are not obliged to convey the information contained in your will to the beneficiaries or other family members. Upon death, beneficiaries of a will are notified by the executor who you appoint to look after your estate.

Can I make provisions for children under 18 in my will?

Yes. A 'Testamentary Guardian' can be appointed to take over parental responsibility if both parents die, until the child turns 18.

Can my will be contested?

Yes. There is no guarantee that a will won't be challenged in court. This can happen if a person believes they may be entitled to a greater share of assets than allocated in a will. Some lawyers say that talking to family about your wishes in advance can reduce the chance of a will being contested but this is not always an option. The possibility of your will being contested is one reason why you should seek legal advice when preparing a will.

How trusts can help provide for loved ones.

A trust is a legal entity that manages and distributes assets to beneficiaries. Put simply, it's a structure for looking after assets – such as money or property – for the benefit of another person.

Trusts are very popular in Australia and an option for providing ongoing support and care for family members. Trusts can be established while you are still alive, or they can be written into your will or a separate document to take effect upon your death.

The benefits of trusts.

- A child or adult with a disability can benefit from the assets without having direct control over spending
- Explicit instructions can be included regarding how the trust can be used
- Provision can be made for housing as well as other needs such as care and support, maintenance and personal expenses
- Protects your assets
- Potential tax benefits.

Selecting a trustee.

A trustee is the person or people who administer the trust according to the wishes you set out in the Trust Deed. Trustees can be family members or friends. It's also possible to appoint the Public Trustee in your state, a private trustee company or a professional advisor such as an accountant. Fees apply when anyone other than a family member or friend becomes a trustee and these fees are taken from the money held in the trust.

Being a trustee is a big responsibility, so finding the right person or people is important. Trustees should be independent, trustworthy, financially astute and willing. It's a good idea to choose someone who the person you care for knows and who understands their needs and preferences so you have confidence they will be at the centre of any future decisions.

You can support the trustee in their decision making by preparing information such as your Emergency Care Plan and other important details that only you know about such as the preferences, personality, communication style and abilities of your loved one.

What you need to know about trusts.

- If you plan to establish a trust while you are still alive, do you have the assets to put into the trust? Once an asset forms part of a trust, it cannot be removed.
- Trustees do not have any additional powers such as guardianship or management of any financial assets that are included in the trust.

- A trust does not create new resources so be realistic about what can be achieved with the assets placed in a trust.
- Build in flexibility to accommodate changing circumstances – include guidelines for decision making rather than hard and fast requirements.
- Taxation and financial implications – check with your accountant regarding costs and taxes.

Special Disability Trusts (SDT).

Since 2006, families have been able to establish a Special Disability Trust to make financial provisions for current and future care and accommodation needs of family members with a severe disability. Such trusts can pay for care, accommodation, medical costs and other needs of the beneficiary.

While beneficiaries can be any age, they must meet the eligibility criteria including the legal definition of “severe disability” by the Social Security Act 1991. It is recommended that an assessment of the beneficiary take place prior to the preparation of any trust deeds to ensure the criteria are met. An SDT can only have one beneficiary.

A Special Disability Trust can be set up while you are alive, or in your will as a testamentary trust.

What are the advantages of Special Disability Trusts?

- Tax concessions may be available
- An SDT can have assets worth up to \$626,000 without impacting income support payments such as the Disability Support Pension
- The beneficiary is eligible to work up to seven hours per week
- Assets to any value can be contributed or gifted to the trust at any time.

What can the funds be used for?

Special Disability Trusts are intended to cover reasonable care and accommodation needs of the beneficiary.

The trustee is able to:

- Pay for medical and dental expenses, including private health insurance
- Pay maintenance expenses for property assets covered by the trust
- Spend up to a certain amount (\$12,250 in 2019/20) on discretionary items not related to care and accommodation needs, in compliance with the relevant legislation.

The rules around Special Disability Trusts are complex so it is important to obtain independent legal and financial advice.

For more information, check out:

- [Special Disability Trusts – Getting Things Sorted](#)
- [Special Disability Trusts Questions & Answers](#)
- [Special Disability Trusts](#)

The information on Special Disability Trusts has been prepared with the assistance of the above documents.

Administrators and guardians.

You may recall that earlier in this document, we talked about informal and formal decision making (see page 26). We mentioned that when a person turns 18, they are considered an adult under law and are able to make decisions for themselves.

But what happens if the person is unable to make decisions for themselves? Or if there is a conflict about how the person's care needs should be fulfilled? How can you be sure that the interests of your loved one will be safeguarded?

Let's take a look at the role of administrators and guardians in the decision-making process.

Administrators.

An **administrator** (called a 'financial manager' in some states) **can be appointed for an adult who, because of a disability, is unable to make their own reasoned decisions.**

An administrator makes financial and legal decisions about things such as buying and selling property, banking, paying bills and managing debts.

A relative or friend who knows the person makes an ideal administrator. However, if there is no informal network, the Public Trustee in your state, a solicitor, accountant or organisation can be appointed. Joint administrators can also be appointed, such as one family member plus the Public Trustee.

According to the WA Public Trustee, "the role of the administrator is to use the person's money or assets to maximise his or her quality of life."⁸ An administrator must support the person to make their own decisions where possible. They must also take into account their desires and preferences as well as those of family members or other interested parties.

An administrator cannot make decisions about:

- Lifestyle
- Location or nature of accommodation
- Care or health care.

Administrators must account for all income, expenditure, assets and liabilities of the represented person and provide annual financial reports to the designated authority.

Guardianship.

A **guardian** can make **personal and health-related decisions** for a person with decision making disability.

Appointing a guardian is a last resort legal option to safeguard a person's interests when there is no suitable informal support available or parties are in conflict about the needs and interests of the person.

A guardian may be a friend or relative of the person with a disability, or the Public Guardian may be appointed. Guardianship can be full (covering all personal and health decisions) or partial (covering some decisions only). It is usually of limited duration, such as one year, followed by a review.

Things a guardian can make decisions about:

- Accommodation and living arrangements
- Health care including consenting to medical and dental treatment
- Education and training
- Whether the person is allowed to work and the nature/location of work
- Hygiene and clothing
- Supports and services to use
- Legal matters not relating to finances or property.

A guardian must take into account the person's wishes and preferences when making decisions and act in their best interests. In cases where a guardian and an administrator are appointed, they must consult each other and work together to make decisions.

Things a guardian cannot do:

- Make financial decisions
- Discipline the person
- Vote on behalf of the person in an election
- Make a will on behalf of the person
- Consent to the adoption of a child
- Consent to marriage or civil union.



Appointing an administrator or guardian.

Appointing an administrator or guardian falls under state and territory legislation. Therefore, the process for appointing an administrator or guardian is different in each state and territory. The legal process for appointing both an administrator or guardian involves completing a formal application which is then assessed and decided upon by an administrative tribunal.

Some other terms you may have heard.

Public Guardian: The Office of the Public Guardian (OPG) is a statutory office established in some states and territories to protect the rights, interests and wellbeing of adults with impaired decision-making capacity. The OPG can make personal, health and legal decisions if the Public Guardian is their guardian or attorney.

Public Trustee: The Public Trustee can act as a person's financial administrator or attorney if they need assistance with financial affairs due to intellectual disability, psychiatric illness, acquired brain injury or age related illness.



Part 10

Handy resources.

Self-care and emotional support.

- [Raising Children](#)
- [Better Health Victorian Government](#)
- [Queensland Government](#)
- [Carers NSW](#)
- [Carers Australia](#)
- [Carer Gateway](#)
- [NSW Health](#)
- [Beyond Blue](#)
- [Association for children with a disability](#)
- [Looking after yourself as a carer](#)

Emergency planning.

- [Emergency Care Plan](#)
- [Carer Gateway – Planning for emergencies](#)

NDIS-related resources.

- [My circumstances have changed. What next?](#)
- [How to set and achieve your goals](#)
- [Attending university: How the NDIS can help](#)
- [Thinking about finding a job?](#)
- [Resources to help you find a job](#)
- [Specialist Disability Accommodation](#)
- [Supported Independent Living](#)
- [Individual Living Options](#)

Decision making and future planning.

- [People with disability and supported decision-making](#)
- [WA Public Advocate – FAQs for parents of children with a decision-making disability](#)
- [Disability Legal Services](#)
- [Helping people make decisions](#)
- [Supported decision making communication strategies](#)

Wills and Trusts.

Department of Social Services – [Special Disability Trusts](#)

Services Australia – [Special Disability Trusts](#)

[Planning for the future: People with Disability](#)

Special Disability Trusts – [Getting things sorted](#)

NSW Trustee and Guardian – [Trusts](#)

[How to write a will](#)

[Making a will](#)

Guardianship and Administrators.

QLD Public Trustee – [Disability and aged support services](#)

QLD Public Trustee – [Guardianship and financial administration](#)

[NSW Public Guardian's Office](#)

NCAT NSW – [Guardianship](#)

VIC Civil and Administrative Tribunal – [Appointing a Guardian or Administrator](#)

VIC Office of the Public Advocate – [Guardianship](#) and [Administration](#)

WA Public Trustee – [Private Administrator's Guide](#)

ACT Public Trustee and Guardian – [Guardianship](#) and [Guardianship for Private Guardians](#)

SA Civil and Administrative Tribunal – [Guardianship](#)

NT – [Adult Guardianship](#)

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8. WA Public Trustee, Private Administrator's Guide.

About Leap in!

Leap in! was established to help people with a disability, their families and support networks navigate the NDIS with confidence.

As a registered plan manager, Leap in! provides proactive support to help participants get the most from their NDIS Plan.

We specialise in supporting our members at each step of the NDIS process – from preparing for a first NDIS Plan to managing budgets and paying providers.

Get choice and control over how NDIS funds are used, with financial and administrative support that saves time and reduces stress.

Contact Leap in!

Call **1300 05 78 78**

Email crew@leapin.com.au

Visit leapin.com.au

Other titles in the Leap in ebook series

- **The Essential NDIS Guide: An introduction to NDIS basics.**
- **Supported Independent Living: Achieving your goal to live independently.**

Leap in!

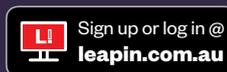
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The Leap in! crew acknowledge the traditional owners of the land on which we work and live. We acknowledge the stories, traditions and living cultures of Aboriginal and Torres Strait Islander peoples on this land and commit to building a brighter future together.