

WHY SUCCESSION PLANNING MATTERS

A resource for families to plan for the future



Expanding Ideas; Creating Change

Anne Cross Leadership Initiative



CRU

Expanding Ideas; Creating Change

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Acknowledgements

We acknowledge the traditional owners of all the lands on which we meet, work and live and recognise this land always was and always will be Aboriginal and Torres Strait Islander land. We pay our respects to elders past and present.

This booklet has been produced to share the work and thinking of many families who have been proactive in building and safeguarding a good life for their family members with a disability. In particular, we acknowledge the work of Jeremy Ward. Jeremy lived in Brisbane – he was both a brother and father of women with disabilities. His daughter Mena was one of his greatest teachers. Jeremy was also a lawyer and advocate and was instrumental in establishing several organisations in Brisbane, including Pave the Way. During his time at Pave the Way (2002-2013), an initiative hosted by the Mamre association, he wrote and presented many times on the topic of succession planning. He was deeply committed to assisting other families to prepare for the future of their loved ones. Sadly, Jeremy passed away in 2022. The authors of this book have attempted to capture and share some of his wisdom.

We would like to acknowledge with gratitude the time afforded to this project by our focus group members, Leanne Burke, Luke Garske, Carly Lassig-Cutler, Laura Listopad, Julie van Oosten and Sherryn West.

CRU would like to acknowledge the contribution of Rebecca Altaffer in the development of this booklet. It was a pleasure to collaborate with her to draw on the ideas and writings of her father, Jeremy Ward. Her efforts and the generosity of the Ward family have helped to ensure that these messages will remain relevant and accessible to people with disabilities and their families now and into the future.

These booklets have been developed as part of the Anne Cross Leadership Initiative, a partnership between Uniting Care Queensland and CRU, created to honour the contribution of Anne to UCQ during her years as the Chief Executive Officer. The initiative aims to contribute to strong, principled leadership amongst people with disability and families across Queensland to work towards better lives for people with disability.



Mena and Jeremy Ward.

Introduction

“As Mena grew to adulthood and moved into her own home, and as Margaret and I grew older, our thoughts turned more urgently to what would happen to all that we had put in place when the time came that we could no longer provide the love and support she needed. It is the question that keeps all parents such as us awake in the early hours of the morning. We knew that Mena could not rely on disability service organisations or on government, but rather, it would be other people – people committed to her – who would keep her safe along with our vision for her.” (Ward, 2015, p.177)

What will happen when I am no longer here or no longer able to do what I am currently doing are questions that loom large for families. Contemplating our mortality can be daunting enough without trying to envision the future for our loved ones. These are important questions that require intentional consideration. This is why succession planning matters.

Jeremy's work had a number of central messages, firstly that we must act now rather than leave things to chance. By being proactive today, we can make a significant impact in shaping the future of the people we care about.

Another central message is to remember that no single individual or measure can keep people safe or happy, but a range of people and safeguards can help. Essentially it is people - people who are informed about and connected to our family members with a disability – who will keep them from harm.

Although this publication is primarily designed for parents and families of individuals with disabilities, we understand that many people with disabilities will also be considering their future as they grow older. We hope this resource is as valuable to you and those committed to supporting you on this journey.

When planning for the future of your family member with a disability, we suggest that some strategies are more effective than others. For example, it can be assumed and even advised that setting up a will or a trust, ensuring you have a significant funding package, and finding a good service will help keep your family member safe. While these things can all be valuable and important safeguards, experience has shown that additional measures are necessary to ensure your family member's safety and wellbeing in the future.

Likewise, choosing segregated options has sometimes felt much easier and less risky than living in the community. However, experience has shown us that living an ordinary life in a community where the person is known and valued is actually much safer. We know that abuse is much more prevalent behind closed doors and in segregated settings.

We hope this booklet will assist more families to have the conversations they need to have with each other now and in the future. The aim of this booklet is to help you begin.

Six Actions

Built on the wisdom of families over time, we invite you to consider six actions you can do now to increase the chances of your family member with a disability sustaining a good life and being safe into the future.

- 1. Invite people in.** Ensure that people you trust know your family member and know what is needed to support them into the future.
- 2. Give trusted people the information they need.** Trusted people will need all the information necessary to succeed you as your family member's primary support.
- 3. Support decision-making.** Continue to practice supported decision-making with your family member so they not only build their 'voice', but others learn to 'hear' their preferences.
- 4. Plan.** Work out what you want and the steps you will need to achieve it. Don't wait for others.
- 5. Compile necessary resources for the plan.** Consider the resources needed to implement the plan in the long term and set up your will and estate accordingly.
- 6. Clarify what's paid and unpaid.** Of the many roles you play, determine which roles should be done by family or friends in your absence and what can be done by paid support.

“
Give me six hours to chop down a tree, and I will spend the first four sharpening the axe.

Abraham Lincoln. ”

Reflection

**We want to start with some hard questions – don't worry if you can't answer these yet.
We hope this book will help you make a start.**

Consider the **three** most important things you are currently doing to keep your family member safe.

1. _____

2. _____

3. _____

Now consider how these will be done in the future?

1. _____

2. _____

3. _____

To think about the future, we must look at the present.

What are some of the things you are doing today?

- Monitoring physical and emotional wellbeing
- Physical care
- Routines and schedules
- Medication management
- Mobility assistance
- Regular Exercise
- Hiring, training, and firing staff
- Advocacy
- Building friendship networks
- Therapy and healthcare appointments
- Financial management
- Documentation and paperwork
- Planning for big life-changes
- Companionship
- And more.....

ACTION I

Invite people in

Ensure that people you trust know your family member and know what is needed to support them into the future.



“

When we first called the circle together, Margaret and I had asked that everyone give a commitment for just 12 months, at which time we would review the strategy.... Everyone said that we couldn't get rid of them so easily.

They felt they had received more from their time in the circle than they had given. We had met our original goal, yet everyone knew there was still much to do, and they all wanted to be part of it.

(Ward, 2015, p.50)

”

Start now – in small ways

- Being **known and recognised** in your local community and neighbourhood provides connection and belonging but can also be a safeguard.
- The more often members of a community **witness** people with disabilities in valued roles, the more likely they are to go the distance for them - as neighbours, community members and friends.
- Invite **children from the street** after school (have the best afternoon tea or swing set!).
- Organise **regular, intentional visitors** (weekly coffee dates, dinners, birthday parties).
- As you think about **important companionship** consider finding a flatmate rather than other people with disability in a group setting.

Any opportunity for connection could lead to a deeper commitment in the future.

Think local and typical – how do we all contribute and belong?

- Local playgroups, sporting clubs, scouts etc.
- Local school.
- Church.
- Local gym.
- Doing banking, visiting the local library.
- Going to the supermarket.
- Using public transport.

Build a Support Network (Support Circle)

- We suggest **inviting people** into a semi-formal network that is informed and connected with your whole family. Some families call this their support circle.
- Families have found that long-term safeguarding requires people who will become and **remain committed** to their family members over time.
- These relationships **require more** than a coffee date or a chat in the street (though these things are important).
- Having a network or circle is **not the only way** - but it is a means to developing committed relationships with people who will safeguard your family members when you no longer can.

These networks or support circles can perform several roles:

- **Commitment and security:** it can be a forum for people who know and care and will be there over time to ensure the individual is supported and safe.
- **Planning:** it can be a forum to help plan for their future.
- **Listening:** it can be a forum for listening to an individual's voice and encouraging them to dream.
- **Support decision-making:** a place to support, strategise and assist good decision-making.
- **Advocacy:** members can act as advocates to ensure the individual is treated well and receives the support they need.
- **Consistency:** circle/network meetings can provide a structure and consistent opportunity to gather around family members and bring plans to fruition.
- **Practical support:** members might assist individuals in managing support funds and staff or help with simple tasks at home.
- **Mutual support to each other:** it can be a place to support each other in the mutual goal of safeguarding your family member with a disability (as long as the person with a disability remains at the centre).
- **Reassurance for siblings:** it can be a great source of reassurance for siblings, knowing there are others to help them navigate the future of their family member without the involvement and direction of their parents.
- **Connection:** companionship, relationships, fun, celebration.

To access further resources visit www.cru.org.au/whyitmatters

What about siblings (and other family members)?

- Often, parents **ask their other children** to follow them in caring for their family member with a disability.
- Sometimes parents **make assumptions** about the future of their other children but don't check in with them to understand what they hope for or worry about.
- Some parents report **feeling guilty** and don't want to 'burden' their other children.
- A common assumption is that siblings and other family members will **somehow know** what to do when the time comes.
- When the future arrives, some siblings have inherited a list of 'what' to do for their brother or sister with a disability but remain **unsure about 'how' to go about it**.

Passing on 'The How'

- Many siblings (and other family members) report that they are **already thinking** about their roles in the future and want to be prepared when the time arrives.
- **Deeper conversations** about 'why' parents do something or make certain decisions can equip them to adapt as circumstances change.
- **In reality**, siblings may not take on everything their parents have done or in the way they have, despite their willingness to be involved.
- Siblings (and other family members) report that **information, preparation, and mentoring** can help them to do well when their parents are no longer involved.

Although siblings are often thought of first, other family members and friends are also stepping forward to help. This includes in-laws, cousins, aunts, uncles, nieces, nephews, and even former employees. Sometimes, a family member with a disability lives longer than their siblings. One Mother suggests welcoming three generations to be involved in the life and supported-decision making process of the person with a disability.

To access further resources visit www.cru.org.au/whyitmatters

Summary

Above all else, it will be people who keep people with a disability safe. When parents and caregivers have accepted that they will not be alive or available forever, they have found creative ways to ensure trusted people will be there for their family member with a disability. Some families have adopted a 'network' or 'circle of support'. Siblings or other family members or friends of people with a disability are often prepared to be involved and are most successful when shown the way. Support networks or 'circles' have shown to be vital to the person, their siblings (and other family members) who are succeeding their parents. Circle members often say it's an honour to be invited into such an intimate space with the person and their loved ones.

How can I find people? Who can I ask?

- Questions to ask yourself:**
- Who's already showing interest in my family member?
 - Whose advice do I trust?
 - Who enjoys the company of my family member?
 - Where will my family member find like-minded people aligned with their passion?
 - Am I thinking locally?
 - Am I thinking creatively?
 - Am I willing to keep conversations open with their siblings?

- Remember to:**
- Think local
 - Choose people who will likely stay committed
 - Think creatively
 - Talk to siblings openly and often.

Activity

Can you name anyone in your family member's community who will likely remain dedicated to supporting them in the long term?

Start a list of people you might consider inviting into a support network for your family member with a disability.

1. _____

2. _____

3. _____

4. _____

5. _____

“

My sister's circle became a part of our lives and when the time came to invite my brother and me in, it felt like a natural transition. Our voices, as siblings were listened to and when appropriate, challenged. The circle became a comforting routine, bringing people together with a common purpose, taking some of the mental load off us as a family.

Rebecca Altaffer

”

ACTION 2

Give trusted people the information they need

Trusted people will need all the information necessary to succeed you as your family member's primary support.



“

We brought all our written information together into a document called *All About Mena* ...

The contents were comprehensive, covering everything from our vision and goals for Mena. It included her story and her typical day, relationships and important people in her life, service and funding, communication and support, health and medical issues, legal and financial information, and crisis/ emergency plans....

”

(Ward, 2015, p.180)

Recording Information

- Parents keep an enormous amount of information in their heads.
- Many families have found it helpful to **record important information** about their family member with a disability. It's advisable to use a system that allows for easy updates and sharing specific information with particular individuals.
- Families can **make this accessible** to the people who come into their daily life and those who will play an important role in the future.
- **Asking supporters** what else they need to know can help when refining and developing the document.
- This record can allow interested parties to be involved and builds a **deeper understanding of your family member** with a disability which, in turn, keeps them safe.
- This resource could have **multiple uses** and can be adjusted to fit your family member's needs. For example, you can use aspects of it to share the story with their support network, train support staff, or inform professionals like doctors, lawyers, and financial advisors.
- The information that can (and should) be included is limitless. **It may include:**
 - Your family member's vision (it may be that you hold a vision for them until they claim their own).
 - Who your family member is; what they love.
 - The important people in your family member's life.
 - Their hopes and goals, needs and preferences.
 - How they communicate.
 - Other plans for your family member.
 - Personal information.
 - Medical information and details of medication.
 - Details of what important documents exist and where they are located, e.g., Wills, names and contact details of important people, emergency contacts and relevant professionals.

These days we have an abundance of technology that can help us record important information about our family member and securely share this information with trusted others.

To access further resources visit www.cru.org.au/whyitmatters

Summary

Keeping a record of important information about your family member is a vital step toward ensuring their safety and well-being in the present and future. To ensure that the records are accessible, flexible, and accurate, we recommend designing and building records that can be easily adapted for different circumstances and updated regularly.

“

Our vision for Mena, was in each version so that doctors, emergency staff, support workers, lawyers and financial advisors all saw the big picture in which they played their part.

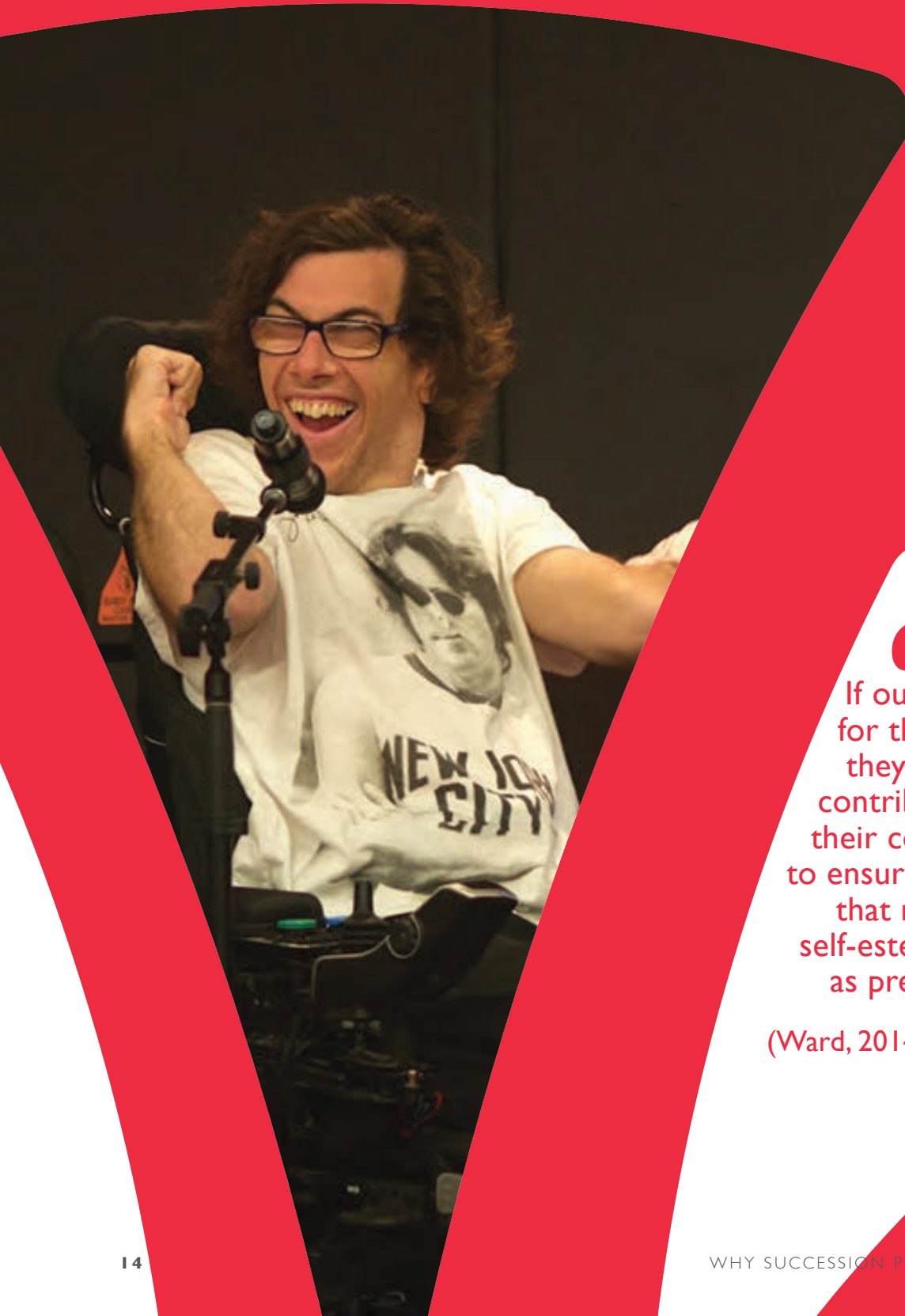
”

(Ward, 2015, p.180)

ACTION 3

Support decision-making

Continue to practice supported decision-making with your family member so they not only build their 'voice', but others learn to 'hear' their preferences.



“

If our vision and plan for their future is that they be independent, contributing members of their community, we need to ensure that we do nothing that may devalue their self-esteem and their image as presented to others.

(Ward, 2014, p.20) ”

With them, not about them

- People with a disability may need **support**, but decisions must be made **with them, not about them**. They must be at the centre of decision-making.
- **Making choices** is central to living a good, valued life.

Listen Closely

- We know that many people don't have a reliable means of communication and are at risk of their **preferences never being heard**.
- It is also risky if **only one person** can interpret what someone wants or needs.
- If someone cannot communicate, we **can listen more closely** to what their movements or expressions tell us. Listening includes **watching for gestures, expressions, and other forms of communication**. Ensuring more people know how to read how a person communicates is an important safeguard.
- We can ask ourselves, **'What are we not understanding?'**

A safeguard

- When a person with a disability can grow and **practice** their **decision-making** muscle with the support of others they trust, they are being indirectly safeguarded.
- When people with a disability are listened to and **encouraged to make choices**, they will gain practice and become better placed to speak up for themselves when needed.
- **Keeping a record** of decisions, and sharing these with trusted people, makes them stick.

Support Networks can help

- Having an **established support network** that is focused on supported decision-making can assist siblings and family members in keeping their loved ones with disabilities at the forefront of decision-making.
- **Keeping a record** of decisions and sharing them with trusted people is vital for long-term planning and safeguarding.

Summary

People with disabilities who have **experience making decisions** tend to be more **capable** of advocating for themselves when necessary, ultimately helping to sustain their preferred lifestyle and keep them safe. It is important to involve them in decision-making, even if they require support. Support networks or circle meetings provide an excellent platform for these important discussions.

To access further resources visit www.cru.org.au/whyitmatters

How can you listen more closely to your family member with a disability?

How can you increase the number of people who can hear their voice?

ACTION 4

Plan

Work out what you want and the steps you will need to achieve it.
Don't wait for others.



“

The future is going to happen.
Rather than simply let it happen, we can plan for the future that we want now. ”

(Ward, 2014, p.5)

What is planning?

- Planning is about more than solving specific problems as they come up. In this booklet, planning means **envisioning a good, valued life** and taking steps to make that vision a reality.
- Planning gives people with disabilities and their families **power and autonomy**, reducing the chances of being controlled by funding limitations or the promise of reform.
- Having a plan **helps keep people safe**.

Thinking about the future begins now

- As we prepare for the future, it's important to **consider the present**. Specifically, how are we ensuring that our family member with a disability is experiencing a fulfilling life?
- **What measures can we take** to ensure their safety and security in the years to come?

Begin with a clear vision

- For people with disabilities, imagining **and describing their desired future** is essential to planning.
- If you don't envision a good, valued life for your loved ones, history tells us that **others won't either**.
- So, this is a **time to listen** to the person's voice. To ask yourselves, what are they saying with their words, actions, reactions and behaviour? What are they not saying?
- Be clear about **what is not wanted** for your family member just as you are clear about what is.
- It may be that you **hold a vision for them for a time**, until they can claim their own.

Can you dare to dream on their behalf?

From the Ordinary to the Extraordinary

When crafting a vision, families have found that the components of a good life for their family member with a disability are **ordinary but essential elements** of most people's lives.

These include:

1. Having people who love and care about them.
2. A place to live that is their home.
3. Being known and valued in their community.
4. Being financially, physically, and emotionally secure.

For a person with disability, these ordinary elements of life have been much more difficult to attain than for those without a disability. Wanting these things has been viewed as unrealistic and extraordinary.

Activity

Write down your vision so you can tell others:

To access further resources visit www.cru.org.au/whyitmatters

Planning a good, valued life

- To achieve this vision, it's important to **start with a plan**. This will help you identify what needs to be done and determine the first step towards the goal of a good, valued life for your family member with a disability.
- Planning can be an **intentional, structured process** that helps people set clear goals and actions to achieve these goals.
- Additionally, it can also be a **state of mind** that influences our everyday thinking.
- It works best when both approaches are at play. For example, having a structured plan to refer to and share with others makes it easier to distinguish between choices as they arise, thus providing freedom and clarity.


Formal planning session

We recommend that you coordinate a formal planning session.

While there is no perfect planning template for this, it helps to have a structure to follow.

We suggest several steps to get you underway:

1. Invite people into the discussion.
2. Use a facilitator to keep the process focused.
3. Adopt a procedure or series of steps toward identifying some actionable goals.
4. Don't forget your vision!



Vision without
action is a daydream.
Action without vision
is a nightmare.
Japanese Proverb

To access further resources visit www.cru.org.au/whyitmatters

Inviting siblings into planning

- Parents have found that when they welcome their children and extended family into the planning process (via a support network or other mechanisms), their combined vision for their child with a disability is stronger and more likely to be **adopted and supported**.
- Many parents and siblings have discovered that **passing on the vision** is as important as the details of a plan itself. Circumstances change, but a vision will **remain constant**.
- We know that **each family is different**, and some parents will feel uncomfortable laying down a list of ideals for their other children to carry on.
- We suggest that parents **welcome all their children** into the planning and visioning for their family member with a disability and leave the question of commitment up to them.
- Here are some **helpful tips** for inviting siblings into planning:
 1. **Begin early with conversations** about their sibling with a disability – be open and honest. Give them space to be the same.
 2. **Include** siblings and family members in decision-making conversations and other tasks when they are ready and willing.
 3. **Prepare to share** all the relevant information about the person with a disability with them, including where to find documents and who to contact in an emergency.
 4. **Start with small tasks** and step back when you feel comfortable – this takes time.
 5. **Work to ensure** that their sibling with a disability is not perceived as a 'burden' to be managed.
 6. **Don't expect** the sibling relationship to be the same as the parent-child relationship.

If there are no siblings or extended family members, a support circle can be a well-defined means of establishing and nurturing the people you want to safeguard your family member when you no longer can.

Summary

Achieving and sustaining a good life requires planning and action. Reviewing plans regularly, especially during significant transitions, and being open to unexpected opportunities that align with your vision for your family member is important. We know planning is hard, but without it, life can be much harder for everyone, especially the person with a disability.

Key steps include:

- Creating a vision
- Developing a structured plan
- Adopting a planning mindset
- Initiating conversations with loved ones early on
- Embracing opportunities
- Involving siblings and trusted people
- Emphasizing the importance of preparation
- Recognizing the value of ordinary experiences, and
- Understanding that a good life is possible.

ACTION 5

Compile necessary resources for the plan

Consider the resources needed to implement the plan in the long term and set up your will and estate accordingly.



“

Members of a support circle can assist our family members informally in numerous ways that can preclude the need for formal appointments as guardian administrator. ”

(Ward, 2014, p.21)

This section focuses on providing clear, concise information to help you navigate the practical application of your plan as it relates to the law.

PLEASE NOTE: This is not legal advice. Legal examples only relate to Queensland legislation. Information will differ in other jurisdictions. The information in this section was originally written by Jeremy Ward (2011) and produced in the document 'Preparing to Make a Will'.

As outlined in Action 4, families have found that planning **must begin with a clear vision** for the life they want. If you are unclear about what you want, your dreams may be limited by the information others decide to give you.

Making a Will and **having some knowledge of the law** is an integral part of planning. It is important to have some understanding of the implications.

Here are considerations you may face as your vision and plan take form.

Wills – better now than never

- **A will** is a legal document that states what you want to happen to what you own after you die.
- A will must be **prepared by a solicitor** as there are several formalities that, if not followed, can invalidate your will or parts of it.
- First and foremost, it is crucial to **have a will now**. A will is always a work in progress, and it is better to have one that does not perfectly reflect everything you want than to have no will at all.
- We recommend you **don't rely on a will kit**; instead, you find a solicitor versed in working with people with disabilities and their families.

Dividing into shares

- If parents have **more than one child**, the question is often, "What share should we give to our son or daughter with a disability?" If parents have done some planning, they will have a better idea of the financial needs of all their children.
- **There is no rule** that says all children must be left equal shares. This points to the need to review your will regularly.

Providing for a person with a disability UNDER 18

- **If the person in question is under 18**, it is very important to appoint a **"testamentary" guardian**, as it is likely that someone will need to have the formal authority to make decisions on issues such as schooling and health care.

Providing for a person with a disability OVER 18

- If your son or daughter with a disability is over 18 but can't manage money, you could consider **setting up a trust** that lasts their lifetime, managed by trustees that you appoint.

Who to appoint as Trustees?

- People you **trust**.
- People with **skills** or **experience** for the job.
- People who will **follow your vision** or take advice from those who will.
- It is best to appoint at least **two trustees**, with one external to the family.
- If family members, take care if they are "residual beneficiaries" due to a potential **conflict of interest**.
- You can appoint **professional trustees** (e.g., solicitor, trustee company, Public Trustee), but they charge fees and can be inflexible.

Tax and Social Security

- Be aware of the potential **Social Security implications** of trust arrangements.
- **Obtain advice** about whether a “Special Disability Trust” is applicable to your situation for this purpose.
- Be aware that you **may need professional advice** about the potential tax implications of trust arrangements.

Presumed Capacity

- When a person turns 18, they are **presumed to have the capacity** to make decisions despite their level of impairment.
- **A guardian or administrator is ONLY appointed when:**
 - Someone has impaired capacity, and
 - There is a need for a decision in relation to a matter or
 - The person is likely to do something that places them (or is likely to place them) at risk and
 - Without an appointment of guardian and/or administrator their needs will not adequately be met, or their interests will not be protected.
- **Many people in Queensland** with impaired capacity **do not** have guardians or administrators.
- **Informal decision-making is often sufficient** because parents, family and friends are available to support and assist individuals.
- **It is critical to seek ample advice** on the matter of guardianship and administration.

What is Guardianship and Administration?

These delineations relate to Queensland law. The terms vary throughout Australia

- **Guardianship** – A guardian has the authority to make personal, non-financial decisions (e.g., where someone lives, health care).
- **Administration or financial management** – An administrator has the authority to make financial decisions, including those relating to property.

“[M]embers of a support circle can assist our family members informally in numerous ways that can preclude the need for formal appointments as guardian or administrator. If necessary, they could attend a QCAT hearing to give evidence of how they provide that support. If there comes a time when a guardian or administrator is needed, and we are not available, then members of a support circle will be an excellent source of potential candidates for these roles.” (Ward, J, 2014, p.21)

Other legal decision-making arrangements to consider are:

- **Statutory Health Attorney** - The decision-making power of a Statutory Health Attorney only lasts as long as the health care decision needs making.
- **Enduring Power of Attorney (EPA)** - Allows a chosen person to make decisions on an individual's behalf, if that person does not have the capacity to do so.

Memorandum of Wishes

- This is a statement of how you want your chosen trustees to use the trust funds.
- This can be included in your will or attached to it – it is more confidential if it is not included in your will.
- It is not binding on trustees, but we can still ask them to read it and sign it.
- We can state that we want the trustees to consult with and take advice from certain people (e.g. support circle, siblings).
- Include
 - Your vision
 - What you want, where you want family member to live etc
 - State what you don't want (e.g. no institution or group home)
 - Make clear you are happy for funds to be spent on things family member enjoys – their passions, their likes (e.g. travel, hobbies, going to the football).

To access further resources visit www.cru.org.au/whyitmatters

When considering legal issues and the future, many of the difficult decisions will be easier if you have:

- A vision for the future of your family member.
- Accepted that it is other people who will keep your family member safe and have taken steps to build networks of support.
- Discussed issues with other key family members, e.g., other children
- Developed plans which:
 - Include consideration of the costs of future support, care and other needs and the share your family member will need
 - Provide for alternative informal decision-makers
 - Identify trustees, and possible future trustees if you become unhappy with your choice of trustee

What to take to the solicitor

Some solicitors have their own checklists for their clients to complete before the first meeting. You should contact the solicitor at the time of making an appointment to find out about this. Assembling all your personal details, e.g., previous will, financial statements, lists of assets, other beneficiaries etc, will also save time and money when you meet the solicitor.

Extra issues to consider

- Writing a will that clearly expresses your wishes is a complex matter. It is important to consult a solicitor so that your will is valid and the terms of the will reflect your wishes.
- It is not desirable to end up with a valid will that does not work as you expect. If a will is poorly written, the results can be costly in emotional as well as financial terms.
- If you die intestate without a will, government legislation decides what happens to your assets. This decision may not be in your son's or daughter's best interests.
- Consider keeping your will with your solicitor. Keep a copy for yourself and tell family members and your executor where the original will is kept. If a will is lost it is deemed to be revoked.
- Keep all your personal papers in one place with an inventory and tell other people where to find them in an emergency.
- A will should be revised regularly to take into account your own changing circumstances and those of your family member with a disability.
- Fees – we strongly recommend that, when you make initial contact with a solicitor, you discuss their arrangements regarding fees. The costs of preparing a will can be considerable as this area of law is very complex.

Summary

On its own, knowledge of the law is not enough to keep people safe, but it is still an integral part of planning. Wills and trusts must be carefully considered and executed with the help of a solicitor who has experience with people with disabilities and their families. Clarifying your vision, crafting a plan, and knowing the various items to take to a solicitor will simplify the process.

Here are some points to remember:

- It is better to have an imperfect will than no Will at all
- Consider writing a Memorandum of Wishes.
- Have a plan first.
- Prepare necessary items before visiting the lawyer.
- Keep your Will in a safe place.
- Tell others where to find your Will.
- There are no rules about sharing assets evenly.
- Consider Tax and Social Security implications.
- Learn about Guardianship and Administration (QLD).
- Revise your will regularly

ACTION 6

Clarify what's paid and unpaid

Of the many roles you play, determine which should be done by family members or friends in your absence and what can be done by paid workers.



“

The future is going to happen. Rather than simply let it happen, we can plan for the future that we want [now]. ”

(Ward, 2014, p.5)

Good quality paid support is not enough

- While no service on its own can keep a person safe, paid support staff can play a vital role in building an inclusive life for someone with a disability.
- Even the best-paid support, however, does not replace the value of having a network of people who can help ensure the safety of your loved one in the future.

Family Business and Service Business

This section draws on the work of Jan Dyke and the Homes West association, in their document, *Choreographing the Future*. They use the terms family business and service business to distinguish between the role of paid and unpaid support.

- While acknowledging that life can be complex, the authors of this work also suggest addressing the areas of overlap between the two. While some issues may blur the lines, others are clear-cut.
- By clarifying the distinction between family and service business, individuals can better plan future roles.
- The commitment of family members to each other generally endures more than the commitment of services to their clients.

Why is this distinction crucial for safeguarding our loved ones?

- Knowing the distinction between family business and service business allows you to plan for a future based on your family member with a disability rather than the direction of a service. This planning can ensure that your family member's vision doesn't become diluted or misdirected. Your vision and planning should intentionally direct the course of their life with paid support as one aspect of that life.
- Even the most committed paid workers will ultimately shift, change, and leave their role. Sometimes paid workers are invited to become members of a person's support network when they leave their paid role.
- Even good services change over time and are still liable to experience turnover and change direction or move from their original vision. No individual committed worker can promise that their organisation will stay constant over time. That is outside their control.
- A group of committed family and friends can more readily make that promise, knowing that even if they were unable to continue as an individual, others from the group can take their place.

Activity

Are there things that are unique to your family? Consider separating those things you would prefer were done by family members vs that which you might leave to paid workers.

(We recommend doing this activity with your family member with a disability, wider family and/or support network)

ROLES	
Family/Support Network	Paid Worker

Family Business

Here are some areas that other families have identified as being exclusively the roles of family (and trusted friends).

- Holding someone's story and understanding of that person's life, culture, and family life.
- Holding an understanding of that person's skills, abilities, likes, dislikes, gifts, and concerns.
- Maintaining a valued role in family life and community life while keeping important dates such as birthdays, anniversaries etc.
- Celebrating significant rites of passage and important events.
- Monitoring to ensure that the expectations of the culture of daily life are maintained.
- Holding the person's medical history.
- Making decisions about health, general nutrition, exercise, and well-being.
- Making decisions about personal finances, personal spending, and long-term financial security.
- Selecting, approving, or rejecting who comes into the person's life to provide paid support.
- Guiding a service to interpret the wants and needs of the person.
- Deciding where the person lives and with whom.
- Daring to dream the seemingly impossible and holding onto dreams about what life could be like.

(Dyke, J, 2005, p.3)

Summary

As you plan it is helpful to differentiate between what is service business and what is family business, and what sits in the grey area between. Clarifying this will help determine who should take on what roles in the future. Formal paid support is an important aspect of life for people with disabilities, but some things are better if done by family and friends. It is important to remember that organisations shift and change, but family and support networks of trusted people are more likely to stay consistent.

Conclusion

None of us has any guarantees about tomorrow, but we offer these six strategies to help you begin thinking and talking about the future. These strategies are more likely to ensure the good lives you are helping to build today as families will survive into the future when you can no longer play the role you currently do. Succession planning asks us to look honestly and openly at today so that we may find the courage to vision, plan, and begin paving the way toward a safe and fulfilling future for our family members with a disability.

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The reality is that the full and positive lives of people with disabilities that we hear and read about do not happen by accident.

These inspirational stories can be told because someone had a vision and belief in what is possible, sometimes against considerable opposition, and planned to make it happen.

”

(Jeremy Ward as cited in Raju, 2012)



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