



PAVE THE WAY

vision to action through planning

Planning for Now Tomorrow and the Future

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Pave the Way

Pave the Way assists families throughout Queensland to clarify their vision for their family member with a disability and to plan to implement that vision. We encourage planning which is vision driven, 'whole of life', developmental, outside service planning and which safeguards family members in the long term. We believe it is other people who keep people safe and support the development of personal networks, including Support Circles. Pave the Way is part of Mamre Association Inc, a family support organisation in Brisbane, and is funded by the Department of Communities, Child Safety and Disability Services.

Pave the Way:

- provides information
- holds individual consultations
- meets with small groups
- conducts workshops (1 day, 2 day, 6 day)
- supports the development of networks and support circles
- provides information on legal issues
- refers to a panel of solicitors experienced in wills and trusts and to other professionals
- develops long-term safeguarding strategies with families.

Jeremy Ward [BA (Hons); LLB] has many years' experience as a parent whose eldest daughter had life-long disabilities and lived in her own home, with a range of supports, for over ten years. Jeremy also had an older sister with a life-long disability. He has many years' experience in the law as it relates to people with disabilities and in working in advocacy organisations with people with disabilities and families. Jeremy was instrumental in the establishment of Queensland Advocacy Inc, where he worked for over ten years as an advocate, lawyer and director. He is a former member of the Queensland Guardianship and Administration Tribunal and former Senior Member of the Commonwealth Veterans' Review Board. Jeremy established Pave the Way in September 2002, where he was Manager and Team Leader until January 2009. He then worked as a part-time consultant with Pave the Way until July 2012.

Disclaimer

With the exception of information relating to Special Disability Trusts, which are established under Australia wide Commonwealth law, the legal information in this Booklet applies only to Queensland law.

Nothing in this Booklet is to be taken as specific legal advice. Each reader should obtain their own legal advice particular to their circumstances and the law in the State or Territory of Australia where they live.

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Part 1 - Developing, Implementing and Safeguarding our Vision and our Plan

Introduction

As we get older the biggest worry for families with a family member with a disability is “What will happen when I die?” Who will be here to look out for our sons or daughters or sisters or brothers when we are no longer around to look out for them? We do a lot of worrying in the depths of the night but how often do we take steps to address our concerns, as we deal with and struggle with the reality of the here and now? Our failure to act is, however, an action in itself. When we say that we have no time or we are too tired or we don’t know where to start or that there is no funding so what’s the point, we are choosing to do nothing.

This booklet, in two parts, is based on reflections on personal experience and the insights from many others. They are my thoughts and views and may not always reflect the views of Pave the Way. My thinking was stimulated by an opportunity to attend a Leadership Workshop in Western Australia in early 2002, run by Planned Lifetime Advocacy Network (PLAN) from Vancouver, Canada, and by discussions with Gillian Chernerts from Toronto, Canada, who has over 30 years’ experience in citizen advocacy, cooperative housing projects and the setting up of support circles. These contacts, and many others, have confirmed what I learnt 30 years ago when I was first exposed to citizen advocacy, that our future safety is about relationships. Interestingly, citizen advocacy was conceived by Professor Wolf Wolfsberger as a response to parental fears about the future. Some years later I was asked to talk to families about wills and trusts and soon realised that planning for the future required much more than simply addressing the legal mechanisms that are available to us.

My reflections are also informed by my work with Pave the Way at Mamre Association in Brisbane for nearly 10 years. I have been privileged to talk with many families throughout Queensland, all of whom are grappling with these issues, either as families with young children or as older families with family members of all ages. I have learnt much from discussions with my former colleagues in the Pave the Way team and with the Pave the Way Reference Group, which met from 2002 until 2011.

The Future and the Present

When we think about the future, we need to remember that the future is not way out there in the distance, in some sort of never–never land. It’s at the end of my next sentence, it’s tonight when we’re on our way home, it’s tomorrow, it’s next week, next year, 30 years from now, it’s when my unborn grandchildren are great-grandparents. When we worry about the future, we need to think about what would happen to our family members if we were no longer here and able to look out for them tomorrow, not only at some distant time when we know we will no longer be able to do all that we did for them today and will do for them tomorrow. What would happen if we were hit by that bus tomorrow and what have we done to plan for the possibility of that happening?

What we can do about the future

When we think about the future we can do a number of things. We can ignore it; we can remain paralysed with fear; we can wait for the elusive funding package; we can hope and believe that someone or some service will step forward; we can expect that other family members will step in; we can trust that the government will provide. When we do these things we will often also be ignoring the present.

Alternatively, we can plan for the future that we and our family members want. The future is going to happen. Rather than simply let it happen we can plan for the future that we want.

.....and the present

As we think about and plan for the future we need also to reflect on the present. What are we doing now to ensure that our family member who has a disability has a rich and meaningful life and is safe and secure? Are we thinking about how we might bring others into their life, how we might challenge them to develop and grow, to bring their contributions to their community? Do we have a vision of what we would like their life to be like now, as well as in the future?

The focus of our vision – family member with a disability

First and foremost the focus of our vision for the present and future is our family member who has a disability. They are at the centre. It is not the demands that we may currently face in providing the day to day support, or in doing the advocacy, or in worrying about the future that we are aiming to alleviate. Rather, it is our family member who has a disability that must be the focus of our vision and our planning.

Having said that, if we plan for an independent life for our family member, we will also be planning for a future where we as their parents, or brothers and sisters, or grandparents, etc, have the capacity to live our lives less focused on them and their needs. A vision for an independent (and interdependent) life for our family member is also a vision for a life for us which is less dependent on meeting their everyday needs.

Our planning framework – our values and beliefs

It is important that we are clear about our values and beliefs when we develop our vision and begin planning. Do we believe that people who have disabilities are people of value, depth, complexity and separate identity, who contribute to society, who bring gifts to the people they know and to their communities? Or do we believe that their disability alone determines their identity, that they have no gifts to offer and merely receive from others, having little or nothing to contribute?

Whatever our values and beliefs, our planning will reflect them. If we don't clarify our values and beliefs before we start, our planning will lack clarity, will be confused and is likely to do our family members harm rather than good. If we are not clear, our planning will be driven by the values and beliefs of others – by government, by the service system, by broader societal values – rather than our own consciously developed values and beliefs. It may take us some time to clarify our own values and beliefs but it is very important that we do so.

What to plan for – our vision

We can't start to plan unless we know where we want to go. Most of us don't plan a holiday without deciding where to go so why would we plan the lives of our close family members without knowing where they want to go with their lives and what lives we want for them? We need a vision of what we and our family members want in the future. The clearer the vision the easier it will be to plan and, importantly, the easier it will be to stick to our plan. There will be many people and organisations and government agencies that will try to change our plans, say that they are unrealistic, that they are not possible "in the real world". We need to be clear about our vision so that we can withstand those pressures. There is great power in having clarity of vision. If we have a clear vision, we will probably be the only ones around the negotiating table who do so and we should be able to direct and influence the debate accordingly.

When developing a vision, a good place to start is to look at what we want for ourselves and our other family members. If we are parents and have other children, we undoubtedly want them to grow up to love and be loved, to have close and valued friends, to have intimate relationships, to live in homes of their own, to contribute to society through work and other activities of their choosing, to be happy, to have fun, to lead rich and rewarding lives, to continue to learn and to grow and to experience all the struggles and challenges and complexities of life.

Why would we not want all of this for our family members who have a disability? It might take longer and be more difficult to achieve some of these goals, but that should not diminish our vision that they are all desirable and possible. Developing a vision is all about allowing ourselves to dream, not about starting with what others, usually with their own agendas, tell us is possible. It is unlikely that our other family members will achieve all we want for them but that does not stop our dreaming and wishing the best for them.

Despite the many changes that have occurred for people who have a disability in recent years, it is still the case that some people will tell us that many people with disabilities cannot live independently, on their own, or with someone they choose. They will tell us that people with disabilities cannot perform meaningful work, have intimate relationships or real friends. They will tell us that they should live with "others of their own kind", in groups not of their choosing, supported only by paid workers, being "minded" and occupied during the day with activities chosen by others, isolated from much that occurs in their local communities, not supported to contribute to society but destined merely to be the receivers of care and the clients of services.

If we allow ourselves to believe that these are the limits of what is possible, that is exactly what our family members with a disability will achieve.

How to develop a vision and plan

When developing a vision and plan, it is important that families are in control. This is definitely not something that services or government agencies should initiate and lead, though they might well encourage and support families to plan. Initially at least, families must take the lead and keep ownership of the process and the outcomes.

Indeed, much of what is discussed during the process will be private to the family, to be shared only with trusted allies and friends.

It is important that families include others in their planning. This allows greater input of ideas but more importantly means that extended family members, close friends and allies, who might be critical to the implementation of the plan now and in the future, are part of the process and share ownership of the outcomes. Some families say there are no such people in their lives. In that case, the first step will be to find and develop at least one or two people to help with the planning.

There is no magic about how best to conduct the planning. Some families might want to ask someone to facilitate a fairly formal process, using one of the various planning tools available, while others will want to follow a more informal process. In either case, it is important that someone takes on the role of keeping a record. The critical point is that once the vision is developed, it is important to keep the vision foremost in all peoples' minds. The vision is what drives the planning, rather than being adjusted or compromised to fit what looks easy to achieve. It might be helpful to appoint a "keeper of the vision" to remind others when they appear to be veering from the vision. Whatever the process, food and refreshments are a must. For many families this will be a new experience and an achievement which needs to be celebrated!

What to put in our plan

When looking at the content of our plan, it is important to focus on all aspects of life -

• home	• spirituality
• work	• health, healthcare
• family, relationships and friends	• financial security
• recreation, play, holidays	• autonomy & decision-making
• passions	• safety and security
• education	

This is not an exhaustive list but is designed to ensure that nothing is forgotten. If you have a particular area that you feel will not be covered by this list (eg, communication), then add it to the list. Following this list can assist you to sort out priorities and make a start on what might otherwise seem daunting and overwhelming.

Goals, action statements, priorities, timelines and review dates (when we check we have done what we said we would do) are important so that there is a clear process for implementing the plan which is understood by everyone. The following is an example:

Goals	Actions	When	Who	Review
Home - Jill will move into a home of her own within the next 3 years	Assist Jill to apply for social housing with the Qld Dept of Housing and Public Works	Next 4 weeks	Jill's mother	3 mths – Jill's aunt
	Find options for Jill to "house sit", to see how she likes living away from the family home and what support she needs	Next 12 months	Jill's planning group	12 mths – Jill's aunt
	Research funding and other support options	Next 12 months	Jill's planning group	12 mths – Jill's aunt

Obviously, the particular circumstances of the individual and family will determine the areas of priority. The plan should also be creative and developmental and flexible enough to adapt to changing circumstances which, even if not apparent at the time, will occur. An analysis of what might change will help predict the areas where flexibility is most important.

The plan should also be realistic and achievable. This does not mean that the vision should be watered down by what is now thought immediately possible, given funding constraints or family resources. Rather, if a goal seems unattainable at the moment, a first step to achieving that goal might be to research how others have achieved a similar goal in similar circumstances. For example, if the goal is independent living but the family member requires a high level of support, there is no funding currently available and the family has limited resources, an initial strategy might be to identify other families who are attempting to achieve similar goals, to share ideas and strategies and to support each other in this struggle. No matter how unachievable a goal appears, there is always a first step that can be made, and a next step, and a next step, and so on.

Some features of a comprehensive long term plan

Our plans need to be comprehensive and include long-term strategies. The following points are worth bearing in mind:

- start to plan early – e.g. attending the local school is more likely to bring our family members into contact with other children in their local community than schooling in a distant suburb, thus beginning the process of local network building – it is never too early to plan, and also never too late
- do what we can from an early age to assist our family members to develop relevant competencies - if we want them to be independent as adults, the more competent they are at every-day tasks, the better placed they will be to face the challenges of independent living

- remain connected to other families to share experiences and challenges, to support each other and to swap the “street knowledge” about strategies, services and supports that we don’t get from information services
- if able to do so, begin a long term investment strategy to reduce our family member’s dependence on public funding
- join and support parent groups, advocacy groups and other organisations and initiatives which aim to stand by people who have a disability and which take political action on their behalf - the stronger such groups, the more likely it is that there will be others looking out for our family members’ interests when we can no longer do so
- join mailing lists and take up opportunities for learning from local training events, conferences and visiting speakers
- accept the reality that our personal career expectations may need to be reviewed in order to meet our goals for our family member with disability.

Benefits of planning

There is no doubt that planning is hard. It takes time, energy, strength and commitment. It forces us to face reality, to confront our fears, to work on clarifying our vision and to take action towards change, often in the face of opposing viewpoints. It often involves stepping off into the unknown.

But planning also brings a feeling of power and control that we don’t have when we allow ourselves to be pushed and pulled by the agendas of others, whether government, or services or even other people in our lives with whom we are connected, such as other family members. Planning can free us, allowing us to take the initiative, to feel in control, that we are the ones with authority. We can put to one side the seemingly endless wait for funding packages, and place in perspective government distractions such as “funding reform”, or claims to want to work in partnership with us, or enticements to participate in “quality assurance” policy development, etc, and focus on where we want to direct our energy. Planning allows us to set the agenda.

Making our plans come true

Plans are useless unless they are implemented. A well developed plan should identify who is to do what and when. There needs to be someone whose job it is to make sure these actions are carried out. The plan should be reviewed regularly and all achievements celebrated. Every 3 to 5 years, or well before a time of significant change (eg, leaving school), a new plan can be developed.

Planning as a way of thinking

Planning is not only something that happens in a particular gathering or meeting. Planning is also a state of mind, a way of thinking. Having clarified our vision and goals, we need to ensure that they inform and direct our everyday decisions and

actions. As we plan what happens in the everyday we need to keep our vision and long term plans in our heads so that the everyday is in step with the broader vision.

What makes and keeps people safe

I think we all know that it is other people who keep people safe – people as ordinary people - not services, not funding packages, not governments, not wills, trusts and other legal structures and mechanisms, as important as all these might be to assist people to achieve a good, fulfilling and rewarding life. A very powerful strategy is to develop a support circle or personal network - a group of people committed to our family member with a disability over the long term. They can join with us while we are still able, then continue that commitment and support when we can no longer do what we do now.

Developing a support circle

In a handout, “*Support Circles*”, provided by Gillian Chernetz from Toronto, a support circle is described as follows:

“A circle is a group of citizens who come together to support and share a relationship with a person who is vulnerable because of having a disability. People who have disabilities are always at risk of becoming isolated and surrounded by people who are paid to be in their life. Together, people in a Support network/circle develop a shared vision of a safe and secure present and future for the individual”.

Gillian Chernetz says that the most important gift we can give to our sons and daughters, brothers and sisters and other family members who have a disability is to develop a support circle. She sees circles performing a number of roles:

- provide companionship, relationships, fun and celebration
- provide practical support by offering assistance in various different ways
- provide a forum for commitment and security – people who know and care will be there over time to make sure the individual is supported and safe
- circle members are listeners who ensure the individual’s voice is heard and encourage people to dream
- help an individual make plans for their future and support, strategise and assist good decision-making
- act as advocates in ensuring the individual is treated well and receives the support they need
- might assist the individual to manage support funds and staff
- provide mutual support to each other.

The first step for those wishing to build a support circle is to list those people in their existing networks who they think would feel comfortable being included in a circle. If a family thinks there is no one to ask, they can sit down with a close friend and brainstorm what their family member likes to do, who meets them in their usual

activities, and who amongst those people might be potential circle members. The next step is to ask!

If the family does not feel comfortable asking, one strategy is to ask a close friend to do the asking, or perhaps a family support worker. Another is to find a facilitator to do the asking and to gather the circle together. In its work over the last ten years, Pave the Way has found that some families prefer to ask others by writing a letter, while others prefer the direct personal approach. Gillian Chernetts says that it is particularly important that the person doing the asking knows the individual or gets to know them and *“sees the person as valued and not as a client who needs to be fixed”*.

The first meeting should be held in a welcoming environment and preferably with a facilitator who is not one of the parents of the individual who has a disability. It will focus on introductions and the individual’s story. Room should be made for people to ask questions and to clarify their role in the circle. The facilitator makes arrangements for the next meeting and the circle builds from there. Pave the Way has found that it is very important that families and all circle members are clear about the purpose of the support circle, which in this context is to focus on long term safeguarding of the family member with a disability. The facilitator might wish to make sure that this issue is discussed at the first one or two meetings. After that, the “agenda” at meetings will be set by the family’s and the individual’s vision for the future.

Key to the success of a support circle or network will be its longevity. Gillian Chernetts makes the following points about how to sustain a circle over time:

- “(a) Circles need to be empowered*
- (b) Circle members need to feel valued*
- (c) Circle members need to celebrate together*
- (d) People in circles share good times and bad times*
- (e) Circles need to come together; although the frequency varies in each situation. Regular meetings for a new circle help people get to know each other and secure the commitment to the process*
- (f) Circles need to feel meaningful for all members. Circles are not on the sidelines of activity. Circle work ebbs and flows just as life does*
- (g) There is no magic number of circle members. Membership evolves over time into a good working number.”*

Further information on setting up a support circle is available on the Pave the Way website or from the Pave the Way office.

Recording important information

A critical part of keeping people safe is making sure that important, relevant information about our family member with disability is recorded, so it is not all locked away in someone’s head, usually one or both of the parents. If that key person is suddenly unavailable (eg, sudden severe illness), others will need to have access to that important information. Sharing such information with others before such an

emergency arises also allows them to feel more involved and helps build the deep understanding needed by those you want to play a long term role in your family member's life. Even if you believe now is not the right time to work on building networks or to set up a support circle, it may be possible to begin to record this information.

Pave the Way has developed a resource for families to assist them with this task, called *A Document of Personal Information: Ideas and Strategies*, which is available on the Pave the Way website or from the Pave the Way office. The information which can be recorded is limitless. It can include your vision and plans for your family member; personal information, including medical information and details of medication; details of what important documents exist and where they are located (eg, wills); names and contact details of important people, such as close family members, emergency contacts, relevant professionals.

This document can be developed in a format that allows easy updating of information and can include photos and copies of other important documents. This resource can be used to share your family member's story with others, such as a support circle, and can be adapted for specific uses, such as the training of support staff and the briefing of professionals, such as doctors, lawyers, financial advisers.

The Personal and the Political

As we build personal networks in the community we build opportunities for our family members to contribute their gifts and strengths to the community and thereby participate in a process of cultural change. In an article, *"Community Engagement"* (1999, Responsive Systems Associates, Inc), in response to the increasing concern of families and others that people with disabilities find less and less opportunities to live with dignity as contributing members of society, John O'Brien wrote:

"A hopeful response to this difficult time calls for two distinct but complementary strategies. One strategy guides political action to entrench a policy of adequate individual funding, controlled by people with disabilities and their families and friends. The other guides a long-term process of culture change through community engagement. While these two strategies each make a necessary contribution, the urgency and clarity of political action can over-shadow the slow and ambiguous work of building wider and deeper relationships with and around people with disabilities and their families."

In our future planning we can incorporate both these strategies. As we engage in the slow process of building networks, we can also work out ways to contribute to the political debates that will impact on our family members. We might participate directly in these debates, or support related community action by joining and participating in advocacy or action groups. Alternatively, we might ask a member of our family member's support circle or network to do so and thus ensure that the circle or network remains in touch with the political, as it helps develop the personal.

Safeguarding our vision and our plans

Perhaps the greatest challenge is to work out how to safeguard our plans into the future. It is one thing to develop and implement a plan but how do we make sure it

continues to be implemented and reviewed and revised after we are no longer able to do that? We can address some issues through our wills and by establishing trusts, but even substantial financial provision will not address all issues. We can't pay for people to be committed to our family members in the ways that we are.

For some families, one safeguarding strategy has involved the setting up of an organisation to monitor what they have put in place. Planned Lifetime Advocacy Network (PLAN) in Vancouver, Canada, takes this approach, through offering life membership, at a fee, to families who see this as a solution.

PLAN places great emphasis on the development of personal networks (support circles). For a family to become a life member of PLAN, they must agree to the development of a network around their family member who has a disability, with the assistance of a paid facilitator employed by PLAN. PLAN then undertakes to continue to provide a facilitator to support the network in the long term, before and after the parents have died. PLAN also undertakes to monitor and provide advice to trustees appointed under the parents' wills and to support the personal network in any advocacy they need to undertake. After the parents die, the life membership fees continue to be paid by a trust which parents set up under their wills.

A limitation of the approach of both PLAN is that all organisations are vulnerable. The safeguards they offer families will last only while they can continue as strong organisations able to deliver on their promises. Further, not all families can afford the cost of joining such an organisation or are willing to embrace the structure they require of families.

Another strategy, which also focuses on the development of support circles, is looking at ways individual support circles can be supported and sustained over time. *Lifetime Circles* in Ontario, Canada, aims to provide a forum for local groups of support circles to meet and support each other; to help with hiring and training facilitators of support circles; to inform members of day to day social, financial, legal and government affairs; and to perpetuate a network of local groups that create individual support circles by assisting in organising new groups and sustaining existing groups.

Pave the Way continues to investigate these strategies and any others that provide ideas for how best to approach this issue in Queensland. Unlike PLAN, Pave the Way does not undertake to be there for families in the long term. Rather, Pave the Way aims to assist families to develop their own long-term strategies to keep their family member safe and secure in the long term.

While Pave the Way believes that a support circle is a very powerful long-term safeguarding strategy, it is only one strategy. The critical issue is for families to accept that it is other people who will keep their family member safe and that they need to develop strategies, relevant to their circumstances, aimed at inviting others to participate in the life of their family member over the long term.

What's the law got to do with all this?

When contemplating what will happen when we die and what we can do to prepare for that inevitable eventuality, many of us think first of wills and other legal mechanisms such as guardianship and financial management. These are important

but, in my view, will be more effective if we have done some work on developing our vision and plans.

Whether or not our family member needs a formally appointed guardian or financial administrator may depend on whether they have a committed group of people around them who are willing to assist them with informal decision-making. The *Guardianship and Administration Act 2000* (Qld) encourages informal decision-making [see for example sections 9(2) and 7(d)]. A support circle might agree to assist our family member in this area, which could alleviate the need for a formal appointment.

Until we have developed our vision and planned the steps we need to take to make our vision a reality, it will be difficult to finalise our wills. For example, if we are parents, one strategy to support our daughter or son who has a disability to live independently might be to supplement government funding through our own resources. Therefore we might want to ensure that we leave sufficient funds in our wills so this arrangement can continue after we die. Until we have developed that strategy, and done some planning, we might not be in a position to decide what portion of our estate to leave our family member with a disability.

Similarly, if we are going to set up a discretionary trust in our wills, we need to appoint trustees. But we may have no obvious trustees to appoint, or those we have might not be young enough. We want our trustees to outlive us! One way of developing potential trustees is to develop a network or support circle.

Nevertheless, it is important to have a will now and not wait until all these plans are worked out to our absolute satisfaction. A will should be seen as work in progress that is reviewed and changed regularly. It is better to have a will that we know does not reflect all our final plans, knowing that we can change it later, than to die without a will.

Part 2 of this booklet addresses these legal issues in more detail.

Part 2 – The Legal Issues

Introduction

In this part of the booklet I will talk about guardianship, financial administration, wills and trusts and show how we can best integrate these legal concepts and mechanisms with our planning for the future.

Guardianship and Administration

Children under 18

Parents are the guardians of their children (unless that power is taken from them) until they reach the age of 18. As children under 18 grow older and their capacity to make their own decisions increases, parental authority in some areas decreases, for example, when consenting to medical treatment. Parents also do not have unlimited powers over their children. They must make decisions in their child's best interests. Further, there are some decisions that parents have no authority to make, for example, decisions relating to sterilisation for non-therapeutic reasons.

Parental guardianship powers cease when children reach 18.

People 18 and over

In Queensland, the law relating to adult guardianship and administration is set out primarily in three pieces of legislation - the *Powers of Attorney Act 1998* (Qld) (Powers of Attorney Act), the *Guardianship and Administration Act 2000* (Qld) (Guardianship Act), and the *Queensland Civil and Administrative Tribunal Act 2009* (Qld) (QCAT Act). Other relevant legislation is the *Public Trustee Act 1978* (Qld) and the *Mental Health Act 2000* (Qld).

Everyone who is 18 or over is presumed, by law, to have the capacity to make decisions for themselves, regardless of whether they have a disability. An example of where this principle is contained in the law is section 5 of the Guardianship Act, which acknowledges that an adult's right to make decisions is fundamental to an adult's inherent dignity.

The Guardianship Act provides that guardianship relates to decisions about personal matters and administration to financial matters.

According to the Guardianship Act, a guardian may be given the power to make decisions about a range of personal matters, such as:

- where they live and with whom they live
- whether they work and where
- education and training
- service provision – which services and which service provider
- licences and permits
- day to day issues such as diet and dress

- health care
- legal matters of a non-financial nature.

An administrator, on the other hand, may be given power to make decisions about money and property. These powers include:

- paying maintenance and accommodation; paying debts
- receiving and recovering money
- carrying on a business
- signing contracts; performing contracts previously entered into
- paying rates and taxes
- arranging insurance and paying premiums
- undertaking real estate transactions
- approving investments
- taking legal action relating to financial matters.

Any person aged 18 or over, who is not a paid carer or health provider for the adult and who is “appropriate” can be appointed guardian or administrator. In the case of administrator, people declared bankrupt, or seeking to avoid bankruptcy through provisions of bankruptcy legislation, cannot be appointed. A paid carer does not include someone on the Carers Payment or Carers Allowance.

Both guardians and administrators can be given limited authority (eg, restricted to decisions about where someone lives, or to the management of a large investment portfolio), or they can be given “plenary” authority to make all guardianship or all administration decisions. In exercising these powers both guardians and administrators must apply the general principles that are contained in the Guardianship Act. These principles include recognising the rights of all adults to the same basic human rights, an adult’s right to respect for his or her human worth and dignity, an adult’s right to be a valued member of society, the importance of encouraging and supporting an adult to live a life in the general community and the importance of encouraging and supporting an adult to achieve their potential (see Schedule 1 of the Guardianship Act).

The same individual or individuals can be appointed as both guardians and administrators, if appropriate. If there is no appropriate individual, the Adult Guardian can be appointed as guardian (but not administrator) and the Public Trustee as administrator (but not guardian). Private Trustee companies can also be appointed as administrators.

Capacity to make decisions

A guardian and/or administrator can be appointed only where a person lacks capacity to make decisions for themselves. Schedule 4 of the Guardianship Act defines “capacity” in the following terms:

- “**capacity**” for a person for a matter, means the person is capable of –*
- (a) understanding the nature and effect of decisions about the matter;*
 - and*
 - (b) freely and voluntarily making decisions about the matter;*
 - and*
 - (c) communicating the decisions in some way.”*

For a person to have capacity, all three elements of this definition must be satisfied. Thus, if your family member who has a disability appears to understand the nature and effect of decisions but is unable to communicate them in some way, they may have “impaired capacity”. This does not mean that anyone who cannot speak has impaired capacity. If they can communicate their decisions “in some way”, and otherwise meet the definition, they will have capacity.

Capacity varies according to the nature of the individual’s impairment, the nature and complexity of the decision or decisions to be made and the degree of support they are provided by family and close friends.

Who decides capacity?

The QCAT Act established the Queensland Civil and Administrative Tribunal (QCAT). This relatively new tribunal, which came into effect in December 2009, has replaced a number of tribunals and disciplinary and appeals bodies, including the former Queensland Guardianship and Administration Tribunal. In the area of guardianship and administration, the main role of QCAT is to determine whether someone (referred to as the “adult”) has impaired capacity; if so, whether they need a guardian or administrator appointed and, if so, whom to appoint. Any interested person can make an application, including a person whose capacity has been called into question. They can apply to QCAT for a declaration of capacity. Schedule 4 of the Guardianship Act defines “an interested person” as “*a person who has a sufficient and continuing interest in the other person*”.

When dealing with settlements or damages awards in favour of an adult with impaired capacity, the Supreme Court and District Court also have these powers.

When is a guardian or administrator appointed?

Section 12 of the Guardianship Act requires that, for QCAT (or the Supreme or District Court) to appoint a guardian or administrator for a person, three requirements must be met:

- “The tribunal may, by order, appoint a guardian for a personal matter, or an administrator for a financial matter, for an adult if the tribunal is satisfied –*
- (a) the adult has impaired capacity for the matter, and*
 - (b) there is a need for a decision in relation to the matter or the adult is likely to do something in relation to the matter that involves, or is likely to involve, unreasonable risk to the adult’s health, welfare or property;*
 - and*

(c) *without an appointment –*

- (i) *the adult’s needs will not be adequately met; or*
- (ii) *the adult’s interests will not be adequately protected”.*

The critical issue with these provisions is that, for an appointment of a guardian or administrator to be made, it is not sufficient that a person has impaired capacity. There must also be a need for a decision to be made, or evidence that the person will be at risk, and that their needs will not be met adequately, or their interests protected, unless an appointment is made. Thus it is not sufficient that a parent or other family member wants to be appointed guardian or administrator for a family member with impaired capacity. It must be shown that an appointment is the only way to meet their needs or to protect their interests.

This requirement in the Guardianship Act reflects the view that people with disabilities should not have their rights taken away without good reason. Other provisions in the Guardianship Act support this principle.

Section 5 of the Guardianship Act states that:

- “(a) *an adult’s right to make decisions is fundamental to the adult’s inherent dignity;*
- (b) *the right to make decisions includes the right to make decisions with which others may not agree;*
- (c) *the capacity of an adult with impaired capacity to make decisions may differ according to –*
 - (i) *the nature and extent of the impairment; and*
 - (ii) *the type of decision to be made, including, for example, the complexity of the decision to be made; and*
 - (iii) *the support available from members of the adult’s existing support network;*
- (d) *the right of an adult with impaired capacity to make decisions should be restricted, and interfered with, to the least possible extent;*
- (e) *an adult with impaired capacity has a right to adequate and appropriate support for decision-making”.*

There will not be a need for an appointment if a person’s needs are being met, or their interests protected, through informal arrangements. For example, a young man with impaired capacity who cannot manage his financial affairs may have only a modest bank balance and receive only the disability support pension as income. If his family has set up arrangements with Centrelink and his bank, such that they can assist him to manage his pension and bank account safely without any difficulties, there is likely to be no need for an administrator to be appointed.

The Guardianship Act encourages such informal decision-making and the involvement of others to assist someone whose capacity is impaired. Importantly it recognises that a person’s capacity will vary according to *“the support available from members of the adult’s existing support network”* [section 5(c)(iii)].

“Support network” is defined as follows:

“support network”, for an adult, consists of the following people –

- (a) members of the adult’s family*
- (b) close friends of the adult*
- (c) other people the tribunal decides provide support to the adult.”*

A close friend of a person is defined as a person who has a close personal relationship with the first person and a personal interest in the first person’s welfare. (Guardianship Act, Schedule 4).

An individual’s “support network” would include people in a typical support circle.

Section 7(d) of the Guardianship Act states that the Act:

“encourages involvement in decision making of the members of the adult’s existing support network”.

Any powers exercised under the Guardianship Act should be done so taking the following into account:

“.. the importance of preserving, to the greatest extent practicable, an adult’s right to make his or her own decisions”; and

“The importance of maintaining an adult’s existing supportive relationships...”

(Principle 7(2) and 8, Schedule 1 of the Guardianship Act).

Thus, setting up a support circle has the potential of bringing together a group of people who could be recognised under Queensland law as having a role to play in assisting our family members with decision-making and in influencing who might be appointed to formal roles of guardian or administrator, if such formal appointments are necessary.

When a guardian or administrator is appointed for a person, that person loses their right to make the decisions that the guardian or administrator is authorised to make. The QCAT decision transfers some or all the person’s decision making authority to someone else. The limitations in the person’s competency become clear for all the world to see, including, of course, those who do not know them and who might judge them by those limitations alone.

As family members, we need to ensure that we do not take steps that unnecessarily limit our family member’s autonomy. 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.

For example, even if our family member with a disability cannot manage their money without assistance, if they can sign a withdrawal slip adequately (their mark will often be sufficient), and they can go to the local bank with assistance, their conducting their own transactions over the counter, with support, will not only be enjoyed by them and contribute to their feelings of self-esteem, but will also enhance their image positively within their community. They will be seen in the positive and valued role of bank customer, rather than the devalued role of someone who lacks capacity.

If, as family members, we wish to be appointed guardians and/or administrators, we need to ensure that our motives are not driven by our sense of entitlement (“I have

always looked after him so I have the right to be his guardian”), or by what we think might best assist us in our advocacy (“I need formal authority when I speak on her behalf”). It might be the case that we need formal authority because others are attempting to make a decision without authority. For example, a funding agency or disability service organisation might state that the only place our family member can live is in a group home because of the limitations of funding. In that case, seeking formal authority might be necessary so that it is clear that we can make the decision about where our family member lives. But if we simply want formal authority just in case we need it at some time in the future, we may be seeking to take away the autonomy and valued status of our family member without good reason.

As pointed out in the first part of this booklet, one way to support our family members to participate in decisions about their life is to set up a support circle. If members of the support circle were to agree to sign an agreement with our family member, if that is possible [remember the definition of “capacity” explained above], which states that they will support our family member in decision making, such an agreement could be used in any proceedings before QCAT as evidence of *“involvement in decision making of the members of the adult’s existing support network”*. If we found ourselves before QCAT unwillingly (perhaps a service provider has brought the application), and wish to oppose the appointment of a guardian or administrator (perhaps the service provider wants the Adult Guardian or Public Trustee appointed), such an agreement could support a submission that existing informal arrangements are satisfactory.

Similarly, someone acting against the interests of our family member might seek appointment after we have died and such an arrangement could be a safeguard against such an application being successful.

Even without such an agreement, members 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.

Statutory Health Attorney

The Powers of Attorney Act gives family members authority to make almost all health care decisions for a family member who has impaired capacity. The exceptions include:

- removal of tissue while alive for donation to someone else
- sterilisation
- termination of pregnancy
- participation in special medical research or experimental health care
- electroconvulsive therapy (ECT) or psychotherapy.

Only QCAT (or the Mental Health Tribunal in the case of ECT or psychosurgery) can consent to the above procedures.

If the only reason for seeking the appointment of a guardian is so that someone has formal authority to make health care decisions, there may be no need if an appropriate statutory health attorney is available. There is no need for statutory health attorneys to be appointed. They gain their authority purely by virtue of legislation, or “statute”.

Section 63(1) of the Powers of Attorney Act states that *“the first, in listed order, of the following people who is readily available and culturally appropriate”* is the statutory health attorney for the adult in question:

- “(a) a spouse of the adult if the relationship between the adult and the spouse is close and continuing;*
- (b) a person who is 18 years or more and who has the care of the adult and is not a paid carer for the adult;*
- (c) a person who is 18 years or more and who is a close friend or relation of the adult and is not a paid carer for the adult.”*

When making decisions on behalf of an adult, statutory health attorneys must comply with the health care principle under the Power of Attorney Act and Guardianship Act. In essence, this principle states that statutory health attorneys must be satisfied that:

- *“the health care is necessary and appropriate to maintain or promote the adult’s health or well-being, and*
- *is in the adult’s best interests and to the greatest extent possible, reflects the adult’s views.”* (QCAT website, <http://www.qcat.qld.gov.au/matter-types/guardianship-for-adults-matters/principles-of-the-act>, July 2015).

If there is no one listed in section 63(1) who is *“readily available and culturally appropriate”*, the Adult Guardian becomes the statutory health attorney. [Section 63(2)]. A *“person who has the care of the adult”* includes someone who provides, or who arranges to have provided, *“domestic services and support”* for the adult. [Section 63(3)]. Importantly, when an adult resides in an institution (including a *“group home, boarding house or hostel”*), he or she *“remains in the care of the person in whose care the adult was immediately before residing in the institution”*. [Section 63(4)].

If there is a dispute between statutory health attorneys, or a statutory health attorney makes a decision contrary to the health care principle, the Adult Guardian can be asked to mediate a dispute, and, if mediation fails, step in and act as statutory health attorney.

These provisions mean that, in most situations, a parent is statutory health attorney for their adult son or daughter who has impaired capacity for making health care decisions. No further appointment is needed for them, or other close family members, to make health care decisions. There is no need for them to seek appointment as guardian to make these decisions. If there comes a time when parents or other close family members are unable or unwilling to carry out this role, other members of a support circle might be able to do so in their capacity as “close friends”. The Powers of Attorney Act defines “close friend” in the same terms as the Guardianship Act (see above).

Enduring Power of Attorney

Under the Powers of Attorney Act, an enduring power of attorney (EPA) is a document which, if we have the capacity to do so, any of us can sign. An enduring power of attorney:

- appoints one or more other people as attorneys to make decisions for us,
- states whether those decisions are of a personal or financial nature, or both,
- states when the authority of the appointed attorney may be exercised –
 - financial matters - immediately upon signing or in specific circumstances or on specified occasions or during periods when we lose capacity
 - personal matters - only during periods when we lose capacity.

Where our family member has impaired capacity, this mechanism of substitute decision making is likely to be of no use, because the person signing an enduring power of attorney must have the capacity to do so. Capacity to sign an EPA requires an understanding that, when signing the EPA:

- we can specify or limit the power we give to our attorney/s
- we can specify when the power begins
- once the power begins, our attorney/s have full control
- we may revoke the appointment at any time, so long as we still have capacity
- we can appoint one or more people as attorneys
- our appointment can cover personal and financial matters
- we can make specific directions
- the appointment of attorney/s continues after we lose capacity.

As parents and family members, we should all consider signing an enduring power of attorney, just as it is advisable that we all have a will. These are important documents which we should consider when formulating our overall future plan for our family members with a disability, particularly if their interests are likely to be affected if we can no longer sign documents, operate bank accounts etc. For example, if we have set up informal financial management arrangements for our family member, in which we hold funds jointly with them in a bank account, it might be important that someone can sign for us if we suddenly lose capacity.

We can also give directions under our EPA, making it clear to our attorney/s that we agree to their using our money to benefit our family member with disability. This could be important if our planning relies on using our own funds to help support our family member. An example could be that we pay for private health insurance for our family member and we want that to continue even if we lose capacity ourselves.

Wills and Trusts

What is a will?

A will is a legal document that states what we want to happen to what we own after we die. It is very important that a will is prepared by a solicitor as there are a number of formalities, which, if not followed, can make our will, or parts of it, invalid.

According to sections 10 and 11 of the *Succession Act* 1981 (Qld) (“the Succession Act”) our will must be:

- in writing
- signed by us (or for us in our presence if we cannot sign our name)
- signed in the presence of at least two witnesses
 - who must be present at the same time
 - who must sign their names in our presence but not necessarily in the presence of each other
 - who must not benefit under our will unless there are at least two other witnesses who will not benefit, or all other people who will benefit under the will consent to the witness receiving their benefit, or the Supreme Court orders otherwise.

Not all property is covered by our will. Property or money held as “joint tenants” (perhaps real estate or bank accounts) is not covered. Instead, when we die, the surviving joint tenant receives the money or property, irrespective of what we have stated in our will. On the other hand, if we own property with others as “tenants in common”, our share is included in the property that we can leave to others in our will.

Similarly, directions given under superannuation and life insurance policies, and discretionary powers of superannuation trustees, can affect what happens to these assets, irrespective of what we state in our wills. We need to ask our solicitors for specific advice on these issues.

Wills need not be in complex legal language. It is reasonable to ask solicitors to use simple language. However, in order to address all relevant issues and complex Government legislation and policy, our wills might require lengthy, detailed provisions.

Some terminology

When we make a will we are known as the “testator”. The property that we leave in our wills on our death, whether real estate, household contents, vehicles, jewellery, money in the bank, shares or other investments, is called our “estate”. The people to whom we leave our estate are called “beneficiaries”. We must appoint an “executor” (or executors) whose role and responsibility is to ensure that the wishes expressed in our will are followed and that our estate is distributed in accordance with those wishes. We appoint a “trustee” (or trustees) whenever we leave any part of our estate “on trust” for someone, for example, a child under 18 or an adult family member who cannot manage their own affairs.

The same person can be both executor and trustee, but they are different roles. The role of executor finishes when the estate has been distributed, whereas the role of trustee continues for as long the trust runs, which might be for many years. If we have children under 18, we can appoint a “testamentary guardian” to make personal decisions concerning such matters as health care, schooling and where and with whom our children live.

Who can make a will?

Only people aged 18 and over can make a will, unless they are married, or contemplating marriage, before reaching 18 years. A will by someone under 18 made in contemplation of marriage has no effect if the marriage contemplated does not take place.

Legal capacity

Only people who have the capacity to make a will can do so. For someone to have capacity, they must:

- understand that a will is a statement of what will happen to their property when they die
- be aware of what property they own
- be aware of their relatives and friends and whom amongst these people they should include as beneficiaries in their will
- not be delusional, such that this impacts on the decisions about disposing of their estate
- not be subject to some external pressure or undue influence that results in them distributing their property in a way that they would not otherwise have done.

It is only necessary that someone has capacity at the time they sign the will. Someone with a fluctuating condition, such as early onset dementia or perhaps bipolar disorder, might have capacity to sign a will one day yet lack capacity on another day. In such a situation it is important that relevant expert evidence about the person’s capacity is obtained on, or as near as possible to, the date the will is signed.

When should we make a will?

All of us aged 18 or over should have a will. It is far better to have an imperfect will than none at all. We can always change our will when our circumstances change or when we have finalised some aspect of our plans for our family member that requires our will to be amended.

When should we review or change our will?

We should review our will at least every five years to ensure that there has been no change in the law or our circumstances that require our wills to be modified. We should also make a new will when we marry, because, with a few exceptions, our old will is cancelled automatically unless it was made in contemplation of marriage. Those exceptions include allowing gifts to, and appointments of (eg, as executor), the person we are married to at our death. If we get divorced we need to make a new will because any gifts to our divorced spouse, and many appointments of them to roles such as executor or trustee, will be cancelled by our divorce unless our contrary intention is clear.

What happens if we cannot make a will?

The Supreme Court of Queensland has the power to authorise a will to be made, altered or revoked for a person without testamentary capacity (section 21 of the Succession Act). The Court can only make an order while the person is alive and can order that the costs of the Court application come from the person's assets.

According to section 24 of the Succession Act, before making the order, the Court must be satisfied that:

- the person making the application is an “appropriate” person to do so
- all persons with a proper interest in the application have been allowed representation before the Court
- there are reasonable grounds to believe that the person for whom the order is sought lacks testamentary capacity
- the proposed will, alteration or revocation is (or may be) one that the person would make if they had testamentary capacity, and
- it is appropriate for the Court to make the order.

While this is a relatively new provision, being introduced in 2006, there have been a number of applications to the Supreme Court seeking the approval of a will for an adult with impaired capacity. The decisions in those cases indicate the Supreme Court's willingness to take a common sense approach and to infer from the evidence, and from all the circumstances, the appropriate terms of a will for that person (for example, see *Deeke v. Deeke & Anor* [2009] QSC 65).

What happens if we die without a will?

If we die without a will, government legislation determines who receives our property after we die, under what are called the “rules of intestacy”. These rules also apply to someone who can't make a will because they lack capacity and for whom the Supreme Court (see above) has not authorised the making or amending of a will. The rules are complex but some of most relevance to families with a family member who has a disability are:

- if we die leaving a spouse (includes defacto spouse) and no children – spouse receives estate

- if we die leaving a spouse + children:
 - our spouse gets a set amount (currently \$150000) + “household chattels” + half (if we have only one child) or one third (if we have more than one child) of the remainder – our children who survive us share the balance
- if we die leaving no spouse but children:
 - if all our children are living when we die – our estate is divided into equal shares among them
 - if not all our children survive us and our child or children who died before us had no children, our surviving children share equally
 - if not all our children survive us and our child or children who died before us had children, those children (our grand-children) will share their parent’s share equally
- if we die without a spouse or children our estate will go to our next of kin in the following order of priority: parents; brothers and sisters; grandparents; uncles and aunts – then to Government. If our brothers or sisters are eligible and any die before us leaving children (our nieces/nephews), those nieces and nephews share their parent’s share of our estate. Similarly, if our uncles and aunts are eligible and any die before us leaving children (our cousins), those cousins share their parent’s share (schedule 2 of the Succession Act).

Thus, if we die without a will, our property will be distributed according to these rules, which make no special provision for people with disability. If our main asset is the family home, and it is registered in our name alone, it might need to be sold in order that the estate can be distributed. This could place our surviving spouse and/or our son or daughter with a disability at great risk and undermine our plans for their future.

Issues to consider when person with a disability cannot make a will

If your family member can’t make a will because they lack capacity, it is important to check what will happen to their money and property under the rules of intestacy. This will be particularly important if they have acquired significant assets in their name, perhaps through a bequest from another relative or they have been awarded a court payout as a result of an accident. In these circumstances you should seek advice from your solicitor. If the rules of intestacy lead to an unsatisfactory result, it might be worth considering an application to the Supreme Court seeking authorisation of a will to be made for them.

The impact of these rules might suggest to you that it would be best to plan for your family member with a disability to acquire some assets in their own name and that any significant assets that you want to leave for their benefit be held within a trust structure (see below).

Providing for children under 18

When we have children under 18 the share of our estate that we want to leave them must be held in trust until they are 18. If we wish, we can extend the trust until they

reach a later age, say 21 or 25. These rules apply irrespective of whether they have a disability.

For children under 18 we can appoint a guardian, known as a “testamentary guardian”. When one parent dies the surviving parent becomes joint guardian with the testamentary guardian, unless the will stated that the appointment of testamentary guardian does not take effect until both parents have died. In this context guardianship means having responsibility for the child’s long term welfare, not the day to day custody. A child’s guardian has authority to make important decisions such as where the child lives, their schooling and most medical decisions. We cannot appoint a testamentary guardian for our son or daughter with a disability who is over 18 and any appointment for a child under 18 terminates when they reach 18 (see part 5A of the Succession Act).

Providing for a person with a disability

If we have a son or daughter under 18 who has a disability, it will be particularly 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. We need also to consider the need for a testamentary trust that continues after they reach 18. If our child with a disability is very young we will need to review our will regularly, particularly if their competencies change as they grow older.

If we have other children we will need to decide what share we leave to our son or daughter with a disability and what share to our other children. Until our son or daughter with a disability reaches adulthood, it might be difficult to make these decisions. This points again to the need to review our will regularly. Even when they are adults, our plans and circumstances will change and provisions in our wills need to be reviewed regularly. We need to obtain specific legal advice as all our circumstances are different.

In some families, it might be appropriate to leave a greater share of the parents’ estate to the family member with a disability, at least on trust during their lifetime, because their need is likely to be greater than other family members. Our planning will help us determine their level of need, particularly for paid support. In other families an equal share between children will be appropriate.

Leaving an inadequate share to person with a disability

The biggest mistake we can make is to leave nothing in our will to our son or daughter with a disability. We might be advised to do this on the grounds that if we leave everything to our other children they can provide for their sibling at their discretion and there will be no problems with Centrelink benefits etc. However, apart from the lack of safeguards in such a strategy, our son or daughter with a disability has a right to expect that we provide for them along with our other children. While money will not make them safe, the more financial security we can provide them, the better they, and those standing by them, will be able to withstand changes in the policy and practices of government and services.

Further, if our son or daughter with a disability has been dependent on us to provide for them well into adulthood, they have a legal right to an “adequate provision” from

our estate. In some circumstances, this might mean they have a greater claim than do their siblings. Our will could be challenged in the Supreme Court by them, or by someone acting on their behalf, such as the Public Trustee or an appointed administrator, under “Family Provision” laws, on the basis that we neglected to provide adequately for them. These Court applications can be very stressful and the legal costs of these proceedings are likely to come from our estate, thus reducing its value to all our beneficiaries.

A Family Provision application can also be made when the rules of intestacy result in our family member with disability being left an inadequate provision in the estate. This is yet another reason why we should have a will and not die intestate.

What happens if a relative with a disability cannot manage money?

If our son or daughter with a disability has sufficient capacity to manage their financial affairs, we can provide for them in the same way as for our other children, by direct gift in our will, or, if they are children, in a trust until they reach adulthood.

If they do not have sufficient capacity to manage their own financial affairs, it is possible that a direct gift might be suitable, particularly if it is small and this approach fits with existing arrangements we have set in place, that allow our executor to release funds directly to them. However, if our executor was not prepared to release funds to them directly, an administrator may need to be appointed by QCAT.

Alternatively, and usually preferably, we can leave their share of our estate to them on trust. If we have set up an appropriate trust during our lifetime, one option could be to direct that their share goes into that pre-existing trust.

A “testamentary trust” - a trust created in a will

As noted above, when we leave a share of our estate to a child under 18, we cannot leave it to them directly - we must leave it to them on trust. We set up a trust in the will and appoint a trustee (or trustees) to administer the trust for their benefit.

If our family member with a disability has impaired capacity and is over 18, or is under 18 but we know they will not be able to manage their financial affairs when they have the legal right to do so on turning 18, we can set up a testamentary trust in our will that lasts throughout their lifetime.

Under a trust, money or property is transferred to one person (the trustee) to be managed by that person for the benefit of another (the beneficiary). The trust we set up needs to be tailored to meet the individual needs of our son or daughter with a disability. If we have not clarified our vision for what we want for them, and not developed a plan to bring that vision to reality, it may be difficult to design a trust arrangement that meets their needs. In any event, specific legal and accountancy advice will be necessary.

There are different types of trusts, including fixed trusts, discretionary trusts, hybrid trusts (a combination of fixed and discretionary) and special disability trusts. A fixed trust states clearly what the trustee must do, for example, give our son or daughter \$10000 per year. A discretionary trust gives our trustee wide discretion. It might direct the trustee to invest the funds and pay only the income to our son or daughter

with a disability, at the trustee's discretion, or it may allow the trustee to use both the capital and the income for their benefit, at their discretion.

The benefit of a fixed trust is that we can direct and limit the trustee's powers. We can exercise some control over how the trust funds are administered even after we are dead. The limitation of a fixed trust is that it is inflexible and does not give the trustee the flexibility they may need to address unforeseen circumstances in the lives of our son or daughter with a disability, or changes in law and government policy that might affect them. Regular payments of money are also likely to be interpreted as income.

A discretionary trust, on the other hand, allows flexibility to a trustee to manage tax and social security issues so that they have minimum negative effects. Note, however, that where the beneficiary of the trust is a pensioner, the trust may be treated as their asset. This means that it will be subject to the Centrelink (and Department of Veterans Affairs) assets test, unless it attracts the concessions available to a Special Disability Trust (see below).

A trustee under a discretionary trust can adjust the level of payments or financial support according to the needs of the beneficiary with a disability, rather than being forced to pay them a certain amount every year, regardless of their needs. Thus, a trustee with wide discretionary powers can save money to purchase expensive equipment, or to pay for a holiday, whereas a trustee under a fixed trust might not so easily do so.

The difficulty with a discretionary trust is that we need to place more trust in the trustees we appoint. The wider their discretion, the more we need to trust them.

One way of dealing with this issue is to direct that the trustees must administer the trust according to certain principles, for example the objects in the *Disability Services Act 2006* (Qld) or the principles in the *Guardianship and Administration Act 2000* (Qld). An example of a possible trust clause that includes this type of direction to trustees may be found at page 273 of *Include Me In: Disability, Rights and the Law in Queensland*, Queensland Advocacy Incorporated, 1994:

"To my trustee on trust to pay or applying during A's lifetime, from the income arising therefrom or from the capital thereof if the income should be at any time inadequate for the purpose such sum or sums as the trustee in his absolute discretion shall think fit to A or for or toward A's maintenance, advancement or benefit at such time or times and in such manner as the trustee shall think fit whether there shall or shall not be any other fund available for the same purpose so as to support and assist A to participate in society in a positive way in accordance with the principles and objectives of the Disability Services Act 1992(Qld), s 9, and from and after A's death, upon trust as to the capital by which the fund shall not have been expended and as to any unapplied income to B"

It should be noted that the law has changed since 1994. The objects of the Disability Services Act 2006 are found in section 6 of that Act. Alternatively, rather than referring to the Disability Services Act, reference could be made to the General Principles contained in Schedule 1 of the Guardianship Act (referred to above).

Another approach could be to specify that certain payments must be made on a fixed basis (eg, \$3000 for a holiday every year) while allowing our trustees broad discretion outside those specific directions.

Memorandum of Wishes

A very useful strategy is to write a Memorandum of Wishes. We can attach this to our will or include it within the will. A Memorandum of Wishes is not binding on our trustees but has considerable moral force and we can ask our trustees to read and sign it.

A Memorandum of Wishes sets out how we would like our trustees to use the trust fund for the benefit of our family member. We can include our vision for the sort of life we want our family member to have, what we want the trust funds to be spent on and, importantly, what we do not want those funds spent on (eg, not a group home or institution). We can make it clear that we want the trustees to support particular interests and passions of our family member, such as membership of their favourite football club, or an annual holiday at the beach with friends.

Additionally, we can state that we expect our trustees to take advice from a group of people who have the interests of our family member at heart. If we have set up a support circle, the circle members could take on this important role. Ideally our trustees will be members of the support circle.

Residual beneficiaries – when a trust comes to an end

When we set up a trust in our will, we must specify what will happen to any remaining trust monies when the trust comes to an end, usually when the beneficiary, our family member with a disability, dies. Typically, where parents have other children, they will want to nominate those other children, or perhaps their children's children (the parents' grandchildren) in the event that those children die before the trust comes to an end. Where they have given a larger share of their estate to their family member with a disability, parents might see this as a way of compensating their other children for the reduced share they initially received.

If there are no other children, or for some reason parents don't want to nominate their other children as residual beneficiaries (perhaps to avoid conflict of interest as trustees), they can direct that any remaining trust funds go to someone else or perhaps to a charitable organisation they wish to support.

Appointing trustees

A critical decision for many of us arises over the appointment of trustees. We can set up a substantial trust fund but without the right people as trustees, this will be of reduced value. Appointing the right trustees will be particularly important if we set up a discretionary trust. If we have developed a support circle around our family member with a disability, one place to look for trustees will be in that group of people. If we cannot think of potential trustees, this is yet another reason why we should consider the development of a support circle or broad network of people committed to our family member.

We should appoint at least two trustees and we can consider alternative appointees to step in when those we choose first are unable to perform the role. We should talk to the people we are choosing and make sure they are willing to take on the role.

In appointing trustees we should consider:

- people who have the skills and experience for the task – they don't have to be experienced financial managers but they should be comfortable with seeking and following advice from relevant professionals
- people of appropriate age – as we age, we need people younger than us
- people who will follow our vision and plans for the future of our family member, or at least take advice from those who support our vision
- people with minimal conflict of interest – be aware of the potential pitfalls of appointing people whom we have nominated as residual beneficiaries and make sure that at least one of our trustees is not a residual beneficiary.

“Inter vivos” trusts – established during our lifetime

It is possible also to set up a trust for our family member with a disability during our lifetime. These trusts are called “inter vivos” trusts. They are established by a deed of trust rather than a will and while they might be more complicated than a testamentary trust, and possibly more expensive to set up, they are similar in concept. Specific legal and accountancy advice needs to be obtained.

This sort of trust will probably only be considered if we have a substantial amount of money to put aside for the benefit of our family member with a disability before our death. It allows a specific amount of money or property to be set aside and used only for their benefit.

For example, an inter vivos trust might be useful to protect a share in a family windfall, perhaps through the sale of a large family property. Another situation where an inter vivos trust can be useful is where a relative, for example a grandparent, wishes to leave a bequest in their will to our son or daughter with a disability. If there is an inter vivos trust already in place they can leave the bequest to the trustees of that trust, rather than set up a separate trust in their will. An inter vivos trust also has the advantage that, when we die, there is money immediately available to our family member, rather than there being a period when access to assets is frozen until our estate is finalised.

Special Disability Trusts

In 2006 the Commonwealth Government brought in new laws that allow for the establishment of Special Disability Trusts. The key purpose of a Special Disability Trust (SDT) is to allow concessions to people with a severe disability and family members who rely on certain Centrelink or veteran's affairs pensions or allowances.

Following a Senate Committee Inquiry in 2008, the Commonwealth Government allowed some tax concessions and agreed to look at further concessions. In the 2010 Federal Budget, the Commonwealth made further changes, which took effect from 1 January 2011.

Unless it is a Special Disability Trust, assets in a trust set up for the benefit of a person with a disability will be treated by Centrelink and the Dept of Veterans' Affairs (DVA) as the assets of the person. Importantly, this includes a discretionary protective trust set up under a will. This means that the trust assets, and possibly trust income, will be subject to Centrelink/DVA assets tests and income tests, unless the trust attracts the concessions available to a Special Disability Trust. In relation to Centrelink, the current assets test (effective from July 2015) states that a single person receiving a Centrelink pension can have assets worth up to \$354,500 if they don't own their own home, or \$205,500 plus their home if they own their own home, and still be eligible for a full pension. The DVA assets test is the same.

These assets test limits increase each year. Any amount above those limits will be taken into account by Centrelink when deciding the amount they will pay as a pension. The income earned from the trust may also be subject to the Centrelink income test, which currently (July 2015) allows income of \$162 per fortnight before the pension for a single pensioner is affected. When a pensioner's assets and/or income go above these limits, their pension is reduced according to a sliding scale and ultimately they become ineligible for any pension payments.

Special Disability Trusts can be established during our lifetime ("inter vivos") or in our wills. There are specific rules that need to be followed, including that the trust deed must meet certain requirements. Only one Special Disability Trust can be established per person and only for a person with a "severe disability."

Severe Disability

For an individual to be considered someone with a "severe disability", the following rules apply [see section 1209 of the *Social Security Act 1991* (Cth) ("the Social Security Act")]:

- if under 16 they must be
 - a person with a severe disability or a severe medical condition; and
 - another person (the carer) has been given a qualifying rating of intense under the Disability Care Load Assessment (Child) Determination for caring for the child under 16 years of age, and
 - a treating health professional has certified in writing that, because of that disability or condition:
 - the child will need personal care for 6 months or more, and
 - the child care is required to be provided by a specified number of persons.
- if 16 or over, they must be
 - eligible for the disability support pension, and
 - because of their disability, not be working or likely to work for more than 7 hours per week at or above the minimum award wage (this does not include being on the supported wage), and
 - either living in accommodation funded by the Commonwealth/State/Territory Government or their disability must be such that it would qualify a sole carer for the Carer Allowance or Carer Payment.

Special Disability Trust expenditure – what trust funds can be used for

The primary purpose for which SDT funds can be used is “care and accommodation”. In addition to the primary purpose the trust may have other purposes that are:

- both ancillary to the primary purpose and necessary or desirable to facilitate the achievement of that purpose; or
- primarily for the benefit of the principal beneficiary.

Since 1 January 2011, payment of all medical and dental costs is allowed, as is discretionary expenditure.

Care and accommodation

Expenditure for “care and accommodation” includes:

- cost of accommodation and related expenses (eg, rates; maintenance)
- costs arising from the beneficiary’s disability, such as therapy, special foods, aids and equipment, communication devices, modified vehicles
- daily direct care and support costs
- consultations with medical practitioners and related costs
- medicines
- hospital expenses and surgery
- health insurance and ambulance cover.

Care needs must be met in Australia.

Discretionary spending

Discretionary spending allows special disability trusts flexibility to meet the additional costs relating to the beneficiary’s health, wellbeing, recreation, independence and social inclusion. Under the changes that took effect from 1 January 2011, up to \$10,000 per year discretionary spending “*to support social and community participation of the beneficiary*” is also allowed. This amount is indexed annually and currently (July 2015) is set at \$11,000.

Examples of possible discretionary expenditure include:

- food
- household items
- toiletries
- vehicle maintenance and expenses not related to disability
- recreation, leisure, holidays
- computers and other electrical equipment not related to disability
- therapy not related to disability
- household costs, insurances, utilities not related to disability
- household cleaning

- clothing and footwear.

Any of the above expenses which are related to the beneficiary's disability are payable under "care and accommodation".

Expenses relating to operating the trust.

Expenses incurred in operating the trust, such as legal, financial and accounting fees, bank charges and government fees, can be paid from trust funds.

Possible need for two trusts

Any item or expense that does not come within SDT fund uses cannot be purchased with funds from a Special Disability Trust. This means that some families will want to set up two trusts, even taking into account the expanded uses of SDT funds allowable since 1 January 2011. Setting up two trusts under a will (one a SDT, one an "all needs" trust) should not present any difficulties and is an issue to be discussed with legal advisers. An "all needs" trust could pay for expenses not allowed under SDT rules, but money and assets in an "all needs" trust will be assessed by Centrelink as the beneficiary's assets and the income from such a trust might be assessed as the beneficiary's income, depending on the trust provisions.

Concessions

If a trust meets the requirements of a Special Disability Trust, trust funds up to an allowed concessional limit will be exempt from Centrelink/DVA pension assets and income tests. This concessional limit originally was a maximum of \$500,000, but is indexed annually, so that currently (effective from 1 July 2015), this amount has increased to \$636,750. That figure does not include a home where the pensioner lives. Further, when trust assets are spent, they can be "topped up" to the maximum again. This means that if a Special Disability Trust was originally established with \$636,750 and \$150,000 is spent on accommodation for the trust beneficiary, the trust fund can be "topped up" to bring it back to the maximum concessional limit allowed, currently \$636,750.

Income from assets up to the maximum allowed concessional limit in the SDT is also not counted when assessing the individual's pension. However, income from the trust will be taxed and if any income is not spent in any one year, the unspent income will be taxed at the beneficiary's rate of income tax.

Gifts into a Special Disability trust

An additional concession is available to immediate family members who wish to gift up to \$500,000 (in this case not indexed) into a Special Disability Trust and still be eligible for their own (eg, aged) pension. Under social security and veterans' affairs gifting rules, a pensioner can gift only \$10,000 in a single year or \$30,000 over a five year period before the gifting rules apply and their pension is affected. Gifts above these limits are assessed as if they are the pensioner's asset.

Thus parents, or other "immediate family members", can transfer up to \$500,000 into a Special Disability Trust and still be eligible for the aged pension or DVA entitlement. This SDT gifting concession extends to gifts made within 5 years of eligibility for an aged pension or relevant veterans' entitlement.

For example, an elderly widow who receives the aged pension and has a son with a severe disability, wants to sell her home worth \$700,000, move into a retirement

village at the cost of \$250,000, keep \$50,000 for herself and give \$400,000 to her son to help with his support. The “gifting rules” stop her giving away more than \$30,000 over 5 years if she wants to keep her full pension. Giving \$400,000 to her son would also have an impact on his pension. By setting up a SDT for her son, she can sell her house, put \$400,000 in the SDT and neither pension is affected.

For the purpose of a SDT, “immediate family members” are defined by section 23(1) of the Social Security Act as:

- parents (including adoptive and step-parents)
- legal guardians of person with severe disability under 18 (or who were legal guardians when they were under 18)
- grandparents
- brothers and sisters (including adoptive and step brothers and sisters and half brothers and sisters).

Limitations of a Special Disability Trust

There are a number of limitations associated with Special Disability Trusts. These include:

- the definition of “severe disability” is restrictive and is likely to exclude some people for whom responsible families will want to set up a protective trust (eg, person working for award wages in open employment for more than 7 hours per week who needs assistance to manage their money; a family member with a mental illness whose disability is deemed not sufficient for a sole carer to qualify for the Carers Payment or Carers Allowance)
- trust funds can only be used for “care and accommodation”, medical and related expenses and \$11,000 (July 2015) discretionary expenditure, thus possibly leading to the need for two trusts to ensure that all the financial needs of the family member can be met
- once assets are in a SDT, they can’t be withdrawn or used for any other purpose
- only one SDT can be established per person – this could present difficulties for separated or divorced parents who each want to provide for their son/daughter through separate SDTs

Is a Special Disability Trust always needed?

There may be no need for a Special Disability Trust in your will unless you can leave a bequest to your family member with a disability that exceeds the Centrelink assets test limit. For example, a trust fund of \$250,000 will not be affected by the assets test if the individual has no other assets and does not own his/her own home. However, income from a trust fund of \$250,000 in a non - Special Disability Trust might have an impact on a pension, depending on the beneficiary’s level of control over, or benefit from, the trust.

Other issues with a Special Disability Trust – Public/Social Housing concession

The Queensland Department of Housing and Public Works imposes an assets test on eligibility for social housing (previously public housing). This test is very stringent

– a sole occupier of social housing may not be eligible if they have assets of \$87,125 (as at July 2015) or more and where two or more people occupy a social housing dwelling, their combined assets must not exceed \$108,250.00 (as at July 2015).

The Queensland Department of Housing and Public Works, like Centrelink, regards money held in trust as the beneficiary's asset for the purpose of assessing eligibility for social housing, unless the trust is a Special Disability Trust. Thus, even if the amount you can put in trust for your family member is less than the amount that would impact adversely on their pension, if they are living in social housing, or are likely to apply to do so, you might need to set up a SDT to ensure they remain eligible for social housing.

It is particularly important to obtain specific legal and financial advice before deciding whether to set up a Special Disability Trust. Further information is available from the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) - see www.fahcsia.gov.au - and follow link to disability and carers / programs and services / Special Disability Trusts.

Conclusion

While many people think first of wills, trusts and guardianship or money management when they worry about the future, I have tried to show that, while we can and should make a start on these issues, until we have developed a vision and a plan, we will not be in a position to finalise them. Even then, we will need to review our plans, our wills, and any other arrangements we have put in place, on a regular basis.

I have also tried to show the importance of the development of networks of people around our family members with a disability. With proper legal advice, there should be no difficulty in preparing appropriate wills and trusts to provide for family members with a disability, but without a committed network or support circle, it may be very difficult for some families to set up informal arrangements to assist with decision making or to find the right people to appoint as trustees and testamentary guardians. We need to attend to the legal issues when preparing for the time when we are no longer here, but it will be other committed people, not our wills and trust arrangements, that will keep our family members with a disability safe and able to continue to enjoy the life that we have worked hard to build and nurture for them.

Additional Information

1. For information about Pave the Way and details of Pave the Way workshops, information, resources and how Pave the Way works with families, visit the Pave the Way website - www.pavetheway.org.au.
2. Included on the Pave the Way website are a number of documents and information sheets related to planning. These include:
 - *From Dreams to Reality - Ideas and Strategies for Planning*
 - *A Document of Personal Information: Ideas and Strategies*
 - *Information Sheet: Preparing to Make a Will*
3. In addition to the Information Sheet "*Preparing to Make a Will*", Pave the Way has a panel of solicitors to whom families can be referred, as well as information about the availability of other professional assistance - phone 1300 554402 or (07)3291 5800 for a copy of this professional panel document.
4. For more information about PLAN visit their website – www.plan.ca.