

## Planning for now, tomorrow and the future

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### **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 paper is based on reflections on personal experience and the insights from many others. They are my thoughts and views and should not be taken necessarily to represent the views of Mamre Association. My thinking was stimulated by an opportunity to attend a Leadership Workshop in Western Australia in 2002, run by Planned Lifetime Advocacy Network (PLAN) from Vancouver, Canada, and by discussions with Gillian Chernerts from Toronto, Canada, who has over 25 years’ experience in citizen advocacy, cooperative housing projects and the setting up of support circles. These contacts have confirmed what I learnt 25 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 over the last 5 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 also learnt much from discussions with my colleagues in the Pave the Way team and the Pave the Way Reference Group.

## **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 – our family member who has 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. 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. We may take some time, and need some assistance, to clarify just what we do believe and value, but we need to 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 should be better able to direct and influence the debate.

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 and they will only want it revealed to 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	• healthcare
• relationships and friends	• financial security
• recreation, play, holidays	• 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.

Goals, action statements, priorities, timelines and review dates are important so that there is a clear process for implementing the plan that is understood by everyone involved. 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
- 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 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.

### **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 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 to develop a group of people committed to our family member who has a disability, who will stand by them when we can no longer do so, and even while we still can, is to develop a support circle or personal network.

## **Developing a support circle**

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

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 Chernets 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 whom 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 employ a facilitator to do the asking and to gather the circle together. Gillian 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 that 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. Gillian Chernets 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.*

## **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.

As individual families we need to give this issue focus in our planning. One strategy is to ask someone to be the 'keeper of the vision'. This would not be a formal appointment. It would be a request of someone we trust to be in our family member's life in the long term and to take on a role of ensuring that everyone else involved keeps to our vision and plans.

If we set up a support circle, we need to ask that group to develop and maintain a level of consciousness about the need for the support circle to be renewed and sustained in the long term. Regular reviews and discussions will help to keep this issue uppermost in circle members' minds. These are safeguarding strategies which are internal to individual family networks.

Some families have looked to external safeguarding strategies, such as setting up 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.

In Perth, a small group of families has established Personalised Individual Networks (PIN), modelled closely on PLAN in Vancouver. Like PLAN, PIN does not rely on government funding and so charges fees for families to become life members.

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, proposes 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 at Mamre continues to investigate these strategies and any others that provide ideas for how we might best approach this issue in Queensland. Pave the Way works with families throughout Queensland assisting them to develop and safeguard their vision and plans for a good life for their family member, now and in the future.

Unlike PLAN and PIN, 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 provisions for guardianship and financial management. These are important but, in my view, they come after we develop our visions and plans, not before. Legal mechanisms are tools to assist us with planning, not ends in themselves.

Whether or not our family member needs a formally appointed guardian or financial administrator/manager may depend on whether they have a committed group of people around them who are willing to assist them with informal decision-making. Australian Guardianship legislation encourages informal decision-making. 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 know what we want to do 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 able 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 strategy to develop potential trustees is to develop a network or support circle. Until we have set up a network or support circle, we might not be able to finalise the trust arrangements that we want.

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 when our plans are finalised, than to die without a will.

### **Finally .....**

There are no quick or easy solutions to planning for the future. What is essential is that we have a clear vision of what we want to achieve and not be driven by the views of others or the limits of what others say is possible. We don't need funding, services, or governments to assist us to develop our vision and plans.

Developing a vision and planning takes time, energy, commitment and courage. While it is important to start planning as early as possible, it is also never too late to plan. We need to plan to include others in the lives of our family members, to invite others in, in the belief that it is people who keep people safe. In the end, comprehensive, whole of life, vision driven planning allows families to set their agenda.



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