

PAVE THE WAY



FROM DREAMS TO REALITY -

Being clear about a vision for a good life for someone, involves being clear about what is wanted, and just as importantly, what is not wanted, in their life now and in the future. It is often simply a case of naming the ordinary but essential elements of life such as having people who love and care about us, a place to live that is really our home, an opportunity to be known and valued in our community, and being financially, physically and emotionally secure.

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*Ideas and
strategies for
planning*

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INTRODUCTON

Pave the Way's vision is that people with disability throughout Queensland will be supported and safeguarded by their family and important others to achieve a good, secure and meaningful life both now and in the future.

Pave the Way works with families throughout Queensland to clarify their vision for a good life for their family member with disability, to plan towards making that vision a reality and to develop ways to sustain that vision when the family is no longer able to do so. We work developmentally with families to build their own capacities and offer information and resources rather providing case work, advocacy or service development.

We focus on family directed, whole of life, long term planning rather than service planning. We focus also on the importance of developing safeguarding strategies for people with disability including the importance of having other people aware of, and involved in their lives.

"From dreams to reality: ideas and strategies for planning" outlines the approach Pave the Way takes to assisting families with planning.

The future is going to happen. Rather than simply let it happen, or let other people decide the sort of life our family member will live, we can plan for the future that we want.

Many families who have a son or daughter or other relative with a disability are worried that they will not be able to continue to provide the main support for them in the long term.

We can deal with this worry in many ways. We can ignore it or remain paralysed with fear. We might expect that the government or some service will step in. We can live in the unspoken hope that our other family members will be there. And sometimes we do nothing in the belief that we have to have funding before we can begin to think about the future. If we do these things we often also ignore what is happening in the present.

Another way of dealing with these concerns is to plan for the future that we and our family members want.

Planning – more than problem solving

Once we accept that planning is a good idea we often want to find quick solutions to problems in our family member's life: where will they live, who will be their friends, what will they do every day when they finish school?

Good planning, however, is more complex than immediate problem solving. Good planning starts with preparation. Rather than rushing into quick solutions to problems, we need to be clear about the big picture. What kind of life are we imagining for the person we are planning with and for? What is the vision for their best possible life? It may take time to do this preparation but our planning is more likely to be successful in creating a good life for our family member if we take time to clarify our vision and beliefs.

A clear vision – the basis for good planning

Being clear about a vision for a good life for someone, involves being clear about what is wanted, and just as importantly, what is not wanted, in their life now and in the future. It is often simply a case of naming the ordinary but essential elements of life such as having people who love and care about us, a place to live that is really our home, an opportunity to be known and valued in our community, and being financially, physically and emotionally secure.

For most people, the right to such a life is taken for granted. In the case of a person with disability, however, to want these things is often seen as having extraordinary hopes and dreams. Creating such a life can be much harder than it is for people without disability. It is important then to be clear about what we really believe – what our vision for life really is. For family members it is also important to listen to what the person themselves is saying through their words, feelings or behaviour. It is time to think 'big' and not be afraid of challenging our own or other people's prejudices or limited beliefs of what a person with disability can achieve. The details of what constitutes a good life will not be the same for everyone and might well change over time. It is important, however, to start planning for the essential elements of life with the clear conviction that this is worth achieving for everyone.

Where to start

When we are planning with and for a person we love and care about we need to be clear about the starting point. Planning needs to be based on a clear vision for the best possible life for that person as a unique individual:

- Who are they?
- What are their skills?
- What are their gifts?
- What are their passions?
- What is in their life now?
- Who is in their life now?

If our planning is based on the person - what they like and enjoy, what they offer to others, their personal health and safety - then we are more likely to create a future that meets their individual needs; a real life future. If our planning is based on the problems we see then we are likely to create a future that simply "solves a problem". Organising activities that simply fill a day could solve the problem of what our young person will do when school finishes. If we want a life for them that is more fulfilling, however, we need to plan for work and recreation that the person loves and finds meaningful.

Planning in this way takes time. Whether we start early or late in a person's life we need time for everyone involved with our family member to get to know them well enough to work together to plan for a good and whole life.



"PLANNING FOR THE PERSON, NOT THE PROBLEM"

When someone suggested that she and her daughter move into a nursing home together Joan and other members of the family knew that this might solve the problem of where Clare might live but this idea did not fit at all with the vision Joan had for Clare's future. (Read this story in Appendix 1)

What is planning?

Planning is a way of making concrete our hopes and dreams for the future.

At Pave the Way we talk about planning as family directed, whole of life, long term planning, not service planning nor planning only for the purpose of applying for funding. Many families have found, however, that thinking ahead and planning with a clear vision for a good life may be helpful when the opportunity to apply for funding becomes available.

Planning can be an intentional, structured process that helps people set clear goals and actions to achieve these goals. It can also be a state of mind that influences our everyday thinking.

Planning – a state of mind

Planning is an ordinary thing. We all plan to make things happen, consciously or not. When we go on holidays, for example, we plan. We have an idea of where we want to go; we find out about best airfares and places to stay; we organise leave from work and perhaps make arrangements for the pets to be looked after. We may talk to other people who have been where we want to go.

In the time leading up to when we leave, preparation for the holiday can influence decisions we make every day. We design our work knowing that we will be away for some time; we shop knowing that we don't want to leave the fridge full of food; we might be more budget conscious knowing that it might be better to have more money for the holiday rather than spend it unnecessarily now.

Of course it is often the unexpected, unplanned possibilities that can make a holiday wonderful but if we don't plan to get away in the first place the unexpected opportunity won't arise.

Planning for the future for our family member with a disability can happen in the same way.

Planning can be an intentional, structured process or the state of mind kind of planning that influences our everyday thinking and choices. It works best when these two types of planning work together. We might work out our vision and goals in a structured planning session but we need to ensure that our vision and goals then influence the choices we make every day for our family member.



"PLANNING AS A WAY OF THINKING"

"When you are committed to a certain expectation for a way of life, you get to see the opportunities that present themselves."

This story shows that having a clear vision for the kind of life they want for their son has helped this family make decisions when everyday opportunities arise.

(Read this story in Appendix 1)

Structured planning – what does it look like?

Planning with a group of people you know and trust can be very helpful. Ideas are shared; everyone present is able to focus on the issues at the same time and to share a common understanding of the words and ideas used to talk about what the best life for the individual might look like.

“We always knew that this conversation had to happen so it was great when the family and a few close friends finally got together to talk about what Mum and Dad hoped would happen for Ben when they are no longer around.”

There is no magic or recipe to planning. Each session will reflect the style and needs of the family involved. Pave the Way does not use any particular planning program or planning tool. It has developed a simple planning process that can be adapted to meet individual family needs. Families have found this process helpful as means of guiding the discussion and keeping the planning on track.

It is helpful to record ideas visually in lists, tables and other diagrams so that everyone in the group can see and follow the discussion. These notes can become a record of the planning outcomes that is then left with the family.

Planning sessions

- are usually led by a facilitator to allow the family and the people invited to concentrate on the discussion
- follow a structured process that guides the group through stages of thinking
- usually last for about 2 or 3 hours.
- may require more than one session

Before the planning

The facilitator will meet with the family to prepare for the planning session. The discussion will include

- the family's expectations of the planning session
- the process to be used
- who to invite to the planning
- how to invite them

The process

The facilitator will lead the group through discussions which:

- highlight the unique gifts and individuality of the person whose life is the focus of the planning
- clarify the vision that the person and their family have for the future
- identify goals based on the vision
- list actions to begin to achieve these goals.

The facilitator will also ensure that

- the family is comfortable with the design and style of how the planning is done
- planning remains focused on the person's whole life, not limited to planning around the services in their life
- a record is kept of the planning so that the family can refer to and build on this planning in the future

After the planning

The facilitator will contact the family after the planning session to “de-brief”. This will also be an opportunity to talk about any further planning assistance you may wish to request from Pave the Way.



"Having the facilitator guide the discussion seemed to allow my other children to say things they had been thinking about...things they could not say directly to me or my wife. We were quite surprised and encouraged by the depth of their thinking."

You can read an example of notes from a Pave the Way planning session in Appendix 2.

Inviting others

One person can plan by themselves. A couple can plan successfully together for their son or daughter. There is particular power, however, in inviting others to be part of your planning. Having trusted others involved:

- allows greater input of ideas and perspectives
- encourages ownership of the plan by people who have been part of the thinking
- is critical to the ongoing implementation and safeguarding of the plan because other people are committed to it.

Who to invite

- there are no rules to the numbers of people – just one other person is the start of including others in your thinking and planning
- include family members who often appreciate a way to be involved
- consider close friends and people who have shown an interest in your family member
- people who may take on formal roles in the future eg trustees



"OUR EXPERIENCE OF PLANNING"

A family writes about the experience of their first group planning session. Read this story in Appendix 1.

Planning sessions and circles of support

Inviting other people to be part of a planning session is not the same as inviting people to be part of an ongoing network or circle of support. Some families invite people to plan with them at regular intervals each year or when they see a need to think through issues that may be arising. The planning group may vary each time they meet. Other families have an ongoing support circle. Planning together in a structured way is one role the circle can play.



You can read more about inviting other people to be involved in planning or to be part of an ongoing support circle in Appendix 3.

What Pave the Way can offer

Pave the Way offers information about planning through workshops or at an individual level to families. We can also facilitate planning sessions.

Workshops

The following workshops deal specifically with the theory and process of planning:

- 1 day workshop: "*Planning for Now, Tomorrow and the Future*". An introduction to the ideas of vision and planning
- 2 day live-in workshop: "*Vision and Planning*". A workshop offering a longer opportunity to explore what it means to become clear about the vision you have and how to plan for this. Includes an opportunity to see an example of a planning session in progress
- 6 day live-in workshop: "*From Visions to Action through Planning*". A more in-depth experience of working through clarifying the vision which becomes the basis of planning. Held over two long weekends, a few months apart. Participants are offered the chance to invite others to be part of a planning session facilitated by a Pave the Way staff member on the second weekend.

The following workshops are designed to assist families to deepen their understanding of planning and to implement their planning strategies.

- Rolling Conversations
Held over 3 – 5 sessions this series reviews the key concepts underpinning Pave the Way's work and assists families to identify strategies and practical ways to apply the information and ideas to their own situation.
- Developing a Document of Personal Information
A practical, facilitated workshop designed to provide a starting point for families to discover the benefits of developing a Document of Personal Information as a way of involving others, sharing important information and as a safeguarding strategy.

You can find out more about the workshops by looking at the [Workshop Overview](#) on Pave the Way's website. The [Workshop Calendar](#) is updated regularly on our website.

Individual assistance:

A Pave the Way staff member can:

- Meet with you to discuss the sort of planning session you would like and who you would like to invite
- Facilitate one or more planning sessions
- Meet with you after the planning session to "de-brief" and check how Pave the Way might be able to assist further.

"The reality is that the full and positive lives of people with disabilities that we hear and read about do not happen by accident. These inspirational stories can be told because someone had a vision and belief in what is possible, sometimes against considerable opposition, and planned to make it happen." (Jeremy Ward)

If you would like more information about planning, or would like a Pave the Way staff member to facilitate a planning session please, contact us at 07 3291 5800 or 1300 554 402 or through the website: www.pavetheway.org.au.

Further Reading

Pave the Way Resources:

Bourke, Sharon "*Building Intentional Lifelong Safeguards*" This resource about inviting other people to be involved in planning, networks and circles of support is currently being developed and will be available on our website or by contacting Pave the Way.

Ward, Jeremy "*Planning for Now, Tomorrow and the Future*". A resource outlining Pave the Way's approach to clarifying your vision for the future and planning to make it happen. Available on our website under [Resources](#) or by contacting Pave the Way.

Other Resources:

Dyke, Jan "*Choreographing the Future*" Families from the Homes West Association share their understanding and experience in thinking through eleven key elements that they believe will help assure the future for their sons and daughters. The article was written by Jan Dyke from content produced at a workshop she facilitated for Homes West families in 2005. The article is available on the Pave the Way website under [Resources](#).

Etmanski, Al "*A good life for you and your relative with a disability*" An easy to read but comprehensive book about what is important when thinking about the future for a person with a disability. Written for family members by Al Etmanski, a Canadian parent and author who started the organisation PLAN – Planned Lifetime Advocacy Network. This book is available to order online [at www.plan.ca](http://www.plan.ca) or for Australian readers <http://www.cru.org.au/books.htm>

Safe and Secure: creating a future plan for your relative with a disability A resource from the Western Australian organisation, Planned Individual Networks (PIN) which is based on the Canadian organisation PLAN. The resource is specific to the Western Australian legal and state government environment but the general ideas about planning would be useful for all families www.pin.org.au.

APPENDIX 1 - Family Stories

Planning for the person, not the problem

Having a shared a vision for her daughter Clare's future made it easy for Joan and her planning group to discount one suggestion for where her daughter might live.

Joan lives with her daughter, Clare, and together they have a good life worked out. However, Joan was beginning to be concerned about the time when she could no longer do the amount of personal care she now does for Clare. She was also worried about what might happen if she was suddenly taken ill or died. She had recently spent some time unexpectedly in hospital and realised that, although there were many people who cared about her and Clare, no one knew much about what to do for Clare each day. After worrying about this for some time she eventually invited some of her family and friends to meet together to start planning.

The first few meetings were spent sharing what each person knew about Clare and gauging what she thought about their ideas of what she enjoyed doing and what she might hope for in the future. Although everyone knew Clare fairly well the sharing of stories and ideas showed that the group could be more effective than each person individually in supporting Joan to work out what she and Clare might do in the future. The also realised that their talking and planning was beginning to positively influence what was happening for Clare right now.

One important role for the group was to help Joan put together all the knowledge she had about Clare's life – what she enjoys doing, her daily and weekly routine, her medical information, how to use the equipment needed at home and when travelling. This was developing into an important document for family, friends and support workers.

Another area of discussion centred on where Clare might live in the future. Someone had suggested to Joan that Clare might be able to move into a retirement home or hostel with her. At first some of the group thought this could be one solution to the problem of where Clare would live. Joan and others in the group, however, were not convinced. They could see that it could "solve the problem" but it would not suit Clare at all. One member of the group, Michael, reminded everyone of the earlier discussions they had about Clare and what she enjoyed in life. Michael reminded them that Clare loves hearing and feeling familiar people around her. She particularly loves it when the children of family and friends visit her. She loves to go out often and likes listening to rock and roll music from the 50s and 60s.

Sandra, a daughter of one of Joan's friends, agreed that the plan of living in a retirement home would not be good for Clare. Sandra works in Aged Care and spoke from her experience. She told the group that the "small print" rules of many hostels and retirement homes would not allow Clare to live the kind of life that gives her enjoyment nor provide the security of having people around her who know and love her. The group agreed that, based on the vision Joan had for Clare's future, and the kind of life they knew she would want for herself they had to consider other ideas.

(Names of the people in this true story have been changed.)

Planning as a way of thinking – one family's story

"When you are committed to a certain expectation for a way of life, you get to see the opportunities that present themselves."

Planning is such a strange word, isn't it? At first glance I think of planning as getting out the calendar and organising my family. For this article, however, I was asked to write about how my family planned to get to where we are and so I had to reflect on what planning really means.

I think for us planning is committing to what is in our hearts and then putting that into action. In order to put it into action though, we need to be able to articulate what it is we really want.

This journey of becoming clear about what we want and planning to put it into action began for us when my son was in special school in Victoria. Don't get me wrong – the people there were lovely and they certainly were well resourced, but my heart was telling me that this wasn't what was in Dale's best interests. It took a few years to work out what was in my heart. I really had difficulty being able to articulate it. Instincts can be funny things.

When we started the journey to mainstream school there were a lot of barriers and hurdles to overcome and it was made all the more difficult because I could only act on what was in my heart. It's very difficult to convince educators that "it's just not right" and not be able to articulate why or how. We had to get back to the nuts and bolts of it, and work out what it really was that we wanted for Dale. We decided that what we wanted was for Dale to lead a typical and full life.

In order for Dale to have a good and typical life we had to really think of what it was that made up a typical life. Some of those things were having a job, having your own home, friends, family and an active life. When it came down to it, it became clear that a special school experience would not enhance those aims. In fact it would get in the way. I then immersed myself in a culture that supported our ideals, by meeting other parents through Qld Parents of People with a Disability and going to heaps of events that gave us more information. I attended conferences, got involved in QPPD activities, and made a pest of myself with parents who had already gone before us and were also committed to this ideal. I also started working in the area of disability to get an idea of what we were dealing with.

Since moving to Brisbane, Dale has been in a small Catholic school where mostly he has had an inclusive education. There are always things that go wrong but with information and learning from other supportive parents, some great teachers and other allies, we have managed to get him through to grade 7 with some semblance of an education. Next year he will be attending a mainstream high school and although this is really scary, we are confident that this will also be a mainly positive experience.

Our family has had to sit down regularly and look at what Dale needs to be involved with in order to support our ideal of him having a typical life. He needs people around him, and needs to be involved in community activities. Dale is in scouts and gets to do great stuff with that, he has played soccer and AFL and is currently learning bass guitar. As a family we have moved around a lot so community is not something we have known too much about. We haven't had any family around either. We have great neighbours now, though and have made a decision to stay put in order to enhance these opportunities.

When you are committed to a certain expectation for a way of life, you get to see the opportunities that present themselves.

Last year Dale attended one of the Sony Foundation Children's Holiday Camps held at a local boy's college. Dale had been offered this opportunity for the last few years and I had resisted it as it is only for children with disabilities. This didn't fit our ideal of a typical life. We figured Dale needs to go on "normal" camps with scouts or with school. However, this time we thought it would be OK as the Sony camp offered some great activities and Dale would be buddied with a year 12 student from the school.

Dale's buddy turned out to be a great young man. He had a good rapport with Dale and really saw his potential. He also seemed to enjoy Dale's company. They bonded really well. Seeing an opportunity here, I asked him if he would like to hang out with Dale sometimes. He had just finished year 12 and was going to university so we knew that he would be quite busy but fortunately he agreed. He now goes to scouts with Dale and goes on camps with him.

Since then we have been able to get some financial support from our family support agency, the Mamre Association, to actually employ Dale's buddy. This had given us more consistency in the times he spends with Dale and we now feel that we can ask him to do specific things. Mamre negotiated the employment role which was a really important thing for us. What if he said no? Could I handle the rejection on Dale's behalf? It was challenging enough just asking him to hang out! Having someone else do the asking gave us a buffer against some of these concerns.

Part of the role involves assisting Dale to connect with others. An example of this is at scouts where Dale met another young man. The support worker gently kept the conversations going between the boys and eventually Dale and Ben had dinner together. They are still good mates.

When I tell other parents whose children attended that camp about this, they were surprised and told me that they wished they'd thought of it. Their kids had bonded well with their buddies as well. But we saw the opportunity because we visualised a certain way of life for Dale, and had a commitment to making it happen.

This to me, is planning. Sometimes opportunities come out of the blue, sometimes you have to chase them. But if the big picture is firmly in mind, then the steps get lit up on the way.

We have recently needed to ask Mamre to help us take the next step. We have realised (painfully) that any family has the right to thrive. With the pressures facing us at the moment, we have had to drop our expectation of "doing it all ourselves" and asked for help to move things forward. The next planning step for us is to get more people sharing our ideal for a good life for Dale, and having those people share the safeguarding role in that. We have decided to attend Pave the Way's six day workshop, "From Visions to Action through Planning". It's a big step for us, but it fits the big picture so we know that it's right. It's a plan.

Our Experience of Vision Planning

Lou and Jeanette Micallef write about their experience of a planning session held as part of Pave the Way's Six Day Workshop, "From Visions to Actions through Planning". This workshop is held over two long weekends, a few months apart. The first weekend offers an opportunity for people to spend time together as a couple, and as individuals, to think about their son or son or daughter or other family member with a disability and to become clear about the best possible life they can imagine for them. The second weekend is about how to use these ideas as the basis for planning so that their vision for the future starts to become a reality. On this weekend people are encouraged to invite others they know and trust to join a planning session facilitated by a Pave the Way staff member.

The idea of Vision planning had been a part of our thoughts for quite a few years. Work commitments did not allow enough time for both of us to come together to share. Although we had participated in a 2 day Pave the Way Workshop in 2005 and it had made us aware of future possibilities, the task seemed daunting. The Big Question – Where to start? We were not sure what we wanted to do or what we needed to put into place.

When an expression of interest for the Pave the Way 6 day Workshop came along, we jumped at the chance to start the process again. There were less commitments on our time, we both felt ready and saw that there was an opportunity to start the actual process.

Extra incentives – 'Pave the Way' offered assistance and guidance in all aspects. We were ready and wanted to get 'something' done. A working result was our expectation.

For us, starting small seemed the best option to achieve success in getting a planning group going.

We invited –

- Faye, our daughter with a disability, because we felt she understood enough to have an input into her future.
- Our two other children because we felt confident in their understanding of the problems we faced and also we wanted them to be aware of the process we wanted to begin.
- A family friend who we trusted to have a good understanding and provide input.

All were eager to participate.

The process had been explained to us before hand and the meeting was relaxed, easily paced with small breaks and everyone felt comfortable. The time went really quickly and we hoped we could get enough done.

We set some long term and short term goals. Each person took on tasks they felt able to accomplish. A process was established to be continued. All information was documented and shared. Now there are 6 people aware of what needs to be done.

Our challenge is to continue the process – hopefully with the urging of our 'helpers'. As the process becomes documented and more people become aware, it will become easier for others in the future to work together, and with Fay, to ensure the best possible life for her.

APPENDIX 2 – Notes from a Planning Session

Notes from a Planning Session

The following notes are designed to show what a planning session might look like. The scenario is completely fictional but the ideas represented here are based on real planning sessions with families over a number of years. The method used to record the information here is only one example of a variety of different formats that can be used to capture and record the thinking of the planning group.

A planning session like this could happen over 2-4 hours depending on each family and the areas on which they wish to focus. While some families may be ready to move through each stage of this planning process in one session others may simply wish to look at the first stages of getting to know the person and identifying the vision they, and their family, have for the future.

Each family is different and there is no one way to approach planning.

Planning Scenario

Jackie is a young woman aged 19 who lives with her parents and two younger sisters in the family home. Jackie left school 12 months ago.

She spends her weekday mornings working with her mother, Joan, in her home based computer business, taking calls on the phone, doing some filing and trying out any new computer games that her mother orders in. Jackie also helps her father, Steve, prepare the dinner most evenings after he comes home from his job as a social worker with Centrelink. She can now make simple meals with minimal supervision.

Jackie still has occasional contact with two friends from school but otherwise has no close friends. She gets on well with her younger sisters, aged 15 and 13, and also with some cousins who now live interstate. She spends most of her weekends with her sisters, listening to her favourite music or watching DVDs.

Jackie was diagnosed with a mild intellectual disability when she was three and always struggled to learn at school. She also has some hearing loss and experiences difficulty managing money. She understands enough to go to the shops by herself but usually spends any money she has very quickly, mostly on junk food. She likes to get on with people and will give her money away to other young people she wants to be friends with. She has put on quite a lot of weight since leaving school and needs some help with personal care.

Jackie's parents are keen for Jackie to have a full and interesting life and have been working on what they call their "mission statement" for her. Perhaps Steve has spent too long working in the Public Service! After quite a lot of discussion between themselves, and one gathering with some close family members when they visited for Christmas, they came up with the following:

We want Jackie to live an interesting and good life, surrounded by people she loves who care about her. We want her to have fun, to be safe, to have the opportunity to live in her own home and to make a contribution to society through work and other roles she might play in the community.

Jackie's parents want to take this vision for Jackie a bit further and have asked some close friends and relatives to help them. Jackie gets embarrassed when other people talk about her and has chosen to go to the movies with her younger sisters instead of coming to the planning session. Joan and Steve have talked to Jackie about her life and she says that she wants "to have fun, to find a boyfriend, to have her own place like her cousin Ben in Melbourne, and to work in a fashion store like the one where one of her friends, Sarah, from school now works. After the planning Joan and Steve will talk to Jackie and her sisters about what came out of the planning session and ask them to add their views.

The planning session has been going for 1½ hours and the group has just come together again after stopping for afternoon tea. The group is made up of Joan, Steve, Rose (old school friend of Joan) and Natalie, the oldest of her interstate cousins who is visiting during her University mid-year break. Joan and Steve chose Rose because she is a trusted friend who is not afraid to play "devil's advocate" and can "manage" Joan if need be. They chose Natalie because she is from the younger generation and looks out for Jackie's interests. They timed this planning session to coincide with Natalie's visit to Queensland so that she could be present.

Before afternoon tea the group talked about basic ground rules for the planning session; their expectations for the planning session; who is Jackie (her gifts, strengths, challenges, likes and dislikes) and what is happening in Jackie's life now. The group talked about their worst nightmare and their hopes for the "best day" for Jackie. They then looked at Jackie's vision for herself (as told to her parents) and the family's vision for Jackie. Notes from these discussions are set out below.

The next step will be to look at some goals for Jackie, by referring to the different aspects of her life, and then to develop some strategies, or actions, aimed at working towards achieving those goals.

Let the planning continue!!

GROUND RULES

The facilitator works with each group to negotiate how they want to interact as a group. These form the “ground rules” for the planning session.

EXAMPLE

- Confidentiality
- Listen to others
- Keep focused on Jackie
- Keep to the time
- Remember Jackie is not here – what would she say?
- Respect others

EXPECTATIONS

The facilitator may meet with the family beforehand to talk about the expectations they have of the planning session and how it will all happen. When the group meets, each person may be asked for their expectations of the session.

EXAMPLE

- To learn more about what the family wants for Jackie
- To learn more about Jackie
- To end up with some practical strategies
- To move forward
- To feel we are getting somewhere

WHO IS JACKIE?

The focus of the planning session is the family member with a disability so it is important to start with a clear picture of who the group is planning for.

The facilitator invites people in the group, including the focus person if they are present, to talk about what they know of the person – their gifts and talents, the relationships they have in their life, the roles they carry out, the things they are interested in as well as the challenges he or she faces in life.

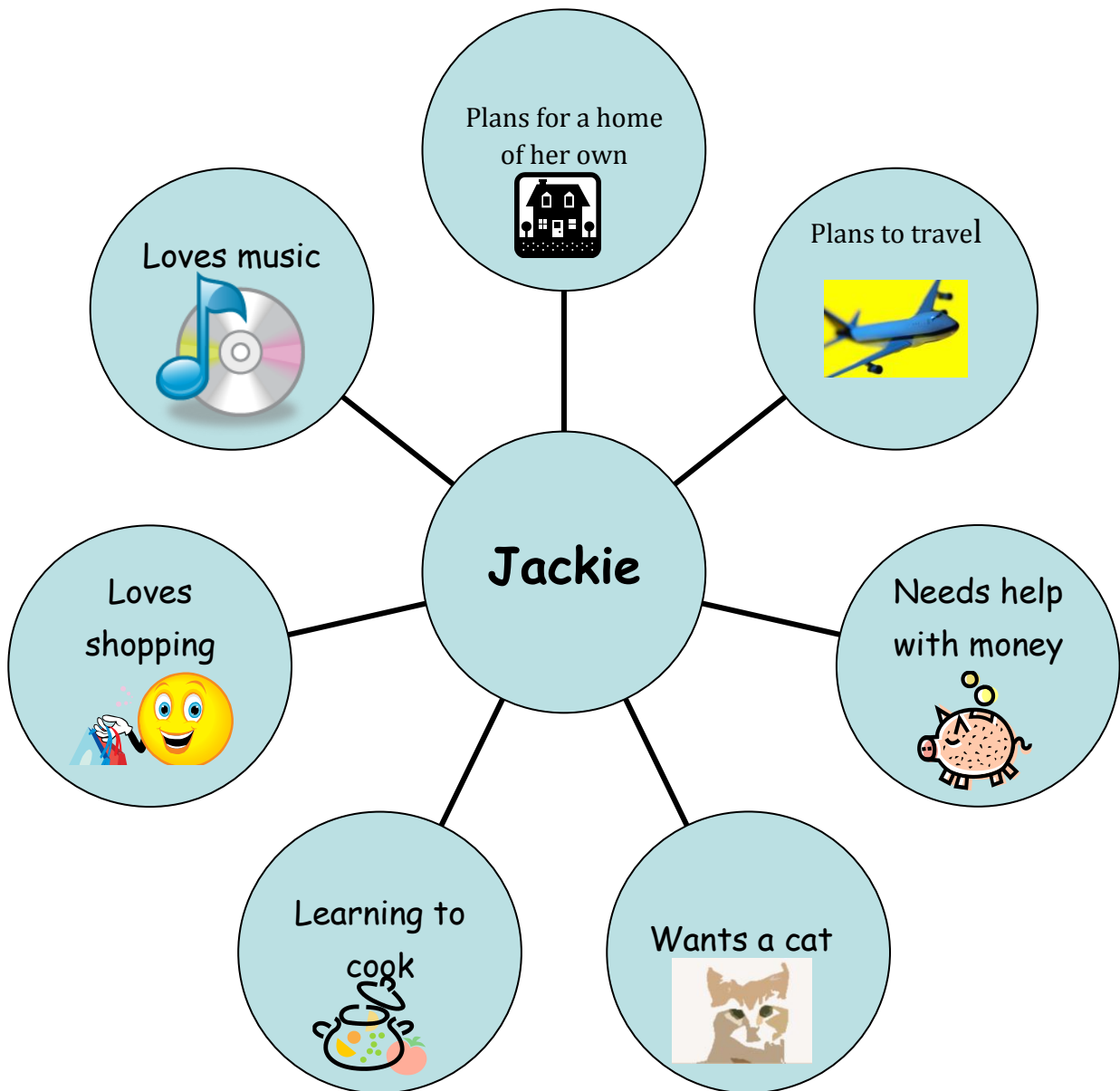
EXAMPLE 1

<ul style="list-style-type: none"> aged 19 	<ul style="list-style-type: none"> oldest sister – very loving towards 2 younger sisters
<ul style="list-style-type: none"> female 	<ul style="list-style-type: none"> loving daughter
<ul style="list-style-type: none"> good friend 	<ul style="list-style-type: none"> likes dance music
<ul style="list-style-type: none"> is pretty 	<ul style="list-style-type: none"> likes boys
<ul style="list-style-type: none"> likes DVDs (music, teenage movies ...) 	<ul style="list-style-type: none"> loves shopping
<ul style="list-style-type: none"> likes clothes, jewellery 	<ul style="list-style-type: none"> collects elephants
<ul style="list-style-type: none"> assists with the family business 	<ul style="list-style-type: none"> learning to cook
<ul style="list-style-type: none"> has household responsibilities 	<ul style="list-style-type: none"> has plans – to travel, to have her own unit
<ul style="list-style-type: none"> needs help with money 	<ul style="list-style-type: none"> needs some help with personal care
<ul style="list-style-type: none"> wears a hearing aid 	<ul style="list-style-type: none"> wants a cat
<ul style="list-style-type: none"> easily pressured by others, especially young people 	<ul style="list-style-type: none"> wants to be treated like everyone else
<ul style="list-style-type: none"> putting on weight 	<ul style="list-style-type: none"> hates dogs

This same information could be recorded in different ways. Visual forms of recording like flow charts and planning webs may appeal more to people than lists and tables. Using simple drawings as well as words can be particularly helpful for people who have difficulty with reading.

WHO IS JACKIE?

EXAMPLE 2



WHAT IS HAPPENING FOR JACKIE NOW?

People are invited to brainstorm everything that is happening currently for the person and also what is not happening. For example, where they live and work, things they do in their spare time, people they spend time with, the responsibilities they have in their life.

EXAMPLE

<ul style="list-style-type: none">left school – now at home a lot	<ul style="list-style-type: none">no spontaneous contact with friends
<ul style="list-style-type: none">helps prepare dinner most nights	<ul style="list-style-type: none">goes to the movies, usually with sisters
<ul style="list-style-type: none">listens to music	<ul style="list-style-type: none">watches DVDs
<ul style="list-style-type: none">not much happening on weekends	<ul style="list-style-type: none">goes to shops
<ul style="list-style-type: none">goes to Blue Light Disco every Friday night	<ul style="list-style-type: none">works in family computer business five mornings a week

JACKIE'S VISION FOR HERSELF

The facilitator will ask the focus person to talk about their hopes and dreams for how they see their life both now and in the future. If the person is not present or is unable to communicate then the family may express what they imagine their family member's vision for their life to be.

A brainstorm of ideas is often a good way to start. This may then be written up as a statement.

EXAMPLE

- To have fun
- To spend time with friends
- To find a boyfriend
- To have her own place like her cousin Ben in Melbourne
- To work at a retail shop ie music, fashion

FAMILY'S VISION FOR JACKIE

A similar process, asking the family to express their vision for their family member.

EXAMPLE

- To live an interesting and good life
- Be surrounded by people she loves who care about her
- To have fun
- To be safe
- To have the opportunity to live in her own home
- To make a contribution to society

DREAMS AND NIGHTMARES

The facilitator will invite the group to describe the best day and worst day imaginable. It is equally important to name both in order to be clear about what you want and what you don't want and need to safeguard against. It can be a difficult moment in the process but the exercise acts as a sharp reminder of the potential for harm and extreme vulnerability on one hand and the potential for enormous growth, development and opportunity on the other.

EXAMPLE

BEST DAY

- Jackie enjoys living in her own home, with or without a flat mate of her own choice
- Jackie is doing the sort of work she likes – proper job with pay
- Jackie has friends who care about her and who phone or drop in spontaneously to see what she wants to do on the weekend
- Jackie is safe and healthy
- Jackie has the right people around her, with the right values, understanding and intentions who support her in decision making and with her personal care needs

WORST NIGHTMARE

- Jackie is overweight and very unhealthy
- Jackie has no one to look out for her – no one who cares
- Jackie is bored and frustrated with little to do that interests her
- Jackie is abused – financially, emotionally and sexually
- Jackie has only paid carers in her life – no friends her own age

VISION TO GOALS – ASPECTS OF LIFE

The facilitator will invite people to nominate goals for some of these aspects of life. Once the goals are listed the group then decides the order of priority for taking the goals to the next step of planning.

The list is not definitive but it is a reminder that the planning is for the whole of life, not just for the area in which services assist the person. Another aspect of life that some people have used, for example, is "communication".

Goal	Priority	Goal	Priority
Home		Spirituality	
Work Jackie is working part time in a retail shop (fashion or music)	****	Healthcare That Jackie becomes fit, has good health and loses 10 Kg in 12 months	***
Relationships and friends That Jackie makes 2 or 3 good friends who are committed to her	**	Financial security	
Recreation, play, holiday	*	Decision-making	*
Passions		Safety and security That Jackie is safe and secure in all aspects of her life without having to rely on her parents	**
Education		Other	

PLANNING TEMPLATE

After identifying goals it can be helpful to think about the role of paid and unpaid supports in reaching these goals. The facilitator asks the group to reflect on what can be achieved through paid supports (Funded \$\$), other financial contributions by the individual, family or others (Unfunded \$\$) or by people in unpaid roles (Informal network). As an example, see "Healthcare".

Informal network	Aspects of life	Funded \$\$	Unfunded \$\$
	Home		
	Work	Disability Employment Service TAFE course	
	Relationships and friends		
	Recreation, play, holidays		
	Passions		
	Education		
	Spirituality		
Friend or family supports Jackie on visits to doctor and dietician.	Healthcare	Paid support worker supports Jackie to visit gym each week.	Jackie pays for gym membership and medications from her own pension.
	Financial security		
	Decision – making		
	Safety and security		

GOALS TO ACTION

This session is largely a sharing of ideas about how to break down each of the goals into simple, specific steps or actions that will help make the goal a reality. This could involve people volunteering to make a phone call, for example, or find out some information. The aim here is start to change ideas into reality so the facilitator will record who has volunteered and the planned date for completion. The "Review" column lists the person who offers to take responsibility for checking that the action has been done.

There may only be time to look at one or two goals but, once the thinking in this way has begun, the group can continue planning together informally or at a later session with the facilitator.

EXAMPLE 1

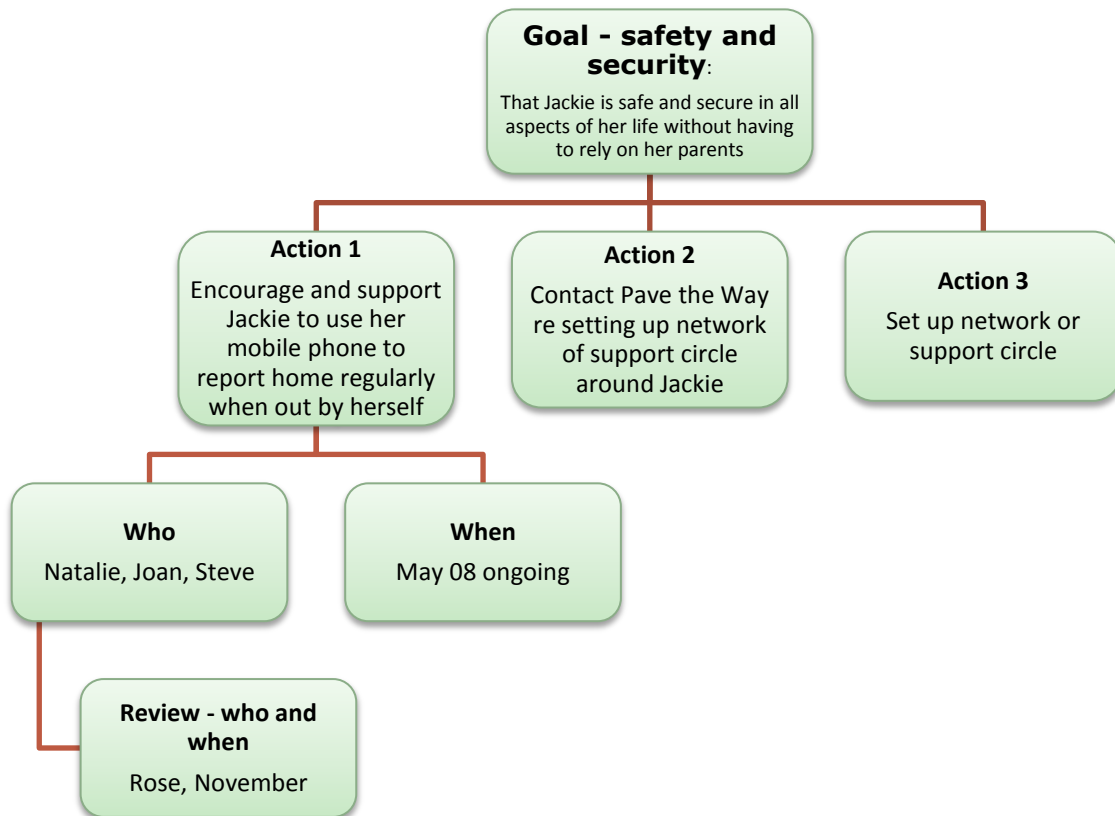
Goal	How to make this happen	When	Who	Review when	Review by
Healthcare <i>That Jackie becomes fit, has good health and loses 10 Kg in 12 months</i>	1. Make appointment for Jackie to see dietitian	May 08	Joan	Aug 08	Steve
	2. Contact friend who owns gym and arrange to take Jackie to see it	May 08	Rose	Aug 08	Joan
	3. If Jackie agrees, book her in to the Gym and arrange to take her for first few visits	May 08	Natalie	Aug 08	Joan
	4. Buy Jackie her own bathroom scales	May 08	Joan and Jackie	Aug 08	Rose
Relationships and Friends <i>That Jackie makes 2 or 3 good friends who are committed to her</i>	1. Talk to Gym owner re ways to connect Jackie to other young people at the Gym	Aug 08	Joan and Natalie	Nov 08	Steve
	2. Organise group of young people to go to coffee with Jackie after Blue Light Disco	June 08	Rose and her daughter (aged 21)	Nov 08	Joan
Safety and Security <i>That Jackie is safe and secure in all aspects of her life without having to rely on her parents</i>	1. Encourage and support Jackie to use her mobile phone to report home regularly when out by herself	May 08 and ongoing	Natalie, Joan and Steve	Nov 08	Rose
	2. Contact Pave the Way re setting up network or support circle around Jackie	June 08	Steve	Nov 08	Rose
	3. Set up network or support circle	Sept 08	Steve and Joan	Nov 08	Rose

Work Jackie is working part time in a retail shop (fashion or music)	Talk with Sarah about how to go about getting a job in retail sector				
	Explore retail courses at TAFE etc	May 2010			
	Research where the local retail shops are (esp music or fashion stores)	May 2010			
	Contact Disability Employment Service	June 10			

GOALS TO ACTION

EXAMPLE 2

This same planning can be recorded visually, for example in flow charts or tree diagrams. The way the information is recorded will reflect the style and needs of each family. While there are many different ways to do this the thinking behind the different ways of recording the notes remains the same: planning starts with the person and the vision and then works towards setting goals and actions.



APPENDIX 3 - Inviting Others

Inviting people in

In this article, Sharon Bourke from Pave the Way writes about different ways people can invite others to be part of their planning. This article was first printed in Mamrebillia, November 2007.

Families share a common concern for the well-being of their sons and daughters now and into the future. Inviting chosen others to support us in our planning for that future can be a powerful strategy to sustain our efforts and our actions and can be a significant safeguard for our sons and daughters. Whilst families seldom find it easy to invite people into places they previously believe they have had sole responsibility, it has been our experience that when asked, people are willing and keen. Family, friends and allies often respond to being asked by commenting that they feel privileged to be asked or that they have wanted to help but were unsure what to do. Our experience supports the comments of Gillian Chernetts who suggests that, if we don't ask others in, we are denying the community of the many gifts that our sons and daughters bring.

There is magic that evolves when people share their knowledge, energy and commitment. Openness, honesty and clear communication are the foundations on which to build strong relationships which will enrich our lives and those of our family members.

There are many different ways we can involve others. Capturing information in writing or through sharing an oral history of our family member will be an investment in their future by guiding people who support them. Involving people in planning the future promotes a deeper understanding of our family member but also provides a step by step approach to laying out a good life and a safe future. Local neighbourhoods and communities where people are known and valued will provide the environment where good lives can be embedded. Support circles is an intentional strategy for safeguarding where a group of committed people meet regularly and engage in conversations that deepen their understanding of the person and the issues they face. These people bring their ideas, energy and commitment.

Families need to be clear about their vision and plan for the future. Planning is not a new concept for families. We plan, we act and review in hundreds of ways each day. Planning for success is a matter of taking time, being clear about the person, the vision, inviting others to join us in becoming more deliberate about strategies that will safeguard our sons and daughters into the future. Sharing the joys and concerns of the journey with chosen others allows for a richer life and forms the very core of a stronger safer community where difference is valued, where gifts are recognized and where we all reap the benefits. It is a different way of thinking and a different way of being.

Families sharing the wisdom – it's a question of asking

In this article, Sharon Bourke from Pave the Way talks with a family about their experience of asking others to be involved in a support circle.

Pave the Way has been fortunate to work with a number of families who are safeguarding the futures of their sons and daughters by inviting others in to assist them with planning and decision making. Tony, Marlene, Deb and Alison Crawford have generously offered their insights about asking others in:

What were the blocks to asking?

We thought people would be too busy, we didn't want to impose.

We didn't know what we were asking of people.

We are very independent – it makes asking others difficult.

We were afraid that people would say no - rejection is difficult.

I would feel sad if they did not feel the way I do about Ali.

We worried that it would have an effect on the relationship afterward if people did not want to join us.

What enabled you to get over the blocks?

For a long time, we didn't; it helped to have Pave the Way involved.

We decided to start with family.

Knowing the right questions - wording the invitation the right way.

In the end, we just bit the bullet - we knew we had to start (something).

Now, we are more deliberate and look for opportunities.

Where did you start?

I started asking people who I thought may say "yes" – people closest to me – people we trusted e.g. family, an ex-worker who had great personal qualities and people who knew Ali. They said "yes".

Has it been worth asking - what are the benefits of a support circle?

This process makes you look at what is there in front of you more closely and deliberately. It has opened up Ali's life considerably.

We look at her life in a different way, we look at Ali in a different way.

We are open to possibilities of a full life with all the opportunities it offers.

We feel comfortable knowing we have the final say.

We have looked at things that we did not want to think about.

Members of the support circle have got to really know Ali better and are aware of the possibilities too.

Some members spoke of wanting to search for a more fulfilling life for themselves after this experience.

Ali is a person in her own right, involved and with talents and gifts. Ali is a band member now.

She has taken direction of her life – she is more capable now than before the circle.

Hints for other families

It can be exhausting – lots of activity generates when you invite others in. Take care, take time out and plan realistically. When you start, you see opportunities everywhere.