

# Building big visions and keeping on track for an inclusive life: What helps?

by Jeremy Ward, part-time consultant to Pave the Way

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**C**entral to families building a vision for an inclusive life for their family members with disability is a belief that such a life is possible: possible for their family member and possible for all people with disability. Wherever families fall short of that belief, people with disability will fall short of getting what we all want — a good, safe and meaningful life.

What helps families put aside the realities of their everyday lives, the pressures from the government, services, society and even their own extended family, to find and nurture a belief in a future for their family members with disability which is positive, meaningful and inclusive? The experience of Pave the Way is that three things can be helpful to families: time to find the right “head” space; a framework of “the good life” and valued roles; and inviting others to share the journey.

## 1. The head space to dream

First, families need the time, energy and “head space” to dream, to clarify their vision of what they really want for their family member. Pave the Way holds live-in workshops where two people from a family join other families in a pleasant environment and are assisted to find that head space through processes and simple time with each other. For most families these weekends require much planning and effort to get away. Yet families invariably say that this was worth it, that they have never spent so much time focussed on this issue. The change of place, with time to relax

and focus on visioning and planning for the future they want, rather than a future others say is the limit of what’s possible, can be life-changing. They also have a good time, with others with shared experiences, reconnecting with some aspects of that good life.

If families don’t have the opportunity to attend such a workshop, an alternative strategy is to make a regular time when these issues can be discussed, where dreaming is allowed. This could be a regular Sunday morning breakfast at a favourite coffee shop, or regular weekend picnics, or one night a week where the television is turned off and a pleasant meal shared over talk about dreams and plans.

If there are older siblings who have left home, or who are living independent lives while still in the family home, regular times can be set to suit their lifestyle — late Sunday brunch perhaps. Some people will prefer to go bush walking or strolling on the beach. Whatever works and fits with the family’s needs.

## 2. A framework through which to dream ~ the “good life” and valued roles

Second, families seem to do best at creating a dream when they have a clear framework, a world view that helps them see a positive, achievable way forward. Being thrust into the world of disability can be frightening, bewildering, traumatic, alienating and frustrating. Without a framework through which to clarify dreams and a vision for the future, families can lose sight of their common values, their belief in what is right, and even their common sense. They find

themselves agreeing to proposals, opinions and advice that they would dismiss in an instant if they had the energy and time to step back and reflect.

There is one framework that many families find useful which is very simple. It is the framework of the “good life”. We all know what it is and we all want it. Why would we not want that for our family members with disability?

In a recent Pave the Way workshop in Brisbane, family members of different ages and from different circumstances, were asked “What is the good life for you?” They came up with the following:

*happy family/family time ~ financial stability ~ good health ~ time out ~ someone that understands and listens ~ quality sleep ~ holidays ~ time with friends ~ communication meaningful relationships ~ security ~ supportive community ~ living in my own home freedom ~ hobbies ~ a good book ~ work: anything that makes me feel worthwhile ~ balanced life ~ exercise ~ movies ~ spontaneity ~ good church ~ good spouse or partner*

A few weeks later, a different group of family members gave similar responses to the same question:

*understanding, meaning and purpose ~ joy ~ holidays ~ good health ~ peace of mind ~ financial independence ~ safety ~ peaceful ~ enjoying family as a whole ~ able to see beauty in things ~ love and support ~ secure in own home ~ opportunities to learn ~ trust in others ~ freedom of choice ~ work ~ hope for the future ~ happy wife/spouse ~ to have time as couple ~ friendship ~ quality of life ~ own time for me*

Over the last seven years, in different parts of Queensland, families have come up with similar responses. They never say they want to live below the poverty line, or somewhere chosen by others, or share with people they don't know, or that they want others to choose their day-to-day activities and routines, or to have few opportunities to contribute to their community, or never to have meaningful and intimate relationships or real friends. They never say they want to be excluded from typical community life, opportunities and activities.

Implicit in many of these elements of the good life are roles, often roles which are valued highly in our society. For example, to say that work is an important element in achieving the good life, is to say that being a “worker” is important, something to be valued. It is to say that a worker is a socially valued role in our society.

It is interesting to note that the families at those two Pave the Way workshops referred to above believe, either explicitly or implicitly, that a good life involves participation in valued roles. Most of the elements of the good life that they came up with can be translated into a role which is valued in our society, such as:

Elements of “the good life”	Valued role
financial stability, security	financially secure person (not person in poverty)
happy family, family time enjoying family as a whole, love and support	Son, daughter, brother, sister, grand-daughter, grandson, spouse, partner
good health	person in good health (not sick, “invalid”)
someone that understands and listens, time with friends, meaningful relationships, love and support, trust in others, friendship	friend, ally
holidays	holiday maker/traveller
security, living in my own home, secure in own home, peaceful	home owner or tenant
supportive community	community member; neighbour
freedom, freedom of choice; own time for me, quality of life	autonomous, free individual
hobbies	hobbyist (perhaps member of a club based on hobby interest)
work – anything that makes me feel worthwhile	worker/contributor
a good book	book reader (perhaps member of book club), library member
movies	movie goer, film festival subscriber
exercise	exerciser (perhaps member of gym, cyclist group, athletics club, rowing club)
good church	church goer/member of church community
good spouse or partner, happy wife/spouse, to have time as couple	spouse, partner
opportunities to learn	student

Thus, to live the good life means being valued by others in the various roles we take on in life. Some families will be familiar with the theory of Social Role Valorisation, developed by the late Professor Wolfsensberger, and the power that valued social roles can play in assisting their family members with disability to achieve the good life.

The valued roles above are all roles that many of us achieve without thinking but which can often only be achieved by people with disability through thought, planning and intentional strategies. They are also roles in the community, not excluded from it. Achieving these roles is tantamount to being included in society. A framework of the good life, and the goal of attaining valued social roles, can provide a powerful focus for families struggling for clarity.

In the workshops that Pave the Way holds throughout Queensland, families are encouraged to focus their vision and planning around all the aspects of life. In the introductory workshop, *Planning for Now, Tomorrow and the Future*, we encourage families to look at different aspects of life and set goals and strategies around them. There is no “disability speak” here, no mention of special schools, accommodation services, group homes, day programs, respite services, family support services, holiday programs, or any other disability specific service or program.

This is whole-of-life planning, not service planning. The aspects of life we encourage families to focus on are universal and include, though are not necessarily restricted to, the following:

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

With their vision uppermost in their minds, families are encouraged to develop simple goals and strategies around these various aspects of their family member’s life. Disability organisations

and services might play a part in supporting the family member to attain goals under some of these aspects of their life, but they do not constitute the person’s life or any one element of it. In individual structured planning sessions that Pave the Way facilitates with families, a similar list of aspects of life is usually followed.

With the time and space to dream and clarify their vision, and a framework of the good life and valued roles through which to implement that vision, families will go a long way to achieving their dreams for their family member. However, if those dreams are to be fully realised and sustained over time, and the goal of an inclusive good life is to stay on track, families need to invite others to join their journey.

### **3. Bringing others into the life of family member with disability**

Third, families will do much better at all of this if they invite other people to share the journey with them and their family members. Other key people can assist the family to firm up their vision, to plan and develop strategies. Importantly, others can take on important roles as parents and other key family members begin to age. In its work with families, Pave the Way encourages and supports families to include others in a number of ways, including: asking them to participate in structured planning sessions; inviting them to join an intentional support network or circle; and sharing important information with them.

People keep people safe, not services, funding agencies, or government departments. Nor do wills and trusts keep people safe, as important as those legal mechanisms are as whole-of-life planning strategies. It will only be other people, committed to the family member with disability, who will ensure that the family’s vision continues beyond the time when parents or other key family members are no longer here.

Including others in planning is a way of helping them understand the complexities and nuances of supporting the family member with disability, and of sharing ownership of the vision and important goals and strategies. People invited to participate in planning may come together only when the family conducts some planning, though they will often assist with the implementation of goals and strategies between dedicated structured planning sessions.

Some families go the next step and set up a support network or circle. In the context of whole-of-life and succession planning, Pave the Way sees support circles primarily as a safeguarding strategy — a group of people who meet regularly and develop a deep commitment to the family member with disability being supported to follow their dreams and the family's vision for them. While support circles usually assist families with planning and implementing goals and strategies, their key purpose is as a forum for commitment and security.

Even if families feel they don't have the capacity to set up a support circle, or to invite others to participate in structured planning sessions, they can share important information. To do this, they need to take information from their heads and write it down. By writing information down, and then asking other key people to read and keep a copy of that information, families are beginning the task of inviting others to share the journey of their family member with disability.

Information written down can include the family's vision for their family member, key goals and strategies, medical and personal information, names of relevant professionals, details of where legal documents are kept, and important day-to-day information relating to diet, equipment, personal care needs and so on. Pave the Way has developed a resource, *A Document of Personal Information: Ideas and Strategies*, to assist families to write down relevant information, and we present workshops throughout Queensland focussed on the task of documenting information.

## **Conclusion**

Building a vision and sticking to it can seem overwhelming at times. The experience of Pave the Way in working with families across Queensland, from all walks of life, is that when families are allowed the time to dream, assisted to develop a framework through which to implement their vision, and encouraged to invite others to share the journey with them, what seems daunting can become excitingly possible.

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