

Pave the Way Newsletter

SEPTEMBER 2011

What do we mean when we talk about a good life?

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"Clarity of Vision: a compass for the journey" is available on our website at
<http://www.pavetheway.org.au/home/stories.php>

In the article, *Clarity of Vision: a compass for the journey*, Wendy Stroeve writes that "having a vision for the life of a person with a disability is about claiming the right to ordinary dreams and believing that they can happen". It is these "ordinary dreams" that Pave the Way refers to when talking with families about the importance of vision and planning in making a "good life" for their son or daughter with disability.

When asked to name what makes their life "good", people answer in remarkably similar ways. They talk about the importance of family and friends, a place to live, good health and economic security, the freedom to indulge in their passions and hobbies. They talk about different versions of the simple things in life that make a difference to every day – the first quiet cup of tea in the morning or a glass of wine with dinner. Others refer to being able to make choices in their life or to take annual holidays. There is nothing particularly unusual about these ideas; they are, indeed, "ordinary dreams". The sad reality, however, is that for people with disability these simple things are often considered extraordinary and are unattainable.

Historically, communities and families have been encouraged to imagine a different life for people with disability; a life channelled into service systems, disconnected from family and community. In many circumstances people are in the position of relying on services not only for specific support but also for meeting their social needs. This path of segregation and disconnection from family and community can begin early in a person's life. If families are not clear about the kind of life they want for their sons and daughters then "ordinary dreams" can rapidly become difficult to achieve.

At Pave the Way we encourage families to develop and articulate a clear vision for the kind of life they want for their son or daughter and to plan with, and for, them to make it happen. The starting point for this planning is the individual: who are they, their passions, skills and interests. Planning is then directed towards concrete steps that can help achieve a good life for them, both now and in the future.

While this may take time, energy and commitment it is worthwhile for us all to consider which part of a good life, which "ordinary dreams", we would be prepared to give up if other people were planning for our future.

If you would like to explore further the ideas in this article, please contact Pave the Way or check our website for stories and articles.

Dates and updates

Yet more changes to the Special Disability Trust rules

In the 2010 Federal Budget, changes to Special Disability Trust (SDT) provisions were announced. The definition of "severe disability" was changed so that a beneficiary of a SDT is allowed to work up to 7 hours per week at or above the minimum wage. The use of trust funds is no longer restricted to "care and accommodation" but can now also be used for all medical and dental expenses (including the cost of membership of private health funds). Funds can also cover the maintenance of trust property assets, and any "discretionary expenditure" of up to \$10,000 per year not related to the care and accommodation needs of the trust beneficiary but which is compliant with SDT legislative requirements.

In the 2011 Federal Budget, the Government agreed to annually index the amount allowed to be spent on discretionary expenditure per year. From 1 July 2011, that amount has increased to \$10,250. The Government also announced that various capital gains tax exemptions will apply to Special Disability Trusts. These exemptions will apply to all transactions since 1 July 2006.

For more detail on changes to Special Disability Trusts contact Jeremy Ward at Pave the Way on 07 3291 5800 or 1300 554402.

Senate Community Affairs References Committee Inquiry and Report - *Disability and Aging: Lifelong Planning for a Better Future.*

In November 2009, the Senate Community Affairs References Committee was asked by the Senate to inquire into and report on "access to planning options and services for people with disability to ensure their continued quality of life as they and their carers age". Pave the Way made a submission to the Inquiry and Catherine Raju and Jeremy Ward appeared before the Committee at its hearing in Toowoomba on 1 December 2010. A copy of the Pave the Way submission is published on the Senate Committee website - www.aph.gov.au/senate_ca.

In July 2011 the Committee published its final report - *"Disability and Aging: Lifelong Planning for a Better Future"*. Copies can be downloaded from the Senate Committee website.

Importantly, the Committee acknowledges the difference between life-long, whole of life, planning and service planning and quoted extensively from Pave the Way's submission on that topic. Pave the Way was also cited, and our work described in some detail, as one of four organisations involved in "long-term planning" throughout Australia. The Committee made 15 recommendations, including that the Commonwealth Government facilitate the provision of specialist financial and legal advice to assist people with planning; that "an integrated and coordinated national approach to planning" be developed; and that funding for "disability planning" be provided in the next Federal Budget, to existing organisations (eg, Pave the Way), to families who want to purchase planning services, and to other organisations wanting to develop planning services.

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Pave the Way's 2 Day Live-in workshop, *Vision and Planning*, will be held in Rockhampton from 18 – 20 November. For more information and to receive an Expression of Interest please contact the office. Expressions of Interest are due by 21 September, 2011.

Speakers from Canada and the USA are presenting workshops for families in Queensland:

Janet Klees

- Townsville. Tuesday 4 October. Phone CRU - 3844 2211
- Brisbane. Saturday 1 October, 11-4pm. Phone QPPD - 38752101

Darcy Elks

- Brisbane. Sunday 18 September. Phone Bespoke - 3622 1222.

Statutory Health Attorneys – making health care decisions

When someone aged 18 or over lacks the capacity to make some or all medical decisions for themselves, there is no need to seek formal appointment as a guardian to make those decisions. Under Queensland legislation family members have authority to make almost all health care decisions for family members with impaired capacity. This includes medical and dental treatment and withdrawing or withholding life-sustaining measures. The exceptions are “special health matters”, including:

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

To obtain consent for these procedures, an application must be made to the Queensland Civil and Administrative Tribunal (QCAT), or the Mental Health Tribunal in the case of ECT or psychosurgery.

Statutory health attorneys are not formally appointed. They gain their authority purely by virtue of legislation, or “statute”. However, all statutory health attorneys must comply with the “health care principle” set out in legislation.

Queensland legislation states that the first, in listed order, of the following people who is “readily available and culturally appropriate” is the statutory health attorney for an adult aged 18 or over:

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

Where no-one is “readily available and culturally appropriate”, the Adult Guardian becomes the statutory health attorney. A person who has the “care of the adult” includes someone who provides, or arranges to have provided, “domestic services and support”.

Thus, in most situations, a parent is statutory health attorney for their adult son or daughter who has impaired capacity for making health care decisions. They do not need to be appointed to make these health care decisions, nor do other close family members. If there comes a time when parents or other family members are unable or unwilling to carry out this role, “close friends” (eg, members of support circle) might be able to do so.

For further information, contact Jeremy Ward at Pave the Way.

In most situations a parent, as statutory health attorney, can make health care decisions for their son or daughter if they are unable to make their own healthcare decisions.

This topic is explored further in “Planning for Now, Tomorrow and the Future”, available on the website www.pavetheway.org.au or by contacting the office.



Pave the Way

Pave the Way assists families throughout Queensland to clarify their vision for their family member with a disability and to plan to implement that vision. We encourage planning which is vision driven, 'whole of life', developmental, outside service planning and which safeguards family members in the long term. We believe it is other people who keep people safe and support the development of personal networks, including Support Circles.

Contact Us

Please contact us if you would like to be on our mailing list, or would like information or assistance developing a vision and plan or developing a support circle or similar network. If you are part of a group of families and would like us to come and talk about these issues, let us know.

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Upcoming Events

Developing a Vision and a Plan – 2-day live-in workshop

Kinka Beach, Yeppoon 18 – 20 November 2011 (PTW)

Planning for Now, Tomorrow and the Future

Mt Ommaney 15 September 2011 (PTW)

Building Lifelong Supports Workshop

Rockhampton 15 September 2011 (PTW)
Far North Qld November 2011 (date tbc) (PTW)

Regional Visits

Julie van Oosten

Bundaberg October 2011 (dates tbc) (PTW)

Catherine Raju

Far North Qld October/November 2011(tbc) (PTW)



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To book into a workshop, please phone the relevant contact. For Pave the Way (PTW), phone (07) 3291 5800 or 1300 554 402. For regional visits please contact Julie van Oosten/Catherine Raju (07) 3291 5800 or 1300 554 402. You can also view the workshop and events calendar online at www.pavetheway.org.au/home/workshop-calendar.php.