

**SENATE COMMUNITY AFFAIRS REFERENCES  
COMMITTEE**

**INQUIRY INTO  
PLANNING OPTIONS AND SERVICES FOR  
PEOPLE AGING WITH A DISABILITY**

**SUPPLEMENTARY SUBMISSION**  
**NOVEMBER 2010**

**BY**

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## 1. Introduction

### 1.1 Amended Terms of Reference of Inquiry into Planning Options and Services for People Aging with a Disability

*Pave the Way* made a submission to the Inquiry into Planning Options and Services for People Aging with a Disability set up under the 42<sup>nd</sup> Parliament. This is a supplementary submission which takes up some additional issues raised by the Amended Terms of Reference to that Inquiry dated 30 September 2010.

## 2. Summary

The additional issues we focus on in this supplementary submission are:

- 2.1 Individualised funding and safeguarding the future for people with disability. (Para 3)
- 2.2 Taxation relief and future planning. (Para 4)
- 2.3 Additional points concerning older parents and carers. (Para 5)
- 2.4 Parents and carers who say they have no-one in their lives. (Para 6)
- 2.5 The cost of providing a service like *Pave the Way*. (Para 7)

## 3. Individualised funding and safeguarding the future

- 3.1 *Pave the Way* strongly supports the notion of individualised funding which allows individuals to, in effect, go into the market place with a set amount of funding and buy the support they need from the service provider that best suits their needs. We see this as offering families who plan for the future of their family members with disability, an additional safeguard against an uncertain future at the mercy of service providers who “take control” of those family members.
- 3.2 Through individualised funding, families are better positioned to set up support arrangements which meet the specific needs of their family members and which are consistent with their vision for the future for those family members. In their future planning, families can support and encourage trusted others in their networks (eg, siblings, other relatives, close friends) gradually to take over the self-directed arrangements they have established through individualised funding. If families do this while

they are still able to be involved with their family member, they will be in a better position to see that the support arrangements they have set up are being continued by those trusted other people in the life of their family member.

- 3.3 *Pave the Way* and Mamre Association describe individualised funding as funding assigned to a specific individual which is in the control of the individual or their family and which can be transferred between services at the direction of the individual or family.

Individualised funding does not mean non-accountability. There are numerous examples of families and individuals who control their own funding while remaining accountable for its proper use within funding guidelines. Mamre Association encourages all families it supports to take more control over their funding, through its policy of *Family Managed Funds*. Under this policy, Mamre delegates the management of the funds for support directly to families by negotiating an agreed sum of money to provide an agreed level of support and then transferring the funds to the family. Mamre does this because it believes:

- Families typically do best when they can identify their own needs, and can plan and direct the services provided.
- Families have the best interests of their son/daughter and overall family at heart and can be trusted to use the money given to them to buy supports that are appropriate for them.
- The relationship between the Mamre Key Worker and the families ensures a high level of accountability without the need for excessive paperwork.
- Families are the experts in knowing their individual's needs and have the knowledge to provide most of the training in the individual's care.

Funds can be used for:

- in home care
- community support
- host family support
- support for the individual on a weekend or holiday away from the family
- support for the individual on a family holiday
- other strategies as negotiated with the Mamre Key Worker.

Currently, approximately 165 families from a total of 200 families supported by Mamre choose to manage their own funds. The maximum amount managed by an individual family is over \$100,000 per year.

[For further information, see the Mamre website: [www.mamre.org.au](http://www.mamre.org.au) and paragraph 3.8 of the Mamre Policy and Procedures, found on the website.]

#### 4. Taxation relief and future planning

- 4.1 Many people with disability throughout Queensland receive no or little individualised funding. Our experience is that, throughout Queensland, approximately 5% - 10% of family members with disability are receiving funding specifically directed towards meeting their needs. To offset shortfalls in funding, families are contributing to direct support costs, supplementing rent and living expenses, purchasing real estate, buying equipment and paying for everyday expenses such as incontinence aids.
- 4.2 *Pave the Way* can cite a number of examples where extended family and close friends are providing financial support. For example, one support circle set up a bank account and individual members make contributions to cover the costs of private rental for a young man who has moved into his own flat. Others, particularly family and friends of young people, seek our advice about setting up a trust for the benefit of the young person with a disability, into which a number of people can contribute.

While there are schemes in all States and Territories that provide subsidies for some equipment items, they invariably do not cover the whole cost and inconsistencies exist from State to State. National incontinence aid funding is limited to \$500 per year, which for some people might cover 4 months supplies. In Queensland there is no support to assist families to purchase and modify vehicles, though in some other states there is limited support.

The cost of modifying a bathroom to make it accessible is likely to be between \$10,000 and \$20,000. The cost of modifications to a small van to make it wheelchair accessible could be \$28,000 (see, for example, [www.fleetworks.com.au](http://www.fleetworks.com.au)). The cost of installing a ramp which meets all safety and access regulations to a low set house is likely to be \$15,000. In Queensland, none of these costs attract any government subsidy. The cost of providing one hour of paid support per week for a year will be between \$1800 - \$2200. A family that wishes to pay for only 10 hours support a week, less than 2 hours per day, will be faced with paying between \$18000 and \$22,000 a year.

Families faced with these large financial commitments look at the tax system and see business tax deductions for equipment, vehicles, conferences, etc, and wonder why those often affordable business

expenses are tax deductible and yet the high costs of providing necessary support and equipment for their sons and daughters are not.

- 4.3 It would be of great assistance to families and other interested individuals if they could claim tax deductions for such contributions which assist with the extra costs of disability. In many cases these costs are very high and a huge drain on the resources of families who often have restricted earning capacity. The Australian Government has recognised the high costs faced by such families. A practical way of providing some additional assistance, would be to allow these expenses as tax deductions.
- 4.4 If families, close friends and allies were able to claim tax deductions for these expenses, families would be able to factor those contributions into their future planning. In their personal financial planning and estate planning, families would be in a stronger position to make financial contributions to plans aimed at securing a safe and secure life within their vision for a good life for their family members.

## 5. Additional points concerning older parents and carers

- 5.1 *Pave the Way* has had experience with many elderly parents of people with disability. We have worked with a number of parents who are retired, some in their 70s and 80s, who are working on many strategies to ensure good lives for their family members with disabilities and their long term safety and security. They are attending our workshops (including live-in workshops), inviting extended family and friends to join them in their planning, setting up support circles and some even joining with other families in developing small, family and community governed services.

For many this has been very difficult, and for some has come after they had thought they had put in place satisfactory arrangements to protect their family members, such as embracing a particular service, only to find that these arrangements were unsatisfactory. *Pave the Way* has had ongoing involvement with two families with parents aged in their seventies, who had to bring their family members with a disability home after they were subjected to staff abuse in residential settings. We have also been involved with families who have had to find alternative accommodation for their family members following unsatisfactory service responses to them. [See, for example, the story on *Pave the Way's* website "Embracing Community Living" by Katatina Listopad.]

In some families, it is other adult children aged in their 50s, siblings of the family member with a disability, who have made the approach to *Pave the Way*, often bringing their elderly parents to our information sessions or

workshops. On occasion we have had elderly grand-parents attend workshops, because they have taken over the direct care role of a grand-child. In one situation, a friend of the family came to a workshop and then asked *Pave the Way* to assist her to set up a support circle around the person with a disability.

Despite the challenges they face, we have had many positive experiences working with elderly family members. Our experience is that the information and strategies we offer is relevant to families of all ages. It is never too early to plan and it is also never too late.

5.2 Thus, we believe that planning options and services for older parents and carers work best when they are part of planning options and services which aim to address the issues faced by families of all ages. While there is an issue of how best to assist older family members to plan, *Pave the Way* does not take a different approach with such families. If their age has resulted in the need for urgent action, or led to a situation of crisis, planning approaches such as *Pave the Way* will be unable to assist them. But if older families have the time to work on clarifying their vision and to do some planning, we have found that our approach is as useful as it is to younger families.

5.3 There is a need for additional services for older families and carers in crisis. These services are not to be confused with whole of life planning options or services such as *Pave the Way*. Rather, they are services which work directly and intensely with such families to assist them to respond to the crisis they are facing. These are in the nature of family support services, funded to support families facing issues requiring a more immediate, "hands on" response.

## **6. Parents and carers who say they have no-one in their lives**

6.1 When we talk to families about the strategies of inviting others to join them in planning and building networks of support, some say that they have no-one in their lives, or that their families and close friends live a long way away. For example, families who have moved from Victoria to work in the mines in Central Queensland often say that they can only make short term friends in mining communities because many people come and go from those communities every two or three years.

This is a significant issue for many families. Where families say they have no-one in their lives, that their families and friends have drifted away, and they want to address this issue, *Pave the Way* offers to sit down with them and talk through how they might build new connections. Usually families

can think of one or two people that might form the beginning of a network and we help them look at ways of building from there.

Where families have family and friends but they live far away, *Pave the Way* talks to them about how they might take intentional steps to give more structure to those networks by using the internet and email, and by taking advantage of annual gatherings such as at Christmas. *Pave the Way* also offers to assist with facilitated planning sessions to help them make difficult decisions, such as whether to leave their work communities and return to live closer to family, or to make a long term commitment to those work communities than originally intended.

*Pave the Way* has yet to find a family regardless of their circumstances who, if they want to embrace future planning, cannot move forward with support and assistance.

## **7. The cost of providing a service like *Pave the Way***

- 7.1 *Pave the Way* estimates the current annual cost of providing a state-wide service such as *Pave the Way* in each State or Territory would be between \$200,000 (ACT; NT), \$300,000 (TAS), \$400,000 (SA) and \$600,000 (QLD; NSW; VIC; WA), or approximately \$3,500,000 recurrently across Australia.

These are broad estimates only, based on the current budget of *Pave the Way* which includes funding for 4-5 staff, part-time consultants, extensive travel and live-in workshops. As noted above, the costs of doing this work across a decentralised state such as Queensland is considerable. We have assumed that similar costs would be involved in doing this work in NSW, Western Australia and Victoria. We have assumed lesser costs for the smaller States and Territories but there may be specific expenses unique to all other States and Territories of which we are unaware.

As noted in *Pave the Way's* first submission to the Inquiry, there is also a need to address the specific needs of particular groups, such as the Aboriginal and Torres Strait Islander community, people from a non-English speaking background, and people with mental illness. Our cost estimates do not include the additional costs of funding specific projects to address the future planning needs of people in these groups.

## 8. Conclusion

8.1 *Pave the Way* has welcomed the opportunity to make a supplementary submission to this Senate Community Affairs References Committee Inquiry. We will also welcome the opportunity to appear before a public hearing in Toowoomba on 1 December 2010.

### Further Contact:

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