

**SENATE COMMUNITY AFFAIRS COMMITTEE**

**INQUIRY INTO  
SPECIAL DISABILITY TRUSTS**

***SUBMISSION***

***BY***

***PAVE THE WAY  
MAMRE ASSOCIATION INC***

***LEVEL 1  
1428 11-14 LOGAN ROAD  
PO BOX 949  
MT GRAVATT Q 4122***

***(07)32915800***

***[pavetheway@mamre.org.au](mailto:pavetheway@mamre.org.au)***

***[www.pavetheway.org.au](http://www.pavetheway.org.au)***

## 1. Introduction and background

### 1.1 Introduction to *Pave the Way*

*Pave the Way* is a team within Mamre Association in Queensland. Mamre Association is a family support community and service based in Brisbane. *Pave the Way* is funded to provide succession planning resources and support to families throughout Queensland who have a family member with a disability. *Pave the Way* began in September 2002 as a very small project funded by Mamre Association, before receiving funding from Disability Services Queensland.

The aim of *Pave the Way* is to assist families with a family member with a disability to develop a vision for now and the future, to plan to implement that vision and to safeguard that vision and the individual with a disability in the long term. The focus of *Pave the Way* is on supporting families to take initiative to address their fears about “*What will happen when I’m gone?*”

The approach of *Pave the Way* has been to provide families with information and strategies around these issues and, where families have sought it, individual consultations and assistance. We provide in depth opportunities for families to focus on future planning through 2 day and 6 day live-in workshops. *Pave the Way* also provides information and guidance in relation to legal issues relevant to planning and preparing for the future, including Special Disability Trusts. *Pave the Way* refers families to a panel of solicitors in Brisbane and throughout Queensland experienced in wills and trusts and with working with families who have a family member with a disability.

*Pave the Way* is the only project in Queensland which attempts to offer a State-wide, comprehensive, vision driven, developmental approach to assisting families to plan for and safeguard the future. In our work throughout Queensland over the last 5½ years we have traveled to all major centres, sometimes on a number of occasions, and spoken with hundreds of families about planning for the future. We have visited Cairns, Mareeba, Innisfail, Ingham, Mt Isa, Cloncurry, Townsville, Charters Towers, Ayr, Home Hill, Mackay, Gladstone, Rockhampton, Emerald, Biloela, Longreach, Gympie, Hervey Bay, Murgon, Esk, Sunshine Coast, Caboolture, Gold Coast, Beaudesert, Ipswich, Gatton, Boonah, Toowoomba, Warwick, Stanthorpe, Goondiwindi, Tara, Dalby, Miles, Roma, Chinchilla, Charleville and Brisbane.

*Pave the Way* now has a mailing list of over 900, including 870 families who have a family member with a disability. This submission is based on discussions with many of these families. The work of *Pave the Way* is guided by a Reference Group including family members, committed allies of families in Queensland, and representatives of Mamre Association. Further information about *Pave the Way* is available on our website – [www.pavetheway.org.au](http://www.pavetheway.org.au).

## 2. Terms of Reference

### 2.1 Why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts.

Our experience is that all families see the disability support pension as necessary to the financial well-being of their family members with a disability. Even for families with considerable financial resources, the pension and its associated benefits is regarded as very important. Thus, any policy and legislation aimed at allowing Centrelink concessions to family members so that they may retain the pension is universally welcomed.

However, families with whom *Pave the Way* has discussed the Special Disability Trust (SDT) arrangements are universally critical of the limitations imposed on these trusts.

Families perceive the current legislation as mean spirited and of limited value. Many see the SDT provisions to be little more than an attempt by the Commonwealth Government to encourage families to underwrite the costs of basic care and accommodation, which many families believe is a government responsibility. Families everywhere are already contributing to the financial, emotional and practical support of their family members and see this legislation as an attempt by the Commonwealth Government to have them do more and governments less. The issue of whether this should be the responsibility of State, Territory or Commonwealth governments is irrelevant to most families.

Families also question why they would put their money into a trust which will not be able to be used for expenditure other than care and accommodation. Many families say that the whole point of setting up a trust is so that their family members can continue to enjoy a rich and full life, which is difficult to afford on a pension alone.

Families with a vision for a good quality of life for their family members with a disability want to encourage them to live ordinary lives, to enjoy holidays, to have the niceties of life, just like others in Australian society, as well as to have their basic needs met. Planning for the future is not just about providing care and accommodation.

Families believe that people with disabilities have a right to enjoy life to the full, not to be seen merely as people who receive “care” and are “accommodated”. They have the right to live in a home of their own, to work, to contribute to community activities, to have fun, friends of their choosing and to go on holidays.

When on holidays, or involved in their local communities, many people with a disability need support and often have to pay the expenses of their support

workers (eg, movie tickets, airfares, meals, accommodation) yet payment of those expenses may not be allowed through a SDT. Some will use a modified vehicle, yet payment of the operational and maintenance costs of that vehicle may not be allowed through a SDT where the vehicle is not used for “care and accommodation”. People with a disability have the same range of medical needs as everyone else and families want to ensure that their family members receive quality health care, yet non-disability related medical costs will not be payable from a SDT.

Some families have the financial capacity to purchase a house or home unit for the family member with a disability to live in. If they make this purchase through a SDT, the cost of maintenance which is not due to the person’s disability will not be payable from the SDT.

The current SDT provisions will require families to establish two trusts, with the associated costs and complications, to ensure that all their family member’s needs are met. Families want to make provision for their family members with disability, to the extent that they are able, and are willing to supplement government funded support services where necessary and where they can. Families also want to provide for a broad range of other needs and are often astonished to hear that they will be precluded from using a SDT to do so.

While this initiative was apparently designed to be a benefit to families, many families see it as introducing more complexity. They see in it a need to visit specialist solicitors to have complex documents prepared at the family’s cost.

The \$500000 limit will also be an issue for some families who have considerable assets and are faced with large support costs even where their family member receives government funding. While many families have limited resources, it is nevertheless not unusual for a family in Australia to be able to leave a trust fund well in excess of \$500000. Nor is it unusual for such a substantial fund to be necessary to provide adequately for the family member with a disability.

#### **Example**

A couple has only one child who has a significant disability and is their sole beneficiary under their wills. If they own a typical, unencumbered family home in a capital city (\$500,000), and hold typical assets in superannuation funds (\$300,000 and \$200,000), they could leave a trust fund of \$1M. Families with these sorts of assets are not seen as wealthy families in Australia in 2008 yet they could leave a trust fund well in excess of \$500000.

Alternatively, let us imagine that the same couple has three children, one of whom has very high support needs. The couple has done some planning and know that the costs of paying for the time they currently spend supporting their family member with a disability could never be met in the long term by a trust fund of \$500000. They have been told by their financial adviser that the income

they can expect from a fund of \$500000 in the long term is likely to be approximately \$25000 per year. They also know that even the small, family and community governed service that supports their family member, which keeps administrative costs to a minimum, is unlikely to be able to provide more than 20/25 hours per week in ongoing support on \$25000 per year. They have government funding which currently covers 65 hours per week (the usual maximum in Queensland), and the remaining time that they cover far exceeds the extra 20/25 hours that could be paid for from a trust fund of \$500000.

This couple therefore decides to leave all of their estate, currently \$1M, in trust in their wills for their child with a disability, on the basis that the needs of that child are the greatest, their other children are now adults with sufficient financial independence and those other children will receive a “delayed benefit” as residual beneficiaries under their parents’ wills.

For those few families where the costs are high, and where they do have the financial capacity to contribute significantly more than \$500000, an SDT will be of little assistance.

While the Centrelink “gifting rule” concessions are welcomed by a number of families, especially elderly parents in receipt of the aged pension, these limitations of SDTs also act as a disincentive to this group.

Specific reasons why more families are not using the SDT provisions include:

- 2.1.1 While some families are contemplating including a SDT in their will, the limitations and inflexibility of SDTs means that few families see the SDT as a useful option during their life time. Presumably the very low numbers of SDTs established to date refers only to inter vivos trusts (established during the donor’s lifetime) and does not include testamentary SDTs (established in wills).
- 2.1.2 Many families with a family member with a disability are single income families or otherwise have limited financial capacity. Therefore they do not have the financial capacity to set aside funds during their lifetime to set up an inter vivos SDT even if they see value in the idea. The only time when they might have significant funds to set aside for their family member with a disability will be when they die, and then often when the last parent dies.
- 2.1.3 Many families who do have some financial capacity are looking at more flexible ways to plan and provide for the future of their family member without having to lock away substantial funds. For example, some families have the capacity to purchase a small house or home unit for their family member with a disability but prefer to keep the property in their own name to allow more flexibility, and accept the adverse tax implications of this approach, rather than lock funds away. Planning for the future requires

- planning for flexibility, as circumstances of all family members can change through illness, injury or loss of employment.
- 2.1.4 Despite part of the rationale for the introduction of SDTs being that families might wish to contribute to the costs of accommodation and support provided by non-government organisations or governments, proposals put forward by government and non-government organisations invariably involve inflexible, segregating and congregating options. Increasingly families want their loved ones with disability to live in their communities in their own homes.
- 2.1.5 Families are very reluctant to hand over their own funds to organisations who offer to provide accommodation services for their family members. Families have seen too many organisations and services go off the rails. When given the opportunity to talk about what they really want for their family members with a disability, rather than what they think might be the limits of what is possible, very few families opt for an institutional, group setting administered and run by a service over which they have no control.
- 2.1.6 Many families who are interested in SDTs are hoping that the current provisions will be changed to allow more flexibility and therefore are holding off establishing a SDT.
- 2.1.7 While there is widespread interest throughout Queensland in legal issues relating to wills and trusts many families are reluctant to resolve these issues until they find a solicitor who they are confident is competent and experienced in disability issues.
- 2.1.8 Many families do not see the cost of legal advice, and of establishing and administering a SDT, to be warranted, particularly if it is an inter vivos trust, given the limitations of SDTs.
- 2.1.9 Some families who do see merit in setting up a SDT are precluded from doing so because their family member with a disability does not meet the “severe disability” test.

## **2.2 The effectiveness of Part 3.18A of the *Social Security Act 1991*.**

This section of the *Social Security Act* is headed “Private financial provision for certain people with disabilities”. Providing adequate financial provision for their family members with a disability is an issue of major concern to families who know that the level of support likely to be available to their family members, when they can no longer provide support, will be limited.

While many families are interested in developing informal unpaid supports around their family members, and *Pave the Way* assists many families to achieve

this end, the reality for many is that some amount of paid support will be necessary. Further, the income from a disability support pension is not enough for anyone to live comfortably and families want to leave sufficient funds so that the pension can be supplemented. Many families have limited financial capacity, due to the high costs of disability and their being single income families, but they want to provide what they can.

If this legislation was meant to assist families to provide for their family members with a disability, including through assisting them to plan for their long term financial security, it is extremely limited and ineffective.

Some reasons for this are:

- 2.2.1 The need for SDTs arose from the Commonwealth Governments' policy, implemented through Centrelink, which deems all assets in, and income derived from, protective trusts to be the trust beneficiary's assets and income. Without that deeming policy, there would not have been a need to legislate for SDTs. A simple and effective solution would have been to remove that deeming policy for all properly established protective trusts, whether testamentary or inter vivos.
- 2.2.2 The current legislation is based on an erroneous assumption that the only private financial provision that families wish to make for their family members with a disability is to provide for their "care and accommodation". Many families see this underlying assumption as insulting and demeaning of their family members. People with disability, like all of us, have the right and expectation to live rich and full lives. While the provision of care and support is important, there is far more to life than that.
- 2.2.3 Many families see the limitation of the purpose to which SDTs can be put as portraying the Commonwealth Government's lack of vision for people with a disability. Families see their family members as having the right and capacity to live rich and fulfilling lives in their own homes, whereas this legislation focuses only on people having a roof over their heads with their basic support needs addressed. The vision of the Commonwealth, at least as implied by one Government representative soon after the legislation was introduced, appears to have been that people with disability should live in group settings, supported only by paid workers, and living with other people with a disability who they do not choose to live with. (*Public address by Hon Senator Kay Patterson, Brisbane, 20 November 2006*).
- 2.2.4 As a legislative response to this issue, the use of the *Social Security Act* and Centrelink concessions, is very limited. Even if the limitations and shortcomings of SDTs are addressed, there is much more that a Commonwealth Government could do to alleviate the financial burden on families.

Possible additional Commonwealth responses could be:

- Allow tax deductions for contributions made towards support costs, equipment and special needs items (eg, incontinence pads) and transport needs of people with a disability.
- Work with the States and Territories to investigate the possibility of simple legislation across Australia which could facilitate the purchase of real estate by people with disability who lack capacity, but which does not necessitate the obtaining of administration orders. (Many families talk about buying, or assisting their family members to buy, real estate, but are put off by the need to seek administration orders and the implications of rules of intestacy when their family member dies with substantial property in their name but no will).
- Related to the above, work with the States and Territories to bring in uniform “statutory wills” legislation across Australia for people who lack the capacity to make a will.
- Investigate capital gains tax concessions for real estate purchased for the primary use of a family member with a disability.
- Fund a range of succession planning initiatives throughout Australia, similar to *Pave the Way*, to assist families to plan for the future. (*Pave the Way* has, on invitation, visited Tasmania this year and Victoria last year but we are not funded to work outside Queensland).

### **2.3 Barriers in the relevant legislation to the establishment of Special Disability Trusts.**

Many of the barriers to the establishment of SDTs in the legislation are set out above. In summary these are:

- 2.3.1 The definition of “severe disability” is too restrictive – there are many families who might want to set up a trust fund for their family member with a disability who does not qualify because they receive award wages, if only part-time. There are a number of people working in supported employment who are in receipt of award wages.
- 2.3.2 Once money is in a SDT, it cannot be used for anything other than the purpose of the trust. Unless a family knows that they will never have to rely on funds in a SDT if their family circumstances change, they will not lock money away during their lifetime. Thus, while some families see



some benefit in setting up a SDT in their wills, few see any benefit while they are alive.

- 2.3.3 Trust funds can only be used for “care and accommodation” – thus many families will need at least two trusts, particularly if including a SDT in their will.
- 2.3.4 If trust fund income is not spent in any year, we are told it will be taxed at the highest marginal rate – thus funds will be spent unnecessarily to avoid this high tax burden and there will be no incentive for trustees to save unspent income for later use.
- 2.3.5 The maximum of \$500000 (indexed) is too low even for some families who are not considered wealthy in our society.
- 2.3.6 The limitation of one SDT per person could be a barrier to some families where parents are estranged and reluctant to work together to establish one common SDT into which they both make contributions.

#### **2.4 Possible amendments to the relevant legislation.**

In view of the above comments, *Pave the Way* submits that the following amendments be made to the current Special Disability Trust provisions:

- 2.4.1 The definition of “severe disability” be loosened so that any person in receipt of a disability support pension could be a beneficiary of a SDT. Children could be beneficiaries if their disability is such as to entitle a parent or carer to receive the Child Carer’s Allowance.
- 2.4.2 The assets in a SDT be unlimited. Funds in a properly established protective trust should not be deemed assets and income of the trust beneficiary. If a limit is deemed necessary, it should be set no lower than \$1M indexed.
- 2.4.3 Unexpended income not be taxed at the highest rate but be tax exempt, on the basis that the more income is available in the trust fund, the less demand on government resources. If taxing unspent income is deemed necessary, the tax rate should be the standard superannuation tax rate of 15%.
- 2.4.4 Trust expenditure be allowed to cover all the needs of the beneficiary, not merely “care and accommodation”.
- 2.4.5 There be no limit to the number of SDTs that could benefit any individual with a disability. If an asset limit is deemed necessary, that limit could apply across all SDTs established for a particular individual.

- 2.4.6 Where a SDT is set up inter vivos, Centrelink be given the power to approve the withdrawal of funds by the donor in appropriate “hardship” circumstances for a purpose other than to meet the needs of the beneficiary, eg, where parents or siblings are in financial distress.

### 3. Conclusion

*Pave the Way* has welcomed the opportunity to make a submission to this Senate Community Affairs Committee Inquiry. We would also welcome the opportunity to appear before a public hearing. If the Committee feels it would assist in its deliberations, *Pave the Way* could arrange for families with experience in these issues to attend a public hearing.

Contact person:

Jeremy Ward  
Manager  
Pave the Way  
Mamre Association  
1428 Logan Road  
Mt Gravatt Q 4122

(07)32915800

Email: [jeremy.ward@mamre.org.au](mailto:jeremy.ward@mamre.org.au)