



Submission to the Senate Community Affairs Committee Inquiry into Special Disability Trusts

Disability service providers supporting people with disability and their families constantly hear parents express concerns about the future: “What will happen when I die?” “What is the best way of providing for my son or daughter?” “What can I do to plan for the future?” The introduction of Special Disability Trusts, designed to assist people make additional provision for the support of their family members with a disability, was lauded as a concrete measure to assist some families address these concerns.

So far, however, the Special Disability Trusts have not delivered on their promise. Few have been established—although the level of provision for their establishment in wills is unknown. This inquiry into the barriers restricting their use is very timely.

NDS, therefore, welcomes the opportunity to make comment on how to improve the structure of the Special Disability Trusts to ensure they are a more effective and appropriate means of improving the lives of people with disability.

We recommend some extension of the eligibility criteria and the boundaries of allowable expenditure. We are conscious that liberalising the eligibility criteria and expenditure rules could increase the future risk of the Trusts being misused. However, with the historic and present inadequacy of government funding to meet current and future need for disability services, generous measures to encourage private provision are warranted. In this context overly restrictive rules pose a greater risk (in their discouragement of private provision) than more liberal rules.

Comments are restricted to Terms of Reference (2)(a) and (2)(d).

(a) why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts

- ***Restricted eligibility***

Legislation limits the use of a Special Disability Trust to a 'person with severe disability' (defined by reference to the Disability Support Pension and other criteria). This restriction prevents the use of such a Trust for other people with disability who could benefit, notably those with a significant degree of impairment to management, planning, judgement and/or decision making abilities but which are not of a magnitude to be defined as severe.

Legislation also prohibits the use of a Special Disability Trust to manage compensation payments, even in circumstances where the disability resulting from the injury may be severe. The favourable arrangements for the treatment of the income and assets of a Special Disability Trust could, if permitted, encourage an individual requiring ongoing support services to make some provision for that support to be financed.

- ***Restricted purpose***

Currently, the sole purpose of a Special Disability Trust is limited to meeting the 'reasonable accommodation and care needs' of the person with severe disability. The guiding principle of what the trust can pay for—the cost of accommodation; extra care costs arising from the disability; and incidental expenses such as fees for professional trustees, and investment and accounting expenses—does not adequately allow for the goods and services many families would wish to be able to provide.

People with severe disability in receipt of the Disability Support Pension are on a low income. Many families would like to be able to supplement the participation of their son or daughter with disability in community activities, to purchase goods or to take holidays; the restrictions on the use of a Special Disability Trust do not permit this type of support to be provided – although some of the restrictions are open to interpretation.

- ***Restricted number of families benefit from the initiative***

Many families that have provided support for their son/daughter with disability over many years have limited financial resources. And many parents of a person with disability can expect to live two decades or more once in receipt of an aged pension or when relying on their personal savings. Placing financial resources into a Special Disability Trust—making them inaccessible—is a difficult decision for someone who has limited resources and an indeterminable number of years to live.

Some of these parents, however, may make provision for the future establishment of a Special Disability Trust in their will.

The costs of establishing and administering a Special Disability Trust make it an unattractive option for people unless they have a significant amount of money to invest. NDS recently received this comment:

I am the proud mother of a young woman with a disability. Recently, I had cause to receive financial counselling as a consequence of my retirement. My counsellor investigated the projected outcome of transferring \$100,000 into a Special Disability Trust versus the use of a normal trust established via a will. The end result showed clearly that there would have been around a \$20,000 loss if we had chosen this avenue to pursue. This was on top of the limitations and associated costs of the Special Disability Trust. It seems to me that the benefits of using this system are not of much use to people.

Wealthier parents, who will not be seeking the aged pension, are better placed to seek financial investment advice and to put in place financial arrangements for their family member with a disability (which may include a Special Disability Trust as a component). It is believed that many of these families establish general trusts (which do not have a restricted purpose) to support their family member with a disability.

- ***Restricted access to future planning services and support***

With the increased longevity of many people with disability, families need to consider future disability support arrangements. This planning can be emotionally difficult and administratively complex—involving legal, financial, housing and support, and psychosocial decisions. Older carers, in particular, need support to undertake this planning. Financial planning needs to be viewed as part of a broad package of issues families have to consider as they make arrangements for the future.

In future planning discussions it is important that the person with disability is viewed as an individual in their own right—their future should not simply be determined by others. And in financial planning processes the wellbeing and needs of the person with disability should be considered along with those of other family members.

The booklet developed by the Department of Families, Housing, Community Services and Indigenous Affairs, *Planning for the future: people with disability*, provides useful advice to assist families make arrangements. However, some families require additional advice and support and do not know from where to seek this type of assistance.

There are indications that professional groups from whom families are likely to seek financial planning advice are not as well informed as they should be about the availability and nature of Special Disability Trusts.

(d) possible amendments to the relevant legislation

NDS supports the concept and intent of the Special Disability Trusts. To address some of the barriers to their use, NDS recommends the following changes to the Special Disability Trust rules.

- ***Broaden the eligibility criteria***

In recognition of concerns about the exclusion of people who would benefit from the establishment of a Special Disability Trust, NDS recommends that the eligibility criteria be extended to include people who have significant impairment to management, planning, judgement and/or decision-making abilities, but which are not of a magnitude to be defined as severe.

We acknowledge that identifying objective alternative criteria for determining eligibility will not be easy. An alternative to the current reliance on the Disability Support Pension impairment test is not obvious.

NDS recommends that the Government investigate the merits of permitting people who receive a compensation payment (and otherwise meet the eligibility criteria) to establish a Special Disability Trust to assist in the provision of their long-term support costs.

- ***Broaden the purpose of the Special Disability Trust***

To address families' concerns on the restrictions on allowable expenses (and to recognise the value of community participation), NDS recommends that the guiding principle for 'reasonable accommodation and care needs' be broadened.

The funding rules outlined by the Victorian Department of Human Services in its recently-released draft guidelines for the use of an individualised support package provide a model for how the purpose may be broadened. The draft guidelines (like the Special Disability trust rules) do not allow funds to be used as a form of income supplementation; however, they provide for circumstances where discretion may be exercised:

- Funding should not be used to meet costs that any other community member would reasonably be expected to pay. Discretion may be used where at least one of the following context statements applies:
 - The person's disability prevents them from accessing the service or item in the same way as the rest of the community.
 - There is a benefit to the person's health, wellbeing or fitness that would otherwise be unavailable.
 - Using disability funding for a community service or item is more cost effective than the person being allocated a higher cost, more intensive or restrictive support.
 - Using disability funding for an item or service that is instrumental in assisting the person to achieve the outcome of community access or participation that would otherwise be unachievable.

- The person is experiencing financial hardship in accordance with the Disability Services Undue Financial Hardship Guidelines.
- Disability funding cannot be used for:
 - anything that is illegal
 - gambling; or
 - complementary therapies that are not endorsed as part of a treatment plan and provided by a registered practitioner.¹

The Victorian draft guidelines give examples of broad “outcomes” toward which funds could be directed:

- being able to live as independently as possible
- being able to move to independent living
- continuing to live within a family environment
- to support the caring relationships with family or informal carers
- maximising opportunities for social networks, and community access and participation
- to develop skills and capacity to live their preferred lifestyle

In effect, the Victorian guidelines recognise that the line between community activities which foster social inclusion and disability support is unclear. Broadening the purpose of the Special Disability Trusts would support people with disabilities to live as active and valued members of their communities.

- **Reduce establishment and administrative costs**

NDS recommends the Government seek to reduce the costs associated with establishing and administering a Special Disability Trust—in particular, to reduce the currently onerous compliance burden of reporting and auditing. Apart from accommodation, current legislation only permits the Trust funds to be used for things which directly relate to the disability—determining this can be complex, time-consuming and, at times, hair-splitting.

In distinguishing between costs that arise from a person’s disability and other living expenses, expenditure approval processes may need to consider questions such as:

- What clothing expenditure can be identified as being required because of the disability? (NDS is aware of a person with acquired brain injury who constantly pulls and tears at his clothing so that items wear out quicker than would otherwise be the case.)
- What types (or proportion) of dental expenditure arise as the result of the disability? (Some people require additional dental work because teeth are weakened by medications; others who have impaired communication may not require additional dental work but do require longer dental appointments.)

¹ Disability Services Division, *Disability Services Individual Support package Guidelines (Draft 5 June 2008)* Melbourne, Department of Human Services, pp. 10–11.

- Can non-specialist goods or equipment be purchased on the grounds they are needed because of the disability? (For example, a person with mobility impairment may want to upgrade a garage door or a television because newer models include remote controls.)

A way of simplifying the decision-making on allowable expenditures needs to be found. NDS suggests that where a person's disability has a significant impact on the purchase that the whole cost of the purchase should be allowable.

To assist in the establishment of a Special Disability Trust, families with limited financial resources must have information on how to access low-cost legal and financial advice.

- ***Reduce the taxation payable***

While sympathetic to the taxation arrangements for a Special Disability Trust (which encourage the expenditure of income derived), NDS believes that the interest payable on unspent income should be reduced in circumstances where the Trust holds assets below the asset value limit—that when the Trust holds less than the asset value limit the taxation on interest earned be set at a much lower rate than the current 46.5 per cent. The taxation rate that will apply to the First Home Saver Accounts (15 per cent) provides a possible guide.

NDS recommends that further investigation be made into the merits of waiving the payment of capital gains tax on transfers to a Special Disability Trust.

- ***Indexation of the gifting concession***

Current arrangements allow a maximum of \$500,000 from immediate family members to be considered for the gifting concession. NDS recommends that this amount be indexed, in line with the indexation rate applied to the asset value limit of the Special Disability Trust.

- ***Improve the availability of future planning services***

The complexity of the future planning tasks faced by some families with a member with a disability—on issues of legal, financial, housing and support, and psychosocial arrangements—can be daunting and time consuming.

In addition to the provision of information (such as FaHCSIA's *Planning for the future: people with disability* booklet), many families need support to undertake this work. NDS recommends that increased services to support families engage in this planning for the future be made available.

In addition, further effort should be made to raise awareness and understanding of Special Disability Trusts among the professionals (lawyers, accountants, financial advisers) whom people typically consult when undertaking financial planning.

Families should also be reassured, by a clear statement in the guidelines, that by establishing a Special Disability Trust they will not preclude their family member with a disability from receiving any formal disability support services for which they are eligible.

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About National Disability Services

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes 630 not-for-profit organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.