



**Submission to the Inquiry into  
Special Disability Trusts**

June 2008

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**CA Submission to the Inquiry into Special Disability Trusts**

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## Executive summary

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Australia's 2.6 million carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail. Carers come from all walks of Australian society and come into the caring journey at various stages throughout their life.

Carers Australia welcomed the intent of the Special Disability Trusts (SDT) to allow families to make provision for their family members with disabilities. However, we believe that the initial promotion and marketing strategies did not clearly promote the benefits of the SDTs.

Feedback from carers has highlighted a number of concerns around SDTs including:

- the restrictive nature of the definition of those who are eligible for an SDT
- the restrictive nature of housing options
- the limitations on 'approved' care and accommodation expenses
- financial disincentives such as capital gains tax on the sale of the principal place of residence of the beneficiary and tax on undistributed income of the trust
- the complexity of an SDT
- costs associated with managing an SDT.

Other concerns that need to be taken into account when reviewing Special Disability Trusts include:

- the capacity of carers to plan for the future can be affected by the extent of care giving tasks
- long-term financial planning for people with a disability or illness is both complex and difficult
- financial planning for the future is multifaceted and involves most families with the need to have access to a wide variety of information and outside assistance
- carers often do not know where/how to access this information.

The complexity of legal, financial, housing and psychosocial planning tasks required of families, together with their ambivalence about future planning indicate a need for formal support systems to assist families to plan for the future. Outreach and engagement with caring families; the provision of quality information and advice; the development of high quality family workshops and information tools for the future are required.

Carers need to be able to access legal and financial planning support services that are inexpensive, well informed, and sensitive to disability issues and the needs of caring families.

### Recommendations:

Carers Australia recommends amendments to the current legislation around Special Disability Trusts to:

- allow donations to SDTs to be tax deductible
- remove financial disincentives by:

- allowing the sale of the principal place of residence of the beneficiary to be capital gains tax free and allowing undistributed income to be retained as capital accumulation without being taxed
- broadening the definitions of ‘approved’ care and accommodation expenses
- broaden the definition of a severe disability as set out in Part 3. 18A 1209M. (2) of the Social Security Act to allow more families to utilise SDTs
- allow compensation payments to be transferred to an SDT when the beneficiary is eligible for a disability support pension.

Carers Australia also recommends:

- strengthening Centrelink’s capacity to provide advice around financial planning and cost of living and promoting these capabilities to the community
- providing detailed information and material to community legal centres and other legal professionals to ensure they are able to provide carers with accurate information about legal and financial planning options
- developing and disseminating further information and resources for carers that clearly set out the intent of the SDT and that take account of the diversity of carers.

## **About Carers Australia**

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Association in each state and territory that deliver specialist information, counselling and other services to carers in the community.

Carers Australia is informed about carer issues through its member Carers Association (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

## **About Australia's Carers**

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care.<sup>1</sup> Many carers are termed 'sandwich carers or the sandwich generation' because they care for more than one person – a frail parent, a partner or a child with a disability or chronic condition. The majority of these carers are women.

Carers are the foundation of our aged and community care system, and the annual replacement value of the vital care that they provide is over \$30.5 billion. In 2005 it is estimated that carers provided 1.2 billion hours of unpaid care and the productivity loss of this care is approximately \$4.9 billion.<sup>2</sup> Governments rely heavily on carers' willingness and ability to provide care. Two thirds of all support for people with disabilities, chronic mental or physical illnesses or the frail aged is provided by carers<sup>3</sup>.

According to the ABS 2003 Disability, Ageing and Carers Survey, there are almost 1.25 million people with disabilities that have profound or severe limitations and of those 1.07 million live in private households. 79 per cent of people with a disability living in households received care from relatives and friends, mainly partners, parents or children.<sup>4</sup>

64 per cent of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation.<sup>5</sup> Additionally, family carers sustain the fabric and operational effectiveness of mental health services systems across Australia with individual carers on average contributing 104 hours per week caring for a person with a mental illness. For many carers this time includes periods they are 'on call' or alert for early warning signs arising with the person for whom they care.

The diversity of carers is an important consideration in designing and implementing policies, programs, material, information and resources. The Australian Bureau of Statistics has identified:

- 350,000 Australians under the age of 25 provide care to a family member who has a disability, or a mental or chronic illness<sup>6</sup>
- 170,000 carers under the age of 18<sup>7</sup>
- 31,600 Indigenous carers over the age of 15<sup>8</sup>

- 620,000 of Australia’s carers born outside Australia<sup>9</sup>
- 366,700 of those were born in other than main English-speaking countries<sup>10</sup>.

Caring often has many direct costs for the carer – it can adversely effect their financial position, employment and education prospects, health and wellbeing, and their ability to participate in social and community life. These personal costs often go unrecognised.

## **Carers Australia’s submission**

Our submission addresses matters in 2a and 2c of the terms of reference.

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

Carers Australia welcomed the intent of the Special Disability Trusts (SDT) that would allow families who are in a position to do so, to place up to \$500,000 in trust for the future care and accommodation of a family member with a severe disability. This would not impact on the income and assets test or effect eligibility for Disability Support Pension or Veterans Invalidity Pension: an excellent objective for a minority of families. It allows gifting to the SDT with no impact on the donors’ pension, although Capital Gains Tax must be paid on assets transferred to a trust.

It is understood that only 22 families have established Special Disability Trusts, with a further 100 likely to set these up through bequests. Feedback from carers however, indicates there are a number of reasons for the poor take up of Special Disability Trusts.

- Family carers of people with a severe disability are commonly in the lower income brackets with more than 50% in the lowest 2 income quintiles
  - many will be reliant on income security payments and many will experience reduced opportunities to access paid employment, and their accumulated assets or savings are often limited.
- Many families are overwhelmed at the notion of investing up to \$500,000 for the future care and accommodation of a family member
  - the marketing and promotion strategies used did not appear to clearly promote the benefits of putting smaller amounts in Trust, or the benefits of establishing a Special Disability Trust through a Will.
- It is not uncommon for older families of people with severe disabilities to have expectations that the state will provide ongoing care for their relative when they are no longer able to do so.
- The capacity for families to plan can be affected by the extent of care giving tasks, together with carer age, health status, education levels and access to information
  - older parent carers are usually women, likely to be single, and likely to be experiencing their own health problems
  - there may be heavy caring demands and restricted social networks for both the parent and the person with a disability
  - many parent carers are reluctant to relinquish care or find it difficult to conceive of their caring role ending

- many older families have not executed any plans for their own future, let alone planning for the person for whom they care
- for younger families planning and making provision for the future can be off the radar
- many families may have a preference for assuming a continuity of informal family care arrangements, even though these may not be made explicit.
- Long-term financial and care planning for people with a disability or illness is complex and difficult
  - national and international research has raised the reluctance of many families, particularly those caring for people with decision making disabilities, to plan for the future
  - few families actively make long term or financial plans, and many are ambivalent about future planning
  - trust arrangements can seem meaningless to carers without first having had the opportunity to consider where their family member will live, with whom, how their support needs will be met
  - access to appropriate and easily understood information to assist carers through this process appears to be limited
  - however, family concern about the future of the person with a disability is universal.
- Financial planning for the future is not discreet
  - it is multifaceted and involves most families with the need to marshal a wide variety of information and outside assistance
  - families may need to explore wills and estate planning, substitute decision making provisions such as Powers of Attorney, and a variety of optional trust arrangements
  - families may need an understanding of formal guardianship and financial administration systems
  - very pressing planning considerations include consideration of suitable supported housing arrangements and how these are accessed
  - encouraging relatives and friends to continue their involvement with the person with a disability may also be required and the development of emergency plans can be important.

These are all complex and difficult tasks.

- Special Disability Trusts are one of a number of available legal, financial and substitute decision making tools that are available to families with relatives who are disabled as a means of future planning and of contributing to their relative's ongoing well being.

The complexity of legal, financial, housing and psychosocial planning tasks required of families, together with their ambivalence about future planning indicate a need for formal support systems to assist families to plan for the future. Outreach and engagement with caring families; the provision of quality information and advice; the development of high quality family workshops and information tools about planning for the future are required.

In addition, there is a need to ensure families have access to legal and financial planning support services that are inexpensive, well informed, and sensitive to disability issues and the needs of caring families. These are currently not readily available.

Workforce development is required:

- within Community Legal Centres to ensure the availability of accessible, low cost disability sensitive legal advice to assist families to determine the most suitable legal and financial planning arrangements for them



- among key professionals who work with families of people with a disability, and who can provide them with information and support about available legal and financial planning options which may be relevant to the circumstances of individual families.

### **c) Barriers in the relevant legislation to the establishment of Special Disability Trusts**

Carers Australia watched the emergence of this initiative with great professional interest. We were disappointed to see the emergence of such a complex mechanism; a consequence we imagine of attempts to avoid use of such Trusts for tax avoidance purposes.

- Targeting is assumed to be directed at middle income families rather than those who are very wealthy and have greater options in making future arrangements for their son or daughter. However, longevity and longer periods of retirement for older parents of people with a disability, coupled with anxiety about their personal financial security can act as a disincentive to placing assets in a SDT.

#### **Barriers and restrictions**

- The definition of a severe disability for the purposes of an SDT is too restrictive and precludes those families of a person with a moderate disability who may have financial management, decision making and judgement impairments from utilising an SDT.
- Housing options that can be used by the beneficiary are limited to those funded wholly or in part under agreement between commonwealth, state or territory governments
  - this is a barrier for many families who may wish the Trust to invest in independent housing for their relative, or to invest in unstaffed housing cooperatives.
- Families consider clauses relating to leasing accommodation from a family member severely limits accommodation options for people with a disability.
- The limitations on ‘approved’ care and accommodation as defined in the guidelines are disappointing to families and require modification
  - families are disappointed that items such as medical expenses not related specifically to their disability, day to day living expenses, and general expenses around holidays, audiovisual equipment, clothes, furniture and recreation and leisure activities are excluded from care costs and that ordinary property maintenance and upkeep and utilities costs are excluded from accommodation costs
  - often these costs are beyond the capacity of a person reliant on the disability support pension
  - families may need to set up a second trust to cover these expenses and for many families the costs associated with running two trusts is prohibitive.
- Compensation payments with respect to a traumatically injured person are precluded from investment into a SDT. However, some families and people with a disability may opt to use the SDT as a means of preserving capital to generate income for the provision of additional care and support for their relative, who may also be eligible for Disability Support Pension. This can apply particularly when the person with a disability lacks financial management skills.
- The Special Disability Trust mechanism is too complex and must be simplified and made more responsive to family wishes

- many caring families are daunted by the complexity of Special Disability Trusts.
- Financial disincentives should be removed
  - unexpended income in the Trust in any one financial year can accumulate to meet future needs and not taxed at the highest marginal rate
  - capital gains tax paid on the sale of the primary place of residence when the property is placed in the trust is unfair and would not seem to fit with the intent of the special disability trust.
- There are stringent reporting and auditing requirements, even prior to the Trust becoming operational.
- The costs of managing an SDT can be significant. Prescription about who can prepare annual statements (CPA or Trustee Corporation) adds to the cost. The cost of legal advice about SDTs and investment, accounting and reporting expenses are significant and can mean that in excess of \$100,000 needs to be invested for the mechanism to be worthwhile.
- It is understood that Public Trustee organisations have had minimal demand for the creation of SDTs due to the potentially adverse effect that may result from the limitations imposed under the current requirements.

## **Recommendations**

Carers Australia recommends amendments to the current legislation around Special Disability Trusts to:

- allow donations to SDTs to be tax deductible
- remove financial disincentives by:
  - allowing the sale of the principal place of residence of the beneficiary to be capital gains tax free and allowing undistributed income to be retained as capital accumulation without being taxed
  - broadening the definitions of ‘approved’ care and accommodation expenses
- broaden the definition of a severe disability as set out in Part 3. 18A 1209M. (2) of the Social Security Act to allow more families to utilise SDTs
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Carers Australia also recommends:

- strengthening Centrelink’s capacity to provide advice around financial planning and cost of living and promoting these capabilities to the community
- providing detailed information and material to community legal centres and other legal professionals to ensure they are able to provide carers with accurate information about legal and financial planning options
- developing and disseminating further information and resources that clearly sets out the intent of the SDT and that takes account of the diversity of carers.

## References

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- <sup>1</sup> Australian Bureau of Statistics (2004). 2003 Disability, Ageing and Carers: Summary of Findings, Canberra
- <sup>2</sup> Access Economics (2005). The Economic Value of Informal Care, prepared for Carers Australia
- <sup>3</sup> Australian Institute of Health and Welfare (2001) Australia's welfare 2001. Cat. No. AUS 24. Canberra: Australian Institute of Health and Welfare.
- <sup>4</sup> Australian Bureau of Statistics (2004). 2003 Disability, Ageing and Carers: Summary of Findings, Canberra
- <sup>5</sup> ibid
- <sup>6</sup> Australian Bureau of Statistics (2005a) 2003 Disability, Ageing and Carers, Australia: Caring in the Community, Cat No 4430.0.55.003 Canberra
- <sup>7</sup> ibid
- <sup>8</sup> Australian Bureau of Statistics (2008) The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2008 Cat No 4704.0, Canberra, April 2008
- <sup>9</sup> Australian Bureau of Statistics (2003) Migrants, Disability, Ageing and Carers, Australia, 2003 Cat No 34150DS004, Canberra November 2007
- <sup>10</sup> ibid