

The Senate

Standing Committee on
Community Affairs

Building trust: Supporting families
through Disability Trusts

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42nd Parliament

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EXECUTIVE SUMMARY

Special Disability Trusts (SDTs) were introduced in September 2006 to assist parents and immediate family members wishing to make private financial provision for the current or future accommodation and care of a family member with a severe disability. SDTs were designed to enable families to make these provisions without reducing the person's entitlement to disability support pensions, age pensions, veteran pensions or related benefits.

Only a small number of SDTs have been established and there are substantial concerns about the effectiveness of the current arrangements. The eligibility requirements for SDTs are overly restrictive, such that many people with severe disabilities, including intellectual disabilities and disability resulting from mental illnesses, are not able to benefit from the trusts. The concessional limit on trust assets is too low and does not allow families and carers to effectively provide for the future.

The tax arrangements which currently apply to SDTs diminish their value for carers and people with disabilities. The application of capital gains tax to the sale of a beneficiary's primary residence and the high rate of tax applied to trust earnings are a particular disincentive to investing in the trusts.

The tight restriction on eligible uses of SDTs is a major shortcoming in the current arrangements. People see little point in setting aside funds if those funds cannot be used to provide the accommodation, care and support that their loved one needs to live as independently as possible.

The committee has made several focussed recommendations which will significantly improve the operation of SDTs and fulfil the original intention of assisting families that are able to make private financial provision for a member with severe disability. These recommendations can be implemented quickly through legislative changes. The committee has also made a number of wider recommendations to increase awareness of the trusts and reduce the complexity and costs of establishing and maintaining a SDT.

RECOMMENDATIONS

Chapter 2

Recommendation 1

2.28 The committee recommends that the special disability trust eligibility requirements in section 1209M of the *Social Security Act 1991* be amended to:

- remove section 1209M(b);
- include eligibility requirements which effectively enable those with intellectual disabilities or mental illnesses to become beneficiaries of special disability trusts.

Recommendation 2

2.47 The committee recommends that the asset value limit for special disability trusts in section 1209Y of the *Social Security Act 1991* be increased to \$1,000,000 and annually indexed according to a rate which reflects ordinary investment returns or the Consumer Price Index whichever is greater.

Recommendation 3

2.49 The committee recommends that the provisions relating to the special disability trust gifting concession be amended to annually index the gifting concession limit to the rate applied to the special disability trust asset value limit.

Recommendation 4

2.50 The committee recommends that, if after the adoption of the recommendations in this report there is no improvement in the uptake of special disability trusts after two years, options to expand eligibility for the gifting concession should be reviewed.

Recommendation 5

2.71 The committee recommends that the tax arrangements applying to SDTs be changed so that:

- the sale of a property that is owned by a special disability trust and used by the beneficiary as their principal place of residence be treated the same as any other person's principal place of residence, that is, exempt of capital gains tax;
- the transfer of property and other assets to a special disability trust is exempt from capital gains tax and stamp duty;
- unexpended special disability trust income is taxed at the beneficiary's personal income tax rate.

Recommendation 6

2.111 The committee recommends that the allowable uses of special disability trusts be expanded to include all day-to-day living expenses that are met to maximise the beneficiary's health, wellbeing, recreation and independence.

Recommendation 7

2.112 The committee recommends that unexpended income from a special disability trust be able to be contributed, on a pre-tax basis, to a superannuation fund for the trust beneficiary.

Recommendation 8

2.113 The committee recommends that when a special disability trust is used to purchase a first home for the trust beneficiary, the First Home Owner Grant should apply and be payable to the trust.

Chapter 3**Recommendation 9**

3.28 The committee recommends that the government review appropriate options to provide additional assistance to families establishing and maintaining a special disability trust including low cost legal and financial advice, as well as funding for the development of long-term planning.

Recommendation 10

3.29 The committee recommends that requests for audits of a special disability trust be restricted to one external audit per financial year, unless the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs determines this restriction should be waived.

Recommendation 11

3.30 That the single trust rule in section 1209M(6) of the *Social Security Act 1991* be amended to allow two trusts for each beneficiary.

Recommendation 12

3.51 The committee recommends that Centrelink be designated as the agency responsible and accountable for ensuring that special disability trusts are promoted and understood among families caring for members with disability.

Recommendation 13

3.52 The committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs in partnership with industry bodies and peak carer organisations develop a training package for financial and legal advisers focussed on future planning for carers of people with disability, including special disability trusts.

Recommendation 14

3.53 The committee recommends that the government consider changing the name of special disability trusts, for example to disability support trusts.

CHAPTER 1

INTRODUCTION

Terms of reference

1.1 On 15 May 2008 the Senate referred matters relating to Special Disability Trusts (SDTs) to the Community Affairs Committee for inquiry and report by 18 September 2008. These were:

(1) The Senate:

(a) notes:

- (i) the inclusion in 2006 of Part 3.18A – Private financial provision for certain people with disabilities – to the *Social Security Act 1991* to enable the establishment of special disability trusts, and
- (ii) that since the introduction of Part 3.18A and to 31 December 2007 only 22 trusts have been established; and
- (iii) recognises the potential benefits that special disability trusts can deliver for those living with a disability, but is concerned that there remain barriers to the establishment of special disability trusts that are limiting their wider beneficial application.

(2) The following matters relating to special disability trusts be referred to the Community Affairs Committee for inquiry and report by 18 September 2008:

- (a) why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts;
- (iv) the effectiveness of Part 3.18A of the *Social Security Act 1991*;
- (v) barriers in the relevant legislation to the establishment of Special Disability Trusts; and
- (vi) possible amendments to the relevant legislation.

On 18 September 2008, the Senate extended the reporting date to 16 October 2008.

Conduct of the inquiry

1.2 The inquiry was advertised in *The Australian* and through the Internet. The committee wrote to interested individuals and groups inviting submissions. The committee received 47 submissions relating to the inquiry and these are listed at Appendix 1. The committee held a public hearing in Canberra on 29 July 2008. Details of the public hearing are referred to in Appendix 2. The submissions and Hansard transcript of evidence may be accessed through the committee's website at http://www.aph.gov.au/senate_ca.

Background

1.3 SDTs were developed to assist parents and carers concerned about what would happen to a person with a disability when they were no longer able to provide care. Some parents and carers wished to use their own funds to provide, or to partly provide, for the accommodation and care of a person with a disability but were constrained by social security rules which may have altered their entitlements to disability support pensions, age pensions, veteran pensions or related benefits. They argued these means testing rules prevented them from planning a smooth transition for a person with a disability from family care to alternative arrangements.¹

1.4 On 13 October 2005 then Prime Minister, the Hon John Howard and former Minister for Family and Community Services, the Hon Dr Kay Patterson, announced a \$200 million package which included allowing the establishment of SDTs to assist parents and immediate family members wishing to make private financial provision for the current or future accommodation and care of a family member with a severe disability. Under the new trusts parents or other immediate family members of a person with a severe disability would be able to establish a trust worth up to \$500,000 (indexed annually) for the future care of that person without being affected by social security income tests or gifting rules.²

1.5 Also announced was the establishment of an advisory group to provide advice to government on some of the policy detail of SDTs.³ The advisory group consulted with peak organisations, individuals, parent groups and disability sector organisations and reported on 27 March 2006.⁴ On 20 September 2006 the Commonwealth Government amended the *Social Security Act 1991* to allow families to establish SDTs.⁵ As noted in the terms of reference, only a small number of SDTs have been established to date. The low take-up of the trusts and concerns about their operation expressed by families and carers provided the impetus for the committee's inquiry.

Special disability trusts

1.6 Under a SDT, the parents or other immediate family members of a person with a severe disability, are able to establish a trust to provide for the costs of the

1 Mr Spicer, *Submission 19*, p. 1.

2 Prime Minister John Howard, 'Private Trusts for People with Disability', *Media Release*, 13 October 2005.

3 Peter Yeend and Fiona Childs, 'Families, Community Services and Indigenous Affairs and Other Legislation (2006 Budget and Other Measures) Bill 2006', *Bills Digest*, 14 June 2006, no. 151 2005-06, p. 19.

4 Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *Submission 13*, Ministerial Advisory Group report, 'Planning for sons and daughters with severe disability', 27 March 2006.

5 *Families, Community Services and Indigenous Affairs and Other Legislation (2006 Budget and Other Measures) Act 2006 (No. 82, 2006)*.

accommodation and care of the person. A trust is an arrangement whereby property in a trust is managed by one person (the trustee) for the benefit of another (the beneficiary).

1.7 The concessions in relation to SDTs create exceptions to the ordinary means test rules applying to trusts for a person with severe disability. For SDTs the income and asset test rules and the gifting rules normally applied under the *Social Security Act 1991* and the *Veterans' Entitlements Act 1986* do not apply. This means the income from the trust will not affect the income support payments of the person requiring care. Assets in the trust up to a set limit are not included in means tests. The cap was originally set at \$500,000 and is indexed annually in line with the Consumer Price Index (CPI) (currently \$532,000 as at 1 July 2008).⁶ Consistent with the normal application of the social security assets test, the principal home of the beneficiary is exempt from the assets test.⁷ Also, contributions from immediate family members to the SDT will not be affected by the gifting rules in relation to means testing that would normally apply to the gifting person's social security or veterans entitlements. The gifting concession available is up to the value of \$500,000, which is not indexed.

1.8 In order to qualify as a SDT a trust must meet a number of requirements set out in the *Social Security Act 1991*. These include:

- the beneficiary requirements (section 1209M);
- the trust purpose requirements (section 1209N);
- the trust deed requirements (section 1209P);
- the trust requirements (section 1209Q);
- the trust property requirements (section 1209R);
- the reporting requirements (section 1209S); and
- the audit requirements (section 1209T).

1.9 Significant requirements for SDTs include that:

- a trust must have only one principal beneficiary;
- the principal beneficiary must be assessed as eligible;
- the trust must provide only for the accommodation and care needs of the principal beneficiary;
- the trust must have an independent trustee, or have more than one trustee (e.g. two or more family members); and

6 Peter Yeend and Fiona Childs, 'Families, Community Services and Indigenous Affairs and Other Legislation (2006 Budget and Other Measures) Bill 2006', *Bills Digest*, 14 June 2006, no. 151 2005-06, p.19.

7 FaHCSIA, *Submission 13*, p. 5.

- the trustee must provide annual financial statements and conduct independent audits when required.

Uptake of special disability trusts

1.10 When the measure was announced it was estimated that over four years 5000 people with severe disability would benefit from the establishment of SDTs. This estimate was derived from an analysis of the people reported to have profound core activity limitation and Centrelink data regarding the number of people in receipt of Disability Support Pensions being cared for by parents and/or people with high care needs and unlikely to be able to manage their own affairs.⁸

1.11 The most recent statistics provided by Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) are that at 30 June 2008 there were 33 special disability trusts operating and 262 people have been granted eligibility status as beneficiaries by Centrelink.⁹ However a SDT can be a testamentary trust (established through a will). FaHCSIA and a number of other submissions the committee received suggest that more people may be opting to create SDTs through their wills.¹⁰

Acknowledgements

1.12 The Committee wishes to express its appreciation to everyone who contributed to the inquiry by making submissions or appearing before it to give evidence.

8 FaHCSIA, *Submission 13*, p. 5.

9 Ms Emerson, FaHCSIA, *Proof Committee Hansard*, 29 July 2008, p. 103.

10 FaHCSIA, *Submission 13*, p. 14.

CHAPTER 2

BARRIERS TO THE ESTABLISHMENT OF SPECIAL DISABILITY TRUSTS

2.1 There are several key barriers to the establishment and use of SDTs which contribute to why few families with dependents with disabilities have established SDTs since they were introduced. Witnesses and submissions consistently highlighted problems with the eligibility requirements for SDTs, issues around the provisions for contributing to the trusts, the heavy tax regime applied to the trusts and the limitations on the allowed uses of trust funds. Taken together, these barriers were major disincentives for families that might otherwise seek to establish a SDT.

2.2 These key barriers are discussed in this chapter of the report. Other concerns relating to the operation of the trusts and to wider support for families caring for dependents with disabilities are discussed in the next chapter.

Eligibility restrictions

2.3 SDTs were introduced to assist those families caring for someone who was, and would continue to be, unable to provide for themselves. During the second reading of the Bill which introduced SDTs, then Senator the Hon Kay Patterson noted the measure was 'meant for people who have limited or no testamentary capacity and who cannot manage their own affairs'.¹

2.4 To be eligible to be a principal beneficiary of a SDT, a person must meet the requirements set out in section 1209M of the *Social Security Act 1991*. A beneficiary of a SDT must be:

a person who has reached 16 years of age:

- whose level of impairment would qualify the person for Disability Support Pension or who is already receiving a Department of Veterans' Affairs Invalidity Service Pension or Department of Veterans' Affairs Invalidity Income Support Supplement, and
- who has a disability that would, if the person had a sole carer, qualify the carer for Carer Payment or Carer Allowance or the person is living in an institution, hostel or group home in which care is provided for people with disabilities, and for which funding is provided (wholly or partly) under an agreement between the Commonwealth and states and territories, and

¹ Senator the Hon, Kay Patterson, *Senate Hansard*, 22 June 2006, p.71.

- who has a disability as a result of which he or she is not working and who has no likelihood of working for a wage that is at or above the relevant minimum wage.

2.5 A child under 16 years of age may be the beneficiary of a SDT if they meet the definition of a profoundly disabled child in section 197 of the *Social Security Act 1991*. Centrelink is responsible for assessing the eligibility of persons to be beneficiaries of proposed SDTs. A beneficiary eligibility assessment must be completed by Centrelink prior to a SDT being established

2.6 While the eligibility requirements for potential beneficiaries of SDTs are intended to target the concessions to those with severe disability and high level care needs, a number of submissions raised concerns that the criteria were operating to inappropriately exclude some people. For example the Trustee Corporations of Australia acknowledged that while SDTs are being offered on a targeted basis, the definition of 'severe disability' may be overly-restrictive, limiting the number of people who might potentially benefit from the concessions.² The Activ Foundation also argued that the eligibility criteria should be broadened to allow family members of people with moderate disability to establish a SDT. They noted that many people have 'a level of disability that does not qualify them for government funding, but is nonetheless at a level that means that they lack the management, planning and self care skills necessary to look after themselves...'.³ A number of issues regarding the eligibility requirements were raised including the carers allowance, intellectual disabilities and mental illnesses, institutional accommodation, minimum wages and possible reform to eligibility requirements.

Carer allowance requirement

2.7 The requirement that the beneficiary of a SDT must have a disability that would, if the person had a sole carer, qualify the carer for the carer payment or carer allowance was seen as too restrictive by many submitters. For example Mr Spicer, the former chair of the advisory group, noted that while the existing assessment process was important 'it may exclude some who might not require the degree of care needed to qualify for a carer payment or carer allowance but for whom privately funded support would be the difference between true independent living and ongoing family support or supervision'.⁴

2.8 The former Minister for Family and Community Services, the Hon Dr Kay Patterson noted that in using the carer payment or carer allowance the intention was to define eligibility to be a SDT beneficiary in such a way that it reduced, as much as possible, the need for further assessment. However she gave the example of a family who had to have further assessments because they had not realised they were eligible

2 Trustee Corporations of Australia, *Submission 16*, p. 2.

3 Activ Foundation, *Submission 9*, p. 2.

4 Mr Spicer, *Submission 19*, p. 6.

for the carer allowance, which involved two visits to a doctor and three visits to Centrelink.⁵ She stated:

It seems to me that if you are eligible for a disability pension and you are receiving Commonwealth assistance in a business service, supported employment or day care, it would be hard to say that that person was not eligible to be able to have a special disability trust...It would seem to me that one of the things that are really inhibiting people is that a lot of people have not applied for carers allowance...⁶

2.9 The committee was also concerned to hear that families were having additional burdens placed on them through assessments for the carer allowance or carer payment before they could be considered eligible for a SDT. Mr and Ms Walter noted that the eligibility requirements for SDTs were forcing families to apply for the carer allowance, a 'payment they may have been entitled to receive but not sought to receive in the past.'⁷ Mr West argued that the SDT application process needed to be less bureaucratic. He noted his son, who has cerebral palsy and had received a disability support pension for 22 years would still need to submit doctor and health service reports to verify his condition to apply for a SDT.⁸ Similarly Ms Johnstone commented that the carer allowance forms 'do very little to acknowledge that a person with a significant disability may still have well developed independent living skills, physically able, but nonetheless need the security of SDT...'⁹

Intellectual disabilities and mental illness

2.10 Several submitters noted that the eligibility requirements for beneficiaries of SDTs appeared to preference people with physical disabilities rather than those with intellectual disabilities or with mental illnesses.¹⁰ This accords with feedback which FaHCSIA has received in relation to SDTs.

Many people with disability, such as those with mental illness or impairment (for example autism, schizophrenia, bipolar or obsessive compulsive disorders) may not require care on a daily basis yet they may require ongoing care and supervision in relation to their financial and administrative affairs. At present, people in these categories may not pass the level of care criterion and therefore may not be eligible to be a beneficiary of a Special Disability Trust.¹¹

5 Dr Patterson, *Submission 43*, p. 1.

6 Dr Patterson, *Proof Committee Hansard*, 29 July 2008, pp. 1 and 5.

7 Mr and Mrs Walter, *Submission 21*, p. 4.

8 Mr West, *Submission 33*, pp. 2-3.

9 Ms Johnston, *Submission 45*, p. 1.

10 For example Mr and Ms Walter, *Submission 21*, p. 5 and Carers Australia, *Submission 18*, p. 6.

11 FaHCSIA, *Submission 13*, p. 15.

2.11 In particular, concerns regarding the application process for the carer payment were raised. Mr and Mrs Raine noted that there are not appropriate forms for applying for a SDT from Centrelink. They commented on the situation of their son Steven:

Steven suffers a permanent medical condition, a pervasive developmental disorder, which has been rigorously assessed and legitimately qualifies him for a Disability Support Pension, but this cannot be demonstrated on the 'Carer Payment' application forms which give very little scope to describe psychiatric / psychological impairment.¹²

2.12 The Public Trustees stated that anecdotally most inquiries in relation to SDTs are from the families of individuals with mental health disabilities, rather than physical disabilities. They also highlighted the difficulties in relation to eligibility:

Many persons with a severe mental health disability will meet the pension/support supplement requirements. However, due to the particular nature of many of the more common mental illnesses, one or more of the other criteria may not be fulfilled in many such cases. For example, the person may fail on the requirement that they live in a government-funded institution or qualify for a carer, or they may have a likelihood of working, at some point in time, for an above-minimum wage.¹³

2.13 Some submitters highlighted that people with disability with a significant degree of impairment to management, planning, judgement and/or decision making abilities would significantly benefit from SDTs, but were not eligible to be beneficiaries as their disabilities are not of a magnitude to be defined as 'severe'.¹⁴

Institutional accommodation

2.14 The eligibility requirements in sub-section 1209M(2)(b)(ii) of the *Social Security Act 1991* specifies that where the person with disability is cared for within an institutional/hostel/group home setting, that accommodation must be one that is funded, wholly or partly, under an agreement between the Commonwealth, states and territories. However FaHCSIA noted this may exclude people who live in accredited supported accommodation that is not funded publicly under such an agreement, such as Supported Residential Services in Victoria.¹⁵

2.15 Ms Hughes of Carers Australia also told the Committee this was also a barrier for families starting to think creatively about housing options for family member with disabilities. She argued that SDTs should be able to be used for different housing

12 Mr and Mrs Raine, *Submission 31*, p. 2.

13 Public Trustees of States and Territories and State Trustees Ltd, *Submission 22*, pp. 10-11.

14 National Disability Services, *Submission 15*, p. 2.

15 FaHCSIA, *Submission 13*, p. 15.

options, including independent housing or investment in unstaffed housing cooperatives.¹⁶ The eligible uses of SDTs are discussed further later in this chapter.

Minimum wage

2.16 Concerns were also raised that people with disability who are employed in disability business services and who might receive award wage may be excluded from eligibility. For example Pave the Way, Mamre Association argued that:

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.¹⁷

2.17 The Trustee Corporations of Australia noted that providing for people with mental illnesses has particular difficulties over and above those for a person with physical disability. Due to the fact that mental illness can be episodic and sufferers may do part time or casual work they may find it difficult to qualify for a SDT.¹⁸

Possible eligibility changes

2.18 Given the limited uptake of SDTs to date, the committee received broad support for more flexible eligibility rules concerning who could be a beneficiary of a SDT. However there was little agreement on the detail of how this should be done. National Disability Services acknowledged 'that identifying objective alternative criteria for determining eligibility will not be easy'.¹⁹ Dr Baker of National Disability Services acknowledged that while expanding access to SDTs also risked expanding the misuse of those trusts but argued the greater risk was in deterring people who might be willing and able to set aside assets for the care of a person with a disability. He noted:

In many of these cases the choice really is between a person with a disability being wholly dependent on government or partially dependent, with the supplementation of a special disability trust.²⁰

2.19 A number of submissions suggested that SDT eligibility should be open to anyone who qualified for a disability support pension.²¹ The National Council on Intellectual Disability recommended that all people be eligible to be the beneficiary of a SDT or 'at a minimum that it applies to all person who receive a full or part DSP, but

16 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p.13.

17 Pave the Way, Mamre Association, *Submission 14*, p. 8.

18 Trustee Corporations of Australia, *Submission 16*, p. 2.

19 National Disability Services, *Submission 15*, p. 4.

20 Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 75.

21 For example Pave the Way, Mamre Association, *Submission 14*, p. 9.

that the ABS definition of needing assistance in one or more daily activities be made the criteria.²² Mr Pattison of the National Council on Intellectual Disability argued that as long as people are eligible for the disability support pension, they should be eligible for a SDT. He stated:

I think it becomes very hard to set rules for who is in and who is out, so I would just set the rule, 'Everyone in.'²³

2.20 Similarly Sunnyfield Independence argued that the current restrictions discriminate against people with a disability that do not meet the SDT definition of 'severe disability' and recommended that all people with a disability be able to access a SDT.²⁴

2.21 The Public Trustees suggested that consideration be given to amendments that would increase the prospect of persons with mental health disabilities being eligible for a SDT. They suggested options could include different criteria for persons with such disabilities or requiring a qualifying pension, plus one or more (but not necessarily both) of the carer/institution requirement; and the inability-to-work requirement. Others such as Winacom suggested that any person with an intellectual disability which entitles that person to a disability support pension should be able to access a SDT without reference to carer payment or carer allowance eligibility.²⁵

2.22 Mr and Mrs Walter outlined a number of options to extend eligibility to SDTs. These included allowing persons eligible for a special disability service funded through the Commonwealth State Territory Disability Agreement to be eligible or that eligibility assessments should be made through an independent panel.²⁶

2.23 While agreeing that a more flexible eligibility test could be considered, Mr Ian Spicer argued that 'every effort should be made to utilise an existing assessment test rather than creating a new one'.²⁷ He noted the burden of multiple assessments on people with disabilities and their families and carers.²⁸ Similarly the Hon Dr Patterson noted that 'the intention was to make it easy for genuine applicants to qualify' for SDTs and suggested that criteria be relaxed so that 'older parents and carers do not have to jump through interminable hoops'.²⁹

22 National Council on Intellectual Disability, *Submission 11*, p. 8.

23 Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, p. 34.

24 Sunnyfield Independence, *Submission 46*, p. 9.

25 Winacom Association, *Submission 6*, p. 9.

26 Mr and Ms Walter, *Submission 21*, p. 5.

27 Mr Spicer, *Submission 19*, p. 6.

28 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 73.

29 Dr Patterson, *Submission 43*, p. 1.

Committee comment

2.24 The committee agrees that the eligibility requirements for a person with a disability to be a beneficiary of a SDT should be made more flexible. As a number of witnesses noted during the inquiry, it is difficult to construct objective eligibility requirements which are fair to all. The committee is also conscious that people with disabilities and their families and carers are already subject to many assessments and does not wish to add to that burden.

2.25 The evidence the committee has received indicates that the requirement in section 1209 (b) (i) and (ii) of the *Social Security Act 1991* are the key problem for SDT eligibility. This is the requirement that a beneficiary of a SDT must have a disability that would, if the person had a sole carer, qualify the carer for the carer payment or carer allowance or that the person must be living in an institution, hostel or group home in which care is provided for people with disabilities, and for which funding is provided (wholly or partly) under an agreement, between the Commonwealth, the states and the territories.

2.26 Removing this requirement would mean that to be eligible for a SDT a person would still need to qualify for a disability support pension (or appropriate veteran's entitlement) and would need to have a disability as a result of which he or she is not working and would have no likelihood of working for a wage that is at, or above, the relevant minimum wage.

2.27 The committee is also concerned that the current eligibility criteria are not capturing some people with intellectual disabilities or mental illnesses. The committee considers that SDTs are an appropriate mechanism to assist these individuals. The committee is recommending that changes be developed to the criteria to allow persons with intellectual disabilities or mental illnesses to become beneficiaries of SDTs. These criteria should be developed by FaHCSIA in conjunction with peak disability bodies.

Recommendation 1

2.28 The committee recommends that the special disability trust eligibility requirements in section 1209M of the *Social Security Act 1991* be amended to:

- **remove section 1209M(b);**
- **include eligibility requirements which effectively enable those with intellectual disabilities or mental illnesses to become beneficiaries of special disability trusts.**

Contributions

Capacity to contribute

2.29 Several submissions noted that families of a person with a disability frequently have very limited to capacity to contribute to SDTs.³⁰ The National Council on Intellectual Disability noted that SDTs only address the needs of a minority of families living with disability and that 'the majority of families do not have excess resources to set aside for the future'.³¹ This echoed feedback received by FaHCSIA from consultations in 2007 that indicated many parents, because of the costs of disability and caring, may not have accumulated many assets during their lifetime and may not be able to financially provide for their child's future without significant government assistance.³²

2.30 The Kew Cottages Parents' Association argued that the base threshold needed to make a SDT worthwhile was unachievable for the majority of parents. They indicated that the minimum amount required to counteract the costs and restrictions associated with a SDT was in the order of \$200,000 and that an extremely low number of parents would be able to place this sum or more in a special needs trust for their child.³³ The committee also received evidence that many parents with disabled children may be including SDTs in their wills. Many of these testamentary trusts will be able to incorporate the assets of the estate.

Contributions by beneficiary

2.31 Once a SDT has been established anyone can contribute any amount, subject to a number of exceptions. The SDT beneficiary or their partner may not contribute to SDT, but the beneficiary may transfer to the SDT any assets that are received as a bequest or superannuation death benefit not more than three years after receiving the bequest or benefit. FaHCSIA noted that the reason for this restriction is that SDTs were created to allow for immediate family members to make provision for the beneficiary and were 'not intended to allow the beneficiary to move their assessable assets for social security purposes into an unassessable environment'.³⁴

2.32 However the Winacomm Association argued it was 'very unfair' beneficiaries could not contribute funds to a SDT given that SDT funds were currently only able to

30 For example Autism Aspergers Advocacy Australia, *Submission 2*, p. 2.

31 National Council on Intellectual Disability, *Submission 11*, p. 3.

32 FaHCSIA, *Submission 13, Succession Planning for Carers: Summary of Consultations*, July 2007, p. 6.

33 Kew Cottages Parents' Association, *Submission 8*, p. 3.

34 FaHCSIA, *Submission 13*, p. 6.

be used for accommodation and special needs care.³⁵ Mr Gresswell of the Winaccomm Association argued:

...in relation to funds contributed to the special disability trust, a beneficiary of a special disability trust should be allowed to contribute funds either from superannuation or own savings to the trust as long as the trust utilises those funds for the purposes of care and accommodation for the beneficiary.³⁶

Concessional asset limit on SDTs and indexing

2.33 There is no limit on the value of assets that can be held in a SDT. However where assets in the SDT exceed the concession limit, they are assessable for social security income support purposes. The concession limit was initially set at \$500,000 on 20 September 2006 and is annually indexed to the Consumer Price Index (CPI). On 1 July 2008 the concession limit was \$532,000.

2.34 There was broad support from submitters supporting the recommendation that the concessional limit on trust assets should be approximately doubled to \$1 million.³⁷ The consensus was that there was no clear justification for the current limit and that the limit was too low given the current and likely future costs of care and accommodation for a person with a disability for a long period. Mr Spicer commented:

I think if you are really looking at the provision of care or support for a person with a significant disability the amount of money that would have to be set aside is well in excess of that which might be earned by a \$500,000 trust. It needs to certainly be more than that and it appeared in the submissions and the consultation that \$1 million was getting closer to the mark.³⁸

2.35 Sunnyfield Independence questioned the validity of indexing the concession limit in line with CPI. They argued:

If the trustee accumulates a surplus of income over expenses in the SDT for the future care of the beneficiary with a disability... then over time the disability support pension may be reduced or lost if the accumulated surpluses exceed the amount of CPI indexing.

35 Winaccomm Association, *Submission 6*, p. 11.

36 Mr Gresswell, Winaccomm Association, *Proof Committee Hansard*, 29 July 2008, p. 47.

37 For example The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 4; Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 77; Winaccomm Association, *Submission 6*, p. 5; National Council on Intellectual Disability, *Submission 11*, pp. 8-9; Pave the Way, Mamre Association, *Submission 14*, p. 9; Sunnyfield Independence, *Submission 46*, p. 5.

38 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 70.

2.36 Instead of CPI, they recommended the appropriate indexing factor would be the Official Cash Rate which is a closer proxy for the prudent investment returns a trustee should be striving to achieve for the beneficiary of the trust.³⁹

Gifting concession

2.37 The gifting concession is available to immediate family members of the beneficiary who are of pension age and make a contribution to the SDT. The concession is an exemption for contributions to the SDT of up to the value of \$500,000 from the usual social security or veterans' entitlement rules relating to making gifts or disposal of assets.

2.38 The current definition of 'immediate family member' includes: natural parents; legal guardians (that is, a person who is, or was, the legal guardian of the person with severe disability while that person was under 18 years of age); adoptive parents; stepparents; grandparents; and siblings (that is, brother, sister, half-brother, half-sister, adoptive brother, adoptive sister, step-brother or step-sister).⁴⁰

2.39 Mr Ward of Pave the Way, Mamre Association noted that immediate family members are not the only individuals who make financial contributions to support people with disabilities and that extended family members and close friends often also provide support.⁴¹ The National Council on Intellectual Disability highlighted that the definition of immediate family member does not include other people who may have a special relationship with the person with a disability, such as aunts, uncles and godparents. They recommended that the definition be extended or removed so anyone can contribute to a SDT.⁴²

2.40 Unlike the SDT concessional asset limit, the gifting concession limit is not currently indexed. National Disability Services recommended that the gifting concession limit be indexed in line with the indexation rate applied to the asset limit of the SDT.⁴³

2.41 Some witnesses argued that further incentives could be offered to encourage contributions to SDTs. Several submissions suggested or recommended that SDT contributions could be made tax deductible.⁴⁴ Mr Ward also noted that families were

39 Sunnyfield Independence, *Submission 46*, p. 17.

40 FaHCSIA, *Submission 13*, p. 6.

41 Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 63.

42 National Council on Intellectual Disability, *Submission 11*, p. 6.

43 National Disability Services, *Submission 15*, p. 6.

44 For example Carers Australia, *Submission 18*, p. 10; National Council on Intellectual Disability, *Submission 11*, p. 6; Activ Foundation, *Submission 9*, p. 4; Mr Spicer, *Submission 19*, p. 12.

contributing to SDTs with 'post-tax money that they are saving'.⁴⁵ Mrs Breheny told the committee:

If people are going to take on the whole and sole care of their family member with disability and not apply to the government for funding I do not see why it should not be tax deductible.⁴⁶

2.42 Mr Pattison of the National Council on Intellectual Disability noted that if a person with a disability were receiving support from an organisation that was eligible to be deemed a charity, donations to that support organisation would be tax deductible. However he also noted that this option had received limited support from some families when it had been raised previously.

When we raised that as an option right back at the very beginning, some families said, 'No, we don't want that because we don't want to be seen as a charity. We don't want our son and daughter to start having all these charity rules and everything else put upon them.'⁴⁷

Compensation awards

2.43 Under the current arrangements the assets of a SDT must not include any compensation received by or on behalf of the beneficiary.⁴⁸ The FaHCSIA information booklet on SDTs, *Special Disability Trusts: getting things sorted*, notes that this rule is 'intended to preserve the existing treatment of compensation payments'.⁴⁹ The rule relates to a general social security principle that people who are receiving compensation for loss of income should not also receive income support from the government for the same period.⁵⁰

2.44 Nonetheless, some submissions recommended that people with disabilities (who otherwise meet the beneficiary requirements) should be able to contribute compensation payments into SDTs. National Disability Services noted that the favourable arrangements for the treatment of the income and assets of a SDT could, if permitted, encourage an individual requiring ongoing support services to make some provision for that support to be financed.⁵¹ Ms Hughes of Carers Australia commented:

I think we need to look at the increasing numbers of young people who suffer acquired brain injury through catastrophic injury. Those people will

45 Mr Ward, *Proof Committee Hansard*, 29 July 2008, p. 63.

46 Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 84.

47 Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, p. 28.

48 *Social Security Act 1991*, subsection 1209R(2)

49 FaHCSIA, *Submission 13, Special Disability Trusts: getting things sorted*, 2007, p. 16.

50 FaHSCIA, *Guide to Social Security Law*, Section 4.13.1.30.

51 National Disability Services, *Submission 22*, p. 2.

need to be cared for in some way for the rest of their lives, and their levels of care and therapy will be very high for different periods in their lives. I think that is a group that could really benefit from a special disability trust if some of those compensation payments could be put into it.⁵²

2.45 The Public Trustees noted that they were often the trustees of choice for courts in matters related to accidents and injuries suffered by people involved in motor vehicle accidents, workers compensation and personal injury cases. They highlighted that the NSW State Government has capped awards for workers compensation, motor vehicle compulsory third party personal injury and that due to capping 'awards are not always sufficient to provide full and adequate care and because the award may be over the Centrelink threshold the beneficiary is not eligible for a pension'. If the award was able to be contributed to a SDT, a pension may be available to the beneficiary.⁵³

Committee comment

2.46 Given the high costs of caring for a person with a disability, both currently and into the future, the committee agrees that the current concessional asset limit for SDTs is too low. The committee recommends that the limit be increased to \$1 million and annually indexed according to a rate which reflects ordinary investment returns or the Consumer Price Index whichever is greater.

Recommendation 2

2.47 The committee recommends that the asset value limit for special disability trusts in section 1209Y of the *Social Security Act 1991* be increased to \$1,000,000 and annually indexed according to a rate which reflects ordinary investment returns or the Consumer Price Index whichever is greater.

2.48 The committee agrees that the gifting concession should be indexed to the rate applied to the special disability trust asset value limit. The committee supports measures to encourage the community to assist with the care and accommodation of people with a disability. However the committee was concerned that some proposals to extend the definition of 'immediate family member' would expand the eligibility for the gifting concession inappropriately. In the opinion of the committee, if after the adoption of the recommendations in this report there is no improvement in the uptake of SDTs in the next two years, options to expand eligibility for the gifting concession should be reviewed.

Recommendation 3

2.49 The committee recommends that the provisions relating to the special disability trust gifting concession be amended to annually index the gifting concession limit to the rate applied to the special disability trust asset value limit.

52 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 13.

53 Public Trustees of States and Territories and State Trustees Ltd, *Submission 22*, p. 11.

Recommendation 4

2.50 The committee recommends that, if after the adoption of the recommendations in this report there is no improvement in the uptake of special disability trusts after two years, options to expand eligibility for the gifting concession should be reviewed.

Tax on trust assets and earnings

2.51 The tax arrangements which currently apply to SDTs diminish their value for carers and people with disabilities. The application of capital gains tax to assets transferred to SDTs and to the sale of a beneficiary's primary residence and the high rate of tax applied to trust earnings were of particular concern. These issues are discussed below.

Capital gains tax payable

2.52 FaHCSIA described two possible capital gains tax events in relation to SDTs:

- If a parent purchased a property a number of years ago (after 20 September 1985) and wants to place that property in the Special Disability Trust as the beneficiary's principal place of residence, the property would be subject to capital gains tax.
- Unlike any other owner-occupied property, a Special Disability Trust which owns the beneficiary's principal place of residence incurs capital gains tax if that residence is sold, for example, in order to purchase accommodation for the beneficiary elsewhere so as to be close to services.⁵⁴

2.53 Mr and Mrs Wilson and Mr Gresswell, members of Winacomm Association, emphasised that the first of these capital gains situations is a 'big drawback' to parents making financial provisions for their son or daughter during their lifetime, as they are likely to incur significant capital gains tax.⁵⁵ Similarly members of Autism Aspergers Advocacy Australia observed that most families cannot afford the capital gains payable on stocks and the stamp duty on property if they are transferred into an SDT. They considered that waiver of capital gains and stamp duty on assets transferred into an SDT would 'free up significant opportunities' for families to contribute to the trusts.⁵⁶ Submitters also suggested that allowing tax issues to be deferred until the trust is wound up would alleviate the current disincentives.⁵⁷

54 FaHCSIA, *Submission 13*, pp. 17–18.

55 Winacomm Association, *Submission 6*, p. 9; see also Disability Services Commission, *Submission 3*, p. 2; Kew Cottages Parents' Association, *Submission 8*, p. 3; Activ Foundation, *Submission 9*, p. 3; Mr and Mrs Smale, *Submission 32*, p. 1; Mr Hughes, *Submission 42*, p. 2; Mrs McGarry, *Submission 44*, p. 1;

56 Autism Aspergers Advocacy Australia, *Submission 2*, p. 4.

57 Mr Spicer, *Submission 19*, p. 10.

2.54 Mr and Mrs Walter recommended that:

If it can be shown that a property was purchased solely for the purpose of accommodation for a disabled family member and held in a trust or in the name of the purchaser and never used as a rental investment property it should be able to be transferred to a SDT without incurring Capital Gains Tax.⁵⁸

2.55 The committee received one example where an Australian Taxation Office private ruling had provided exemption for capital gains tax for the transfer of property from an established trust to a SDT.⁵⁹

2.56 The second possible instance of capital gains tax, the sale of a beneficiary's principal residence, was a particular source of consternation among submitters and witnesses to the inquiry.⁶⁰ Witnesses pointed to the inherently discriminatory practice of applying capital gains tax to the principal residence of a person with disability, whose residence is owned by a SDT, but not to the principal residence of any other members of the community. Mr and Mrs Walter asked:

Do you believe it is fair, just and reasonable that some people with disabilities have been singled out to be the only members of our community to pay Capital Gains Tax on the sale of their place of residence?⁶¹

2.57 SDTs are also liable for state and territory taxes and levies associated with transfer or acquisition of property, such as land tax, stamp duty and emergency levies. The FaHCSIA noted that the Western Australian Government offers stamp duty concessions to trusts acquiring property on behalf of disabled beneficiaries.⁶²

Tax on trust income

2.58 Income from SDTs is taxed in the same way as other trusts. The tax-free threshold that applies to individual income does not apply to income from an SDT. Therefore, all unexpended SDT income is taxed and it is taxed at the top marginal rate, currently 46.5 per cent.⁶³

58 Mr and Mrs Walter, *Submission 21*, p. 6.

59 Mr and Mrs Broughton, *Submission 26*, p. 2.

60 See for example, The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 2; Ms Hughes, Carers Australia *Proof Committee Hansard*, 29 July 2008, p. 14; Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 66; Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 79; Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 81 and *Submission 21*, pp. 3 and 9; Kew Cottages Parents' Association, *Submission 8*, p. 3; Activ Foundation, *Submission 9*, p. 3; People with Disabilities Inc, *Submission 12*, p. 2.

61 Mr and Mrs Walter, *Submission 21*, p. 3.

62 FaHCSIA, *Submission 13*, p. 18.

63 FaHCSIA, *Submission 13*, p. 17.

2.59 Witnesses described these tax measures as punitive and a major disincentive to accumulating funds in the trust.⁶⁴ Currently trust funds can only be used for very specific purposes, making it quite possible that not all fund income will be used in a particular year and therefore will be liable for the high rate of tax.

2.60 The tax rate that currently applies to SDT income limits families' ability to accumulate funds in the trust to cover the larger expenses that often occur later in the beneficiary's life. For example, parents may want to save up to purchase independent accommodation for the person with disability or to pay for care and support when they are no longer able to provide these themselves. General health costs also increase later in life. FaHCSIA reported that it had received feedback noting the difficulty families have estimating the level of funds required to pay for a beneficiary's care and accommodation into the future.⁶⁵

2.61 Mr Spicer noted that the high tax rate on undistributed trust income discourages people from setting up an SDT before their death and building it up over time. He pointed to two major consequences: the resources in the trust available for the support of the person with disability are limited, and families are discouraged from planning for the future of their loved one with disability.⁶⁶

2.62 Mr Gresswell, who has made provision for an SDT in his will described the current disincentive for establishing an SDT earlier:

...at the moment to set up a trust to buy him his own accommodation I would be incurring significant income tax from the trust income. That is because right now he does not need a lot of medical care, for instance, but down the track he may well do. At the moment, the situation does not warrant setting up a trust. If it did not have the drawback, yes, I certainly would consider setting it up for him.⁶⁷

2.63 Carers Australia suggested that undistributed income should be retained as capital accumulation within the trust without being taxed.⁶⁸ Representatives from Winacomm Association agreed that no tax should be paid on undistributed income retained in the trust. Mr Gresswell of Winacomm Association Inc, noted that any remaining undistributed income could be taxed at a reasonable rate when the SDT was

64 See for example, Mr Gresswell, Winacomm Association, *Proof Committee Hansard*, 29 July 2008, p. 47 and *Submission 6*; Mr Spicer, *Proof Committee Hansard*, 29 July 2008, pp. 73–74 and *Submission 19*, p. 11; Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 81; Disability Services Commission, *Submission 3*, p. 1; Mr O'Hart, *Submission 5*, p. 10; Public Trustee of Western Australia, *Submission 7*, pp. 2–3; Activ Foundation, *Submission 9*, p. 3; Mrs Breheny, *Submission 24*, pp. 1–2; Sunnyfield Independence, *Submission 46*, p. 14.

65 FaHCSIA, *Submission 13*, p. 17; see also Sunnyfield Independence, *Submission 46*, pp. 15–16.

66 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 73.

67 Mr Gresswell, Winacomm Association, *Proof Committee Hansard*, 29 July 2008, p. 49; see also Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 87.

68 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 14.

wound up.⁶⁹ Winacomm Association considered that 'at worst, tax on unexpended income should be in line with superannuation funds (at 15%)'.⁷⁰ Mr O'Hart suggested that nil tax, tax at 15 per cent similar to superannuation or tax at 30 per cent similar to company tax would all be preferable to the current situation.⁷¹

2.64 Mr Spicer outlined that there are a range of options for rectifying the high tax on undistributed SDT income. These include using special tax rates built into the trusts or deferring tax until the trust is wound up and disbursed.⁷² The Trustee Corporations of Australia and others suggested that it would be appropriate for SDTs to be treated the same way as a compensation trust, where 'the trust and the beneficiary are taxed as one using the beneficiary's tax rate'.⁷³

Other tax concerns

2.65 Mr Gresswell of Winacomm Association raised a further concern about the treatment of undistributed SDT income. He was concerned that SDT beneficiaries may become liable for income tax:

If one assumes that the beneficiary could have other income such as wages from working in supported business service, for example, then with this income added to the income distributed from the special disability trust, it could place them in a tax-paying situation. This would seem to be an anomaly that was not predicted and should be rectified.⁷⁴

2.66 Winacomm Association suggested that unexpended income from the trust should not be included in the income test applied by Centrelink. The Hon Dr Patterson saw merit in applying this approach after a certain age, similar to the superannuation benefits 'enjoyed by people who have the opportunity of super and do not have a disability'. The Hon Dr Patterson suggested 55 years, or perhaps 50 years, would be an appropriate age for this tax concession, given that people with disability usually exhibit ageing issues earlier than those who are not disabled.⁷⁵ Currently separate income tax is not paid on the SDT income, which as discussed above is already taxed at the highest rate, and income generated by the trust is not included in Centrelink income assessment. However these concerns need to be taken into account in making any changes to the existing tax arrangements.

69 Mr Gresswell, Winacomm Association, *Proof Committee Hansard*, 29 July 2008, p. 47.

70 Winacomm Association, *Submission 6*, p. 12; see also *Pave the Way*, Mamre Association, *Submission 14*, p. 9.

71 Mr O'Hart, *Submission 5*, p. 10.

72 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 73.

73 Trustee Corporations of Australia, *Submission 16*, p. 5; see also Mr and Mrs Broughton, *Submission 26*, p. 6; Mr Hughes, *Submission 42*, p. 3; The Hon Dr Patterson, *Submission 43*, p. 43.

74 Mr Gresswell, Winacomm Association, *Proof Committee Hansard*, 29 July 2008, p. 48.

75 The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 4.

2.67 The Public Trustees raised the issue of 'whether a special disability trust consisting of monies arising both from a deceased estate and from an inter-vivos donation will retain the more favourable characteristics of the testamentary trust for taxation purposes'. The Public Trustees called for an Australian Taxation Office ruling on such matters.⁷⁶

2.68 FaHCSIA commented that issues around income tax and capital gains tax on SDTs are issues for Treasury and the Australian Tax Office.⁷⁷ While changes to the tax arrangements for SDTs will indeed require coordination across different government departments, the committee considers that FaHCSIA, as the department responsible for the trusts and the portfolio encompassing disability, has a clear responsibility to work with other areas of government to make sure the trusts work in practice.

Committee comment

2.69 It is obvious to the committee that the tax arrangements that currently apply to SDTs are a major disincentive for families considering setting up such a trust. For families that have already established some private provisions for a loved one with disability, such as purchase of a property, there are disincentives for moving these assets into a SDT. The application of capital gains tax to the sale of beneficiary's principal residence, where that residence is owned by the SDT, is fundamentally inconsistent with the treatment of the principal residences of other members of the community. The committee considers that this is a critical flaw in the current SDT arrangements requiring urgent rectification.

2.70 The committee is strongly of the view that the tax rate that applies to unexpended income returned to a SDT needs to be changed. The current 46.5 per cent tax rate is a major disincentive to using a SDT to build up funds to support someone with a disability throughout their life. Particularly as healthcare and support costs can increase in the later years of life, mechanisms should be in place to support, not discourage, growth of the trust.

Recommendation 5

2.71 The committee recommends that the tax arrangements applying to SDTs be changed so that:

- **the sale of a property that is owned by a special disability trust and used by the beneficiary as their principal place of residence be treated the same as any other person's principle place of residence, that is, exempt of capital gains tax;**
- **the transfer of property and other assets to a special disability trust is exempt from capital gains tax and stamp duty;**

76 Public Trustees of the States and Territories and State Trustees Ltd, *Submission 22*, p. 5.

77 *Proof Committee Hansard*, 29 July 2008, p. 108.

- **unexpended special disability trust income is taxed at the beneficiary's personal income tax rate.**

Eligible uses of the trust

2.72 Currently, the *Social Security Act 1991* states that the sole purpose of a SDT 'must be to meet the reasonable care and accommodation needs of the beneficiary'.⁷⁸ Ancillary purposes, necessary to facilitate this primary purpose are also allowed. Beneficiaries cannot derive an income from the SDT and immediate family members cannot be paid for providing care to the beneficiary or maintenance to their home.

2.73 Guidelines issued by the Secretary of FaHCSIA set out what are considered to be reasonable care and accommodation needs. The guidelines include examples of the kinds of needs that are considered to be reasonable care and accommodation needs, as well as examples that are not. The tight restriction on eligible uses of SDTs was seen as a major shortcoming in the current arrangements.

Care needs

2.74 Under the guidelines care needs are eligible if they arise 'as a direct result of the disability of the principal beneficiary', are for the primary benefit of the principal beneficiary and are met in Australia. SDTs are not allowed to be used for needs that are met outside Australia and needs that 'would be required by the principal beneficiary whether or not the principal beneficiary had his or her disability'.⁷⁹ The legislation also specifically prohibits using the SDT to pay an immediate family or child of the beneficiary for the provision of the beneficiary's care services.⁸⁰

2.75 There was unanimous agreement that the definition of what constitutes an allowable 'care need' is a major problem with SDTs and a big disincentive to setting up a trust.⁸¹ The current arrangements, which require expenses to be directly related to a person's disability, were considered to be complex and difficult. This definition means that many of the needs of people with disabilities cannot be met from the trusts even when money is available. Submitters noted that families face the complexity and

78 *Social Security Act 1991*, Subsection 1209N(1).

79 FaHCSIA, *Submission 13*, Appendix 2, Social Security (Special Disability Trust) (FaHCSIA) Guidelines 2008, pp. 4–5.

80 *Social Security Act 1991*, Subsection 1209R.

81 See for example, Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 13; Mr Gresswell, Winacomm Association, *Proof Committee Hansard*, 29 July 2008, p. 47 and *Submission 6*, p. 4; Mr Ward, Pave the Way, Mamre Association Inc, *Proof Committee Hansard*, 29 July 2008, p. 63; Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 97; Disability Services Commission, *Submission 3*, p. 1; Planned Individual Network, *Submission 4*, p. 2; Public Trustee of Western Australia, *Submission 7*, p.2.

costs of setting up two trusts; one as a SDT and another to meet the other expenses incurred by the person with disability.⁸²

2.76 Submitters pointed out that it is complicated and in some cases impossible to determine what portion of a care cost is directly due to a person's disability. Dr Baker, Chief Executive of National Disability Services, provided an example:

... everyone at one time or another has to visit a medical doctor, but for a person with intellectual disability or for profound communication difficulties that visit to the doctor, which may be for a normal condition that would occur for anyone else, a cold or a flu, may take twice as long because of the communication difficulties. Is it then appropriate to say that half the cost of the medical appointment should be attributed to disability or what proportion? In practice, these are extremely difficult issues to disentangle.⁸³

2.77 Mr Walter also provided an example:

The stupidity of it was that even to the point whereby if someone was in an electric wheelchair the electricity used to charge the battery for that wheelchair each night could be paid by the trust, but no other portion of that electricity bill.⁸⁴

2.78 The Public Trustees submitted that the need for some items may not be directly due to a person's disability, but the use of the items and associated costs are higher because of the person's disability. An example was a computer and access to the internet. Although these may not be specifically related to a person's disability, because of a mobility impairment they may be used often and be particularly important for a person's social connection and wellbeing. Other examples of costs which can be higher because of a person's disability included recreation activities and the costs of the ordinary maintenance and upkeep of a person's residence.⁸⁵

2.79 Some other costs, which can be directly due to disability, are still not eligible:

You cannot pay for utilities but it is well known, for example, that some people are unable to control their temperatures, hence they need air conditioners; good full-blast air conditioners for heating in winter and cooling in summer. That is a direct result of their disability, it is a utility, and yet they have to make an argument for this.⁸⁶

82 Public Trustees of the States and Territories and State Trustees Ltd, *Submission 22*, p. 6; Planned Individual Networks Inc, *Submission 4*, p. 2; Mr O'Hart, *Submission 5*, p. 13; Mr Booth, *Submission 10*, p. 4; Pave the Way, *Submission 14*, p. 4.

83 Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 76.

84 Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 85; see also examples in National Disability Services Ltd, *Submission 15*, pp. 5–6; Sunnyfield Independence, *Submission 46*, pp. 9–10.

85 Public Trustees of the States and Territories and State Trustees Ltd, *Submission 22*, pp. 8–9.

86 Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, p. 25.

2.80 Many costs that cannot be met from a SDT affect the general health and wellbeing of people with a disability. Being able to provide for some of these expenses would contribute to the person's quality of life and help to reduce other expenses associated with poor health later in life. Examples of expenses which submitters and witnesses considered should be eligible included:

- private health insurance, medical and dental treatment;
- white goods, household appliances and furniture;
- utilities;
- clothing;
- property maintenance and house cleaning;
- attending day programs;
- holidays, recreation and entertainment;
- social activities and sporting activities;
- costs of support workers;
- financial and decision making support;
- assistance with nutrition;
- vocational activities;
- special assistance with raising children, for people with mild intellectual disability; and
- 'household costs' paid by individuals in shared supported accommodation, such as groceries, manchester, gardening, cleaning, and household equipment.⁸⁷

2.81 Ms Hope, Section Manager, FaHCSIA, explained that at the time SDTs were introduced the rationale for limiting the uses of the trust funds was that 'the disability support pension was expected to cover the day-to-day living expenses and therefore the care and accommodation requirement was considered to be a reasonable expense, given that the disability support pension should cover the other day-to-day living expenses'.⁸⁸

2.82 Evidence from FaHCSIA indicates that many people do not intend to set up an SDT while they are alive, preferring instead to establish SDTs through their wills.

87 See for example, The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, pp. 2–3; Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, pp. 25 and 29; Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 71; Mr O'Hart, *Submission 5*, p. 7, 12–13; Kew Cottages Parents' Association, *Submission 8*, p. 2; Activ Foundation, *Submission 9*, p. 2; Pave the Way, Mamre Association, *Submission 14*, p. 4; Mr and Mrs Smale, *Submission 32*, p. 1; Mr West, *Submission 33*, p. 2; Sunnyfield Independence, *Submission 46*, p. 12; Carers Australia, *Submission 18*, p. 6.

88 Ms Hope, FaHCSIA, *Proof Committee Hansard*, 29 July 2008, p. 107.

This preference is in part related to the tight restrictions on the eligible uses of SDT funds. Carers see little advantage in locking their assets and funds away in a trust that cannot be used to meet many of the needs of their family member with a disability. FaHCSIA officers acknowledged:

While the assets remain in their total control, they can use them for the person with severe disability if they so choose, in whatever way seems appropriate at the time, and without restrictions on how the funds may be used.⁸⁹

2.83 Sunnyfield Independence considered that the limitations on the use of SDT funds 'perpetuate a paternalistic view toward people with disabilities which is not appropriate in the contemporary environment'. Sunnyfield Independence noted that:

...people with disabilities, even severe disabilities, are able to express their needs and desires, and that they should be able to participate in determining the use of the funds from an SDT rather than have that use dictated to them.⁹⁰

2.84 Sunnyfield Independence recommended that the rules for the use of SDT funds should acknowledge the right of people with disabilities to make their own decisions about their lives and what is important.⁹¹

Daily care fee

2.85 The guidelines issued by the Secretary of FaHCSIA setting out what constitutes reasonable care needs were amended in April 2008 to include a specific example relating to the daily care fee charged by approved residential care providers.⁹² Witnesses noted that such fees cover a variety of living requirements, such as food, water, electricity and fuel for a group-home car. They submitted that it was inequitable that SDTs were allowed to be used to cover these kinds of costs through the daily care fee charged by a residential facility, but not to cover these costs when provided in other ways, for example when purchased directly.⁹³

2.86 FaHCSIA explained that this change to the guideline had been made by the Secretary in response to concerns raised by the Public Trustees about how to treat composite fees, where the portion directly attributed to a person's disability could not be separated out. FaHCSIA representatives indicated that there was some misunderstanding as to what the fee actually covered. Ms Emerson said:

89 FaHCSIA, *Submission 13*, p. 14; see also Mr Booth, *Submission 10*, p. 2; Pave the Way, Mamre Association, *Submission 14*, pp. 8–9.

90 Sunnyfield Independence, *Submission 46*, p. 9.

91 Sunnyfield Independence, *Submission 46*, p. 4.

92 FaHCSIA, *Submission 13*, pp. 8–9.

93 Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 85 and *Submission 21*, pp. 3 and 7; Mr O'Hart, *Submission 5*, pp. 10–11; Mrs Breheny, *Submission 24*, p. 3;

...it is actually quite a limited provision and it refers to a particular group of aged care providers as defined under the aged care legislation. It is a very small additional component of the levy, which cannot be broken down readily into very discrete elements that would exactly match the current guidelines. It is a beneficial interpretation that would allow the whole of that relatively small fee to be included as a legitimate expenditure under the trust. I heard people saying today that it was all the expenses related to somebody's living, but it is not. As I understand it, it is only a very small fee, somewhere in the vicinity of \$30 or under that amount.⁹⁴

2.87 It is not entirely clear how the definition under the FaHCSIA guidelines described above fits with the general understanding of daily care fees. The Department of Health and Ageing (DoHA) describes these fees as a contribution to daily living costs such as 'nursing and personal care, living expenses, meals, linen and laundry, as well as heating and cooling'. Examples on DoHA's website list the basic daily care fee as up to \$32.05 *per day*.⁹⁵ The committee has sympathy with the view of witnesses if such costs are able to be borne from a SDT for eligible people in a residential aged-care facility, but not for those in other care and accommodation settings.

Accommodation needs

2.88 Accommodation needs are currently eligible to be met from an SDT if the need 'arises as a direct result of the disability of the principal beneficiary'. The trust can also be used to purchase or rent property as long as the property is not bought or rented from an immediate family member and is used for accommodation by the trust beneficiary. Payment of rates and taxes on such property is also allowed from the trust. Expenses such as maintenance and utilities for the beneficiary's place of residence are not allowed to be paid from the trust.⁹⁶

2.89 Evidence to the committee's inquiry indicates that there is confusion about the eligible accommodation uses of SDTs. Carers Australia understood that the 'housing options that can be used are limited to those that are funded wholly or in part under the agreement between the Commonwealth and state and territory governments'. Ms Hughes, from Carers Australia commented:

This is a barrier for many families now who are starting to think creatively about housing options for their family member and we believe that the trust should be able to be used for independent housing for their relative or to

94 Ms Emerson, FaHCSIA, *Proof Committee Hansard*, 29 July 2008, p. 106.

95 Department of Health and Ageing, 'Daily care fees', www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf, accessed 20 August 2008.

96 FaHCSIA, *Submission 13*, Appendix 2, Social Security (Special Disability Trust) (FaHCSIA) Guidelines 2008, pp. 6–8.

invest in unstaffed housing cooperatives: different sorts of housing options.⁹⁷

2.90 As noted above, SDTs can be used for independent housing through purchase or rent of property. The restriction to housing funded wholly or in part by an agreement between the Commonwealth and states and territories is one component of the eligibility criteria for SDTs. These criteria were discussed earlier in the report.

2.91 However, as raised by Ms Hughes, the ability to use SDTs for other forms of housing, such as cooperatives and group houses, was less clear. Witnesses recommended that more than one trust be able to be used, to jointly rent or purchase accommodation where two or more people with disabilities choose to live together.⁹⁸ Submitters noted that such provision would be particularly useful for families with more than one child with a disability, as eventually the adult children may wish to live together.⁹⁹ Mr Walter also suggested that SDTs should be able to co-own property with a state housing authority.¹⁰⁰

2.92 Mr Spicer noted that SDT rules need to account for the fact that 'home is not simply a bed'. He suggested that:

Accommodation must take into account the social, emotional and health needs of a person with a disability as well as ensuring that they have a compatible living arrangement with others and are able to participate in and contribute to the community.¹⁰¹

2.93 Mr Spicer highlighted that people with disability are usually unable to move into independent accommodation without a process of transition. As such, services to assist with a gradual transition to independent living, such as respite stays and travel training should be able to be paid for from the SDT.¹⁰²

2.94 There was also uncertainty about the restriction that unless an accommodation need arises 'as a direct result of the disability', SDTs cannot be used to purchase or rent property directly from family members. This rule was seen as limiting some of the most used forms of accommodation for people with disabilities. For example, Mr and Mrs Wilson and Mr Gresswell, Members of Winacom Association Inc, noted that this provision means that SDT funds cannot be used for the construction of

97 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 13.

98 Mr Gresswell, Winacom Association, *Proof Committee Hansard*, 29 July 2008, pp. 47 and 52; Mr Ward, Pave the Way, Mamre Association Inc, *Proof Committee Hansard*, 29 July 2008, p. 66.

99 Winacom Association, *Submission 6*, p. 13.

100 Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 88.

101 Mr Spicer, *Submission 19*, p. 7.

102 Mr Spicer, *Submission 19*, p. 7.

'granny flats' attached to the family home.¹⁰³ They noted that constructing or leasing property from family is in many cases the 'only practical way of protecting the asset from disreputable people wishing to strip the assets of the intellectually disabled person'.¹⁰⁴ Mr Brian O'Hart provided an example where he had tried to establish whether the rent paid by someone with a disability who was highly supported to live in a family owned property could be covered by the trust.¹⁰⁵

2.95 Witnesses also suggested that SDTs should be able to be used to pay an accommodation bond for an aged care facility, although the guidelines issued by FaHCSIA indicate that this is already allowable.¹⁰⁶ However, as outlined in the previous chapter, capital gains tax is payable if the beneficiary's residence is sold to pay for the accommodation bond.¹⁰⁷

2.96 One further issue about using SDTs to purchase property for people with disabilities concerned access to the First Home Owner Grant. Mr Walter wished to ensure that if a SDT is used to purchase a first home for someone with disability, the First Home Owner Grant should apply as it would to anyone with the capacity to purchase a first home directly.¹⁰⁸

Suggested changes

2.97 Submitters put forward various proposals for expanding the eligible uses of SDTs. Planned Individual Networks suggested that the legislation be altered to replace the 'sole purpose' provision with 'The purpose of a SDT is to support the Principal Beneficiary in all their care, accommodation and living cost as reasonably required by the Principal Beneficiary and determined in consultation with the Trustees.'¹⁰⁹ If a restriction is to be maintained, Planned Individual Networks suggested that a clause could be included to require that a minimum of 80% of SDT income be used for care and accommodation purposes.

2.98 The Public Trustees suggested a range of ways to broaden the 'care and accommodation' purpose of the trusts, for example, broadening the definition to include living essentials, including as 'care needs' all expenses incurred for the broader welfare of the principal beneficiary, or including as eligible the care and

103 Winaccom Association, *Submission 6*, p. 7.

104 Winaccom Association, *Submission 6*, p. 11.

105 Mr O'Hart, *Submission 5*, p. 6.

106 Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 79; FaHCSIA, *Submission 13*, Appendix 2, Social Security (Special Disability Trust) (FaHCSIA) Guidelines 2008, p. 7.

107 FaHCSIA, *Answers to questions on notice*, received 2 September 2008.

108 Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 88; Mr and Mrs Walter, *Submission 21*, p. 10.

109 Planned Individual Networks, *Submission 4*, pp. 2–3.

accommodation needs that have an increased cost or incidence because of the person's disability.¹¹⁰ The Public Trustees recommended that SDTs be able to be used for 'both compliant and noncompliant expenditure', or, alternatively the trust be able to be split into sub trusts, one for eligible and one for non-eligible costs, with 'relevant welfare relief only applying to the parts to which the compliant expenditure relates'.¹¹¹

2.99 The National Council on Intellectual Disability recommended that the definition of care be extended to include:

...any support equipment or service a person with a disability requires and where the person is in receipt of a DSP that the definition of care be further extended to include such things as holidays and personal entertainment items.¹¹²

2.100 National Disability Services' perspective was that if a significant component of a cost can be attributed to disability then the whole of the cost should be able to be covered by the proceeds of the trust.¹¹³ Winacom Association considered that 'the allowable expenses to be paid from the SDT should be broadened to cover all reasonable accommodation and care costs necessary to enable the disabled person to live a life comparable to a non-disabled person'.¹¹⁴

2.101 Mr Weir did not see a reason for restricting the uses of the trusts at all. He used an analogy to superannuation and aged care, which are partly funded by government:

...there is no restriction on aged persons on how they spend the money because it is accepted they spend it for their normal living needs. That will include accommodation and care where they need it, but it also includes anything they might need.¹¹⁵

2.102 Mr Ward, Manager, Pave the Way Mamre Association Inc. also did not see the need for any limitations on the uses of SDT funds, other than that the money must be used for the beneficiary.¹¹⁶

2.103 The National Disability Services suggested that the funding rules outlined by the Victorian Department of Human Services in its draft guidelines for the use of an individualised support package provide a model for how the purpose requirement could be broadened. National Disability Services noted that the draft guidelines, like

110 Public Trustees of the States and Territories and State Trustees Ltd, *Submission 22*, pp 2–3.

111 Public Trustees of the States and Territories and State Trustees Ltd, *Submission 22*, p. 2.

112 National Council on Intellectual Disability, *Submission 11*, p. 9.

113 Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 76.

114 Winacom Association, *Submission 6*, p. 13.

115 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 98.

116 Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 64.

the SDT rules, do not allow funds to be used as a form of income supplementation, however, they provide much greater discretion in relation to allowable costs. The guidelines list a number of positive, inclusive objectives to which the funds can be used, such as 'being able to live as independently as possible'.¹¹⁷

Other expenses

2.104 Witnesses raised several other expenses, beyond care, accommodation and living expenses that they suggested should be met from a SDT. It was argued that income from SDTs should be able to be used to make contributions to superannuation and therefore attract the government co-contribution. The Hon Dr Patterson outlined:

Most of these people are on very low incomes, their supported employment or business service employment supplementing their DSP, and they have very little chance of contributing to super. It would seem a way in which they could participate in that co-contribution as low-income earners, if a trust could contribute to super.¹¹⁸

2.105 The cost of administering an SDT was also raised. Ancillary costs, necessary to facilitate the primary purpose of the trusts, are currently allowed to be paid from the SDT. As such, costs of administering the trusts and audits of the trust are met from the trust. However, Winacomm Association Inc noted that this provision is limited as family members are not able to be recompensed from the trust:

In order to find someone in the family who is willing to take on the administration of the SDT we believe that family members should be able to claim recompense for their time at a rate consistent with a commercial organization performing the same task.¹¹⁹

Preventing misuse of funds

2.106 The Winacomm Association argued that checks could be built into the existing system to prevent misuse of SDT funds even if the eligible uses are broadened:

As the SDT is audited and subject to Centrelink scrutiny, it is feasible to place the burden of proof on the Trustees of a SDT, that expenses paid from the SDT are reasonable in each individual circumstance. Centrelink could conduct random audits to monitor this.¹²⁰

2.107 Witnesses for the State Trustees observed that mechanisms exist to ensure that the trusts are not abused. Mr Fitzgerald explained:

For instance, for each trust we need to do a tax return, so that would be one mechanism. The other one would be Centrelink returns each year to ensure

117 National Disability Services, *Submission 15*, p. 5.

118 The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 3.

119 Winacomm Association, *Submission 6*, p. 12.

120 Winacomm Association, *Submission 6*, p. 13.

the compliance status of the trust with whatever rules ultimately are applied to this initiative, even if they are broadened...¹²¹

2.108 There was a strong view that the trusts should be considered in terms of the benefit that can be provided to the person with a disability; the focus should not be on the potential for evasion of tax commitments and responsibilities. Submitters argued that loosening the current onerous restrictions on the eligible care uses of the trusts would be a key step in refocussing SDTs on the benefits for the person with disability.

Committee comment

2.109 The committee is strongly of the view that the tight restrictions on the eligible uses of SDT funds are severely hampering take-up of the trusts. People see little point in setting aside funds if those funds cannot be used to provide the accommodation, care and support that their loved one needs to live as independently as possible. The committee notes that being able to provide better care and living standards for people with disability, for example using SDTs for private health insurance, medical and dental treatment and a range of household expenses and social engagement activities stands to improve their health and wellbeing, as well as relieve some of the stress and burden on their carers.

2.110 The original intention of SDTs was to assist families able to make private financial provisions for the current or future accommodation and care of a family member with severe disability. The committee considers that the eligible uses of the trust must be expanded if this intention is to be given effect.

Recommendation 6

2.111 The committee recommends that the allowable uses of special disability trusts be expanded to include all day-to-day living expenses that are met to maximise the beneficiary's health, wellbeing, recreation and independence.

Recommendation 7

2.112 The committee recommends that unexpended income from a special disability trust be able to be contributed, on a pre-tax basis, to a superannuation fund for the trust beneficiary.

Recommendation 8

2.113 The committee recommends that when a special disability trust is used to purchase a first home for the trust beneficiary, the First Home Owner Grant should apply and be payable to the trust.

121 Mr Fitzgerald, Managing Director, State Trustees Ltd and National President, Trustee Corporations Association of Australia, *Proof Committee Hansard*, 29 July 2008, p. 37.

CHAPTER 3

OTHER AREAS OF CONCERN

3.1 As well as key barriers to the establishment and use of SDTs, concerns were raised about the complexity and costs of setting up and maintaining the trusts. SDTs were not widely known about or understood and there was a perceived need for better information and awareness raising and the provision of low-cost specialist advice. Outside of the specific focus on SDTs, submitters and witnesses suggested other models by which government can support families to provide for dependents with disabilities into the future. The need for better government support, beyond private financial provision, was also raised. These issues are discussed throughout this chapter.

Complexity and costs of SDTs

Complexity

3.2 The complexity of the SDT arrangements was cited as a major disincentive for families seeking to make provision for the future of a person with a disability. It was noted that social security was already a very complex system for families which often involved many different interrelated entitlements and sets of eligibility.¹

3.3 The Trustee Corporations of Australia stated feedback from their members was that 'the average person finds the complexity of the SDT arrangements very daunting and discourages them from pursuing this matter on behalf of a severely disabled dependent'.² This perception was confirmed in submissions the committee received from individuals who had struggled to assess whether an SDT would assist a member of their family who had a disability. For example Mrs Pretzel commented:

I tried to understand the structure and limits of the Trust and quite frankly, I became bamboozled and confused about how it would work and if my brother was eligible or could benefit by it. I also felt embarrassed that despite being a university graduate I could understand VERY LITTLE of the information provided. I thought that if I had so much difficulty in understanding the information, how would people with limited education and understanding fare?³

3.4 One of the reasons that SDTs were seen as complex was that they required families to guess at the care and accommodation needs of a disabled person into the future. The Public Trustees commented that the person establishing a SDT needs to

1 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 15.

2 Trustee Corporations of Australia, *Submission 16*, p. 2.

3 Mrs Pretzel, *Submission 35*, p. 1.

forecast the lifetime of the beneficiary, the cost of their care and accommodation needs and also the prospective investment returns of the trust over their lifetime.⁴ These were concerns that were repeated in submissions. For example Mr and Mrs Sexton commented that:

Management of a trust fund is of concern as it is difficult to assess, project and arrange for the future, particularly in the long term...The effect of a trust fund on the disability support pension in the short and long term is unknown, ie how long will the trust last? What will be the effect of spiralling costs? Who can predict these costs?⁵

3.5 The various restrictions on SDTs mean that families will often need to set up two trusts, a SDT for care and accommodation and another trust for all other life needs of a person with a disability. Planned Individual Networks stated:

This is a burden on families both in cost and understanding of what to most families is a complex part of our legal process...The thought that the two Trusts would be required is just too much for most people and at a very early stage in the planning process it is easy to lose their support and attention.⁶

3.6 Mr Booth noted that parents of a disabled child often did not wish to leave complex arrangements for others to administer when they were no longer able to provide care. He stated:

Having two trusts, governed by different rules, is another significant level of complexity, which is very off-putting for many families, especially if they contemplate the siblings of the person with a disability administering the trusts, and being faced with that complexity.⁷

3.7 As part of the introduction of the SDT arrangements FaHCSIA developed a sample Model Trust Deed. The Model Trust Deed incorporated the recommendations from the Ministerial Advisory Group and contains the clauses that are essential for SDTs to comply with the legislative requirements. The Model Trust Deed was intended to make it easier for families and professional advisers to comply with requirements, and also was also intended to reduce the cost to families of professional services.⁸ However the Public Trustee of Western Australia highlighted the size of the Model Trust Deed as contributing to the complexities of SDTs. They noted that a standard protective trust clause is only one page long while the Model Trust Deed is 18 pages.⁹ Mr Booth suggested that simplification of the SDT rules including

4 Public Trustees of State and Territories and State Trustees Ltd, *Submission 22*, p. 4.

5 Mr and Mrs Sexton, *Submission 41*, p. 1.

6 Planned Individual Networks, *Submission 4*, p. 2.

7 Mr Booth, *Submission 10*, p. 4.

8 FaHCSIA, *Submission 13*, p. 9.

9 Public Trustee of Western Australia, *Submission 7*, p. 4

'simplification of the model trust deed so that it is less daunting to laypersons' would assist the uptake of SDTs.¹⁰

3.8 The Public Trustees commented that there is justified perception that SDTs are 'complex, unwieldy and overly prescriptive'. However they also cautioned that any changes to simplify SDTs would need to be carefully developed. They stated:

...it must be remembered that trusts are a long-term estate planning tool. Any proposed legislative changes will need to take account of, and not inadvertently disadvantage, those individuals who have already put in place (e.g. via their Wills, etc.) estate planning measures based on the current provisions.¹¹

Costs and administration

3.9 A number of submitters noted that the administrative and financial burdens of establishing a SDT were also a significant disincentive to their creation. Many of these costs related to the legal and financial advice which families needed in establishing and maintaining a SDT. For example Carers Australia estimated that setting up an SDT could typically cost several thousand dollars since extensive specialist legal advice is required before a SDT can be commenced.

3.10 The Kew Cottages Parents' Association commented the stringent reporting and audit requirements made administering a SDT onerous and potentially costly.¹² National Disability Services also noted the 'currently onerous compliance burden of reporting and auditing'.¹³ The ongoing costs of maintaining a SDT, such as professional trustee fees, annual reporting and auditing, were also highlighted in submissions. Carers Australia stated:

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.¹⁴

3.11 There were also concerns raised that the costs of SDTs were reducing the benefits for beneficiaries. Mr Spicer noted that for ordinary people the trust structure can appear complex and legalistic with difficult responsibilities for non-professional trustees. This may push families setting up SDTs to appoint a professional trustee which can be expensive and will use up 'a significant amount of the earnings of what

10 Mr Booth, *Submission 10*, p. 6.

11 Public Trustees of States and Territories and State Trustees Ltd, *Submission 22*, p. 4.

12 Kew Cottages Parents' Association, *Submission 8*, p. 3.

13 National Disability Services, *Submission 15*, p. 5.

14 Carers Australia, *Submission 18*, p.7.

are fairly small trusts'.¹⁵ The Public Trustee of Western Australia argued that complying with the terms of SDTs can be expensive and time consuming which can reduce any pension saving which was the original purpose of the SDT.¹⁶ The Winacomm Association noted that the impact of these costs was less income available of the beneficiary of the SDT. They argued:

It is not acceptable for income provided for the needs of people with a disability to be used to pay fees to accountants, tax advisers, financial planners and solicitors when we should be doing everything possible to maximise the amount of income from the trust available to ensure that as many people with a disability as possible have funds available so that they, like us, can lead happy, enjoyable and fulfilling lives.¹⁷

3.12 A number of possible reforms were suggested to assist families with the complexity and costs associated with the SDTs arrangements. Mr Spicer recommended that drawing on the experience of administering superannuation funds, a master trust scheme could be developed to create a process through which SDTs might be administered at a low cost.¹⁸ National Disability Services recommended that to assist in the setting up of SDTs 'families with limited financial resources must have information on how to access low-cost legal and financial advice'.¹⁹ The Winacomm Association recommended that given the potential benefits of SDTs, the government should provide financial assistance to families who can show they have incurred costs of setting up a SDT.²⁰

Trust audits

3.13 Legislation governing SDTs requires SDT trustees to provide financial statements about the trust to the Secretary of FaHCSIA on an annual basis in accordance with the *Income Tax Assessment Act 1936*. A declaration must be included that confirms that expenditure was spent on care and accommodation costs and was not spent for day-to-day living expenses or payments to immediate family members.²¹

3.14 Sunnyfield Independence noted that the current restrictions on the eligible uses of SDTs increases the administrative cost of complying with these reporting requirements:

Sunnyfield will need to replace one monthly invoice containing one amount for board and lodgings, one amount for pharmacy items and other details of

15 Mr Spicer, *Submission 19*, p. 8.

16 Public Trustee of Western Australia, *Submission 7*, p. 4.

17 Winacomm Association, *Submission 46*, p. 1.

18 Mr Spicer, *Submission 19*, p. 17.

19 National Disability Services, *Submission 15*, p. 5.

20 Winacomm Association, *Submission 6*, p. 14.

21 FaHCSIA, *Submission 13*, p. 10.

any other expenditure incurred on behalf of this person with a detailed and voluminous itemised list of accommodation and care costs that comply with the Guidelines and those that do not. This is the only way that we can provide the trustees with the information they need to meet the reporting requirements of SDT.²²

3.15 In addition to the compulsory financial statements, SDT beneficiaries, their immediate family members, legal guardians or long-term guardians, financial administrators and the Secretary of FaHCSIA are all allowed to request that an audit of the trust be undertaken. Copies of any such audit must be provided to the person that requested it, as well as to the beneficiary's legal guardian or financial administrator and the Secretary of FaHCSIA.²³ Mr Booth noted that for some families these reporting and accountability obligations are a disincentive that can tip the balance against using an SDT unless there are clear outweighing benefits.²⁴

3.16 The Public Trustees raised concerns that the audit request provision opens the trusts up for vexatious audit requests. As audits are paid for from the trust, any such vexatious requests are to the detriment of the SDT beneficiary. The Public Trustees also noted that such audit reports may contain personal information about the beneficiary, which an immediate family member would not otherwise be necessarily able to access and which the principal beneficiary may not want them to access.²⁵

3.17 Mr Fitzgerald, Managing Director State Trustees and National President of the Trustee Corporations Association of Australia, provided some context as to the kinds of circumstances in which vexatious requests for audits may arise:

...sometimes we are appointed because a family member has been abusing the person with the disability and the tribunal decides that it is important for an independent administrator to be appointed hence we would be appointed in that sense. In some cases that automatically creates an adversarial situation with the family member who has been removed as administrator.²⁶

3.18 Public Trustees are already subject to external audit and oversight by the Auditor-General and must maintain effective corporate governance, compliance and risk management policies and procedures. Given these requirements, the Public Trustees suggested that they should be exempt from the obligation to have external audits conducted in relation to SDTs.²⁷

22 Sunnyfield Independence, *Submission 46*, p. 12.

23 *Social Security Act 1991*, Subsection 1209S and 1209T.

24 Mr Booth, *Submission 10*, p. 5.

25 Public Trustees of States and Territories and State Trustees Ltd, *Submission 12*, p. 12.

26 Mr Fitzgerald, Managing Director, State Trustees Ltd and National President, Trustee Corporations Association of Australia, *Proof Committee Hansard*, 29 July 2008, p. 43.

27 Mr Fitzgerald, Managing Director, State Trustees Ltd and National President, Trustee Corporations Association of Australia, *Proof Committee Hansard*, 29 July 2008, p. 44; FaHCSIA, *Submission 13*, pp. 3 and 13.

3.19 Some witnesses had sympathy with this perspective. They considered that existing regulations provided sufficient safeguards in relation to the Public Trustees and that the requirement for an annual audit is fair in protecting the interests of family members while ensuring that the funds available to the person with disability are not run down by additional audits.²⁸ Mr Pattison stressed that families do need an annual report providing an account of the trust, its current situation, risk analysis and annual income and outgoings.

3.20 Other witnesses noted that while vexatious audit requests may be made, these circumstances would be quite rare and that regulations should not be made 'in order to mitigate that fairly rare likelihood'.²⁹ Mrs Breheny felt that immediate families contributing to a trust should be entitled to a review.³⁰ Mr Spicer noted that auditing of trusts and trust moneys is important for building confidence in SDTs, but that restrictions to limit the number or type of audits would be appropriate.³¹ Similarly, Mr Weir considered that auditing should be mandatory and that people who have an interest should be able to ask for a copy of the audit.³²

3.21 Mr Gresswell of Winacom Association noted that it should be possible to incorporate into the trust deed provisions that allow for audits but prevent unreasonable requests:

I would imagine that something could be written into a trust deed that would allow for an audit by a family member who has been a donor to the trust about once a year, or something of that nature.³³

3.22 Mr Ward of Pave the Way, Mamre Association, did not agree that public trustees should be exempt from audit requirements applying to private trustees:

I think the trustees need to follow the same rules. I do not accept the argument that professional trustees are necessarily doing a better job than private trustees, quite frankly. Sure, they may be subject to some other accountability requirements but I am not sure that they exist on a case-by-case basis.³⁴

3.23 Planned Individual Networks submitted that SDTs should comply with the same reporting requirements as a superannuation plan, with a mandatory annual audit

28 Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, p. 31.

29 Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 67.

30 Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 92.

31 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 71.

32 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 100.

33 Mr Gresswell, Winacom Association, *Proof Committee Hansard*, 29 July 2008, p. 52.

34 Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 67.

and a copy of the audit to be made available to the list of people that are currently able to request an audit of the trust.

Multiple trusts

3.24 A specific issue raised in evidence to the committee was the current restriction that only one SDT can be set up for any particular person. While setting up multiple trusts would be more expensive than a single trust, due to additional establishment and administrative costs, it was suggested that in some circumstances families may not be able to communicate and work together to create one trust.³⁵ Witnesses did not see any difficulties with allowing more than one SDT per beneficiary, assuming that any cap on trust assets applied across the total of all trusts.³⁶

Committee comment

3.25 The committee recognises that the complexity and costs of establishing and maintaining a SDT are a burden on families caring for a person with a disability. These costs impact on the overall benefits of the SDT to the beneficiary. Unfortunately many of these costs may be unavoidable due to the complexity of the social security and taxation environment in which SDTs exist. The committee agrees that not enough is being done to assist families wishing to establish and maintain a SDT and that the government should assess further initiatives to assist them. These may include assisting families obtain low cost legal and financial advice and rebating part of the costs families incur in establishing a SDT.

3.26 The committee is of the view that clear accountability is essential to protecting the interests of a SDT beneficiary and promoting confidence in the trusts. It considers that provision of annual financial statements to the Secretary of FaHCSIA is important and should be retained. Such statements should also be made available to SDT beneficiaries, their immediate family members and guardians.

3.27 The committee acknowledges the concern that current audit request provisions may leave the trusts open to vexatious audit claims. The committee considers that simple arrangements can be introduced to minimise this risk, while maintaining the entitlement of beneficiaries and family members to information about the trust.

Recommendation 9

3.28 The committee recommends that the government review appropriate options to provide additional assistance to families establishing and maintaining

35 Mr Ward, Pave the Way, Mamre Association *Proof Committee Hansard*, 29 July 2008, p. 64; Public Trustees of the States and Territories and State Trustees Ltd, *Submission 13*, p. 7; Pave the Way, Mamre Association, *Submission 14*, p. 9.

36 Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 66; Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 90.

a special disability trust including low cost legal and financial advice, as well as funding for the development of long-term planning.

Recommendation 10

3.29 The committee recommends that requests for audits of a special disability trust be restricted to one external audit per financial year, unless the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs determines this restriction should be waived.

Recommendation 11

3.30 That the single trust rule in section 1209M(6) of the *Social Security Act 1991* be amended to allow two trusts for each beneficiary.

Other concerns about the operation of Special Disability Trusts

3.31 In addition to the key issues of concern about the establishment, complexity and costs of SDTs that were raised consistently by submitters and witnesses a number of other specific issues were also raised. These included:

- The need for families considering a SDT to have the opportunity to have issues that may require a waiver of certain conditions to be considered and resolved prior to establishing a trust.³⁷
- The need for clarity and transparency as to the meaning of 'reasonable care' and the suggestion that Centrelink publish decisions that have been made on the issue.³⁸
- The need for a list of approved service providers to assist parents in determining what are considered eligible expenses.³⁹
- Families may not wish to lock funds into a SDT in case their own circumstances change. Pave the Way, Mamre Association suggested that 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, for example where parents or siblings are in financial distress.⁴⁰
- The need to protect SDTs under the *Family Law Act 1975* for the benefit of the beneficiary, in the event SDTs are considered in a property settlement between the parties to a marriage.⁴¹

37 Mr O'Hart, *Submission 5*, p. 10.

38 Mr Booth, *Submission 10*, p. 6.

39 People With Disabilities Inc, *Submission 12*, p. 2.

40 Pave the Way, Mamre Association, *Submission 14*, p. 10; see also Ms Dalli, *Submission 37*, p.1.

41 Mr Marks, *Submission 34*, p. 2.

- Allowing SDTs to have more than one beneficiary where there is more than one family member with a disability, to reduce the costs of operating two separate SDTs.⁴²
- Reviewing the requirement that where a professional trustee is not appointed, two family members must be appointed to act as trustees. Sunnyfield Independence recommended this requirement be changed to one family member to make setting up an SDT more possible for families that are sole-parent or one-sibling families.⁴³

3.32 Several of these issues will be resolved with the adoption of the recommendations made in this report. However, the committee considers it appropriate that Government give consideration to the remaining issues in introducing changes to the SDTs.

Information and awareness

3.33 Evidence to the inquiry indicated that SDTs are generally not known about among the families that might use them and the service providers that might recommend them.⁴⁴ The Hon Dr Patterson noted that information booklets had been sent out about the trusts,⁴⁵ but this does not seem to have been very effective in raising awareness. Suggestions were made for increasing awareness of the trusts and making them more easily understood.

Mechanisms for promoting the trusts

3.34 The department described some of the efforts that have been made to promote SDTs, including:

- distribution of information resources on future planning in general and on SDTs, such as the booklets *Getting Started* and *Succession Planning*, through various networks;
- promotion of SDTs on the FaHCSIA and Centrelink websites;
- feature articles on SDTs in newsletters and publications such as Centrelink's *News for Seniors*;
- provision of fact sheets at conferences and expositions and through all Commonwealth respite and care link centres; and

42 Sunnyfield Independence, *Submission 46*, pp. 5 and 19.

43 Sunnyfield Independence, *Submission 46*, pp. 19–20.

44 See for example, Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 86; Mr Drever, *Submission 30*, p. 2; Mrs McKerrell, *Submission 23*, p. 1.

45 The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 2.

- a free call 1800 telephone number to Centrelink's assessment centre, which responds to questions about the trusts and how people can apply to establish a trust.⁴⁶

3.35 Given the current complexities involved in setting up SDTs, better mechanisms for raising awareness and disseminating information need to be developed. The Hon Dr Patterson suggested a website where questions can be posted anonymously and answered by the department. Given that many people considering SDTs may have some of the same questions or encounter the same issues, the committee considers that this kind of forum could be a very useful resource and should be developed promptly.

3.36 People considering SDTs also need to obtain advice specific to their individual circumstances. Submitters commented that many carers cannot afford the legal and taxation advice that they need and many lawyers and financial planners are not aware of SDTs.⁴⁷ The Hon Dr Patterson recommended that professional groups, particularly financial planners and lawyers, be encouraged to develop a unit of professional development on SDTs and planning for the future for people with disability. Names of professionals who have undertaken the training course could be advertised on the website suggested above.⁴⁸

3.37 Mr Spicer also pointed to the need for financial specialists to be well versed in the trusts:

I think we have not...done enough to engage groups like the Financial Planner's Association, the accountants and the various law institutes around the country so that when people are providing good advice on estate planning or financial planning special disability trusts are known to people, people are familiar with their terms and they can provide confident and competent advice to people who are seeking a range of options.⁴⁹

3.38 Carers Australia recommended that 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

46 Ms Emerson, FaHCSIA, *Proof Committee Hansard*, 29 July 2008, pp. 103 and 112.

47 See for example, Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 13 and *Submission 18*, p. 5; National Disability Services, *Submission 15*, p. 3; Mr Spicer, *Submission 19*, p. 13.

48 The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 3.

49 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 71; See also Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 78; National Disability Services Ltd, *Submission 15*, p. 6.

available legal and financial planning options which may be relevant to the circumstances of individual families.⁵⁰

3.39 The Public Trustees noted that they had 'strongly engaged in efforts to foster and improve the viability of the special disability trust initiative', including raising community awareness through seminars for public and estate planning professionals, taking part in radio interviews and publishing and distributing brochures and letters to clients.⁵¹

Who is responsible for promoting the trusts?

3.40 Recognising the current lack of awareness about SDTs, there was discussion at the committee's hearing about which organisations should take responsibility for promoting the trusts and ensuring that reliable information gets out to those who might consider using the trusts. Mr Fitzgerald, representing the State Trustees and the Trustee Corporations Association of Australia, saw a definite role for governments at both federal and state levels. He noted 'if you hook into the state level of government you then also look at a lot of the social workers and those sorts of people who would have a greater exposure to people with disabilities than perhaps people at a federal level'.⁵²

3.41 Mr Gresswell, suggested that Centrelink would be the appropriate agency to take responsibility for promoting SDTs, given their contact with the people that use their services. Mr Gresswell commented:

They run their financial information services with officers there to provide advice to people. I do not see why that could not be extended to provide people with advice on special disability trusts. A lot of it is already in a booklet.⁵³

3.42 Mr Spicer considered that disability organisations and carer organisations could have more of a role in promoting the trusts.⁵⁴ He noted that while there is a definite role for government, and Centrelink in particular, the emphasis should be on government engaging with disability organisations and carer associations so that they have the knowledge and expertise to gain families' interest, to provide some advice, and to provide referrals to organisations that have full technical expertise.

50 Carers Australia, *Submission 18*, pp. 5–6.

51 Public Trustees of the States and Territories and State Trustees Ltd., *Submission 22*, p. 3.

52 Mr Fitzgerald, *Proof Committee Hansard*, 29 July 2008, p. 41.

53 Mr Gresswell, Winacom Association, *Proof Committee Hansard*, 29 July 2008, p. 51.

54 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 69.

3.43 Mr Weir emphasised that the whole community has a role in promoting SDTs and that anyone involved with disabilities can help improve awareness and market the trusts. He saw that FaHCSIA, parents and peak agencies have lead roles to play.⁵⁵

3.44 Dr Baker, Chief Executive of National Disability Services agreed that Government has a clear responsibility for generating information about SDTs, but felt that the lead organisation for disseminating information should be 'the national peak body for financial planners'. Dr Baker noted that while government would need to resource the group to undertake this work, it would be more effective than a government organisation itself promoting the trusts. Dr Baker observed that National Disability Services' members are often more prepared to receive a message from peak bodies than directly from government.⁵⁶

3.45 The FaHCSIA noted that in the past it has developed speakers' kits, providing a package of support materials for speakers such as financial planners and lawyers to use in presentations. Departmental representatives considered that such kits may be helpful in promoting SDTs. Ms Emerson noted that FaHCSIA relies on groups such as the carers' associations and major service providers 'who have audiences that would be interested in this area to really help spread the word a bit'.⁵⁷

What's in a name?

3.46 Submitters and witnesses pointed to problems with the name 'special disability trusts'. Some noted that the label 'special' is marginalising. Mr Weir commented:

There is no special trust about it at all. Parents do not like to think that disabilities are something special. We want to be inclusive. We want to have our kids in the community, not apart from the community, and calling it anything to do with 'special' is not something that parents go for at all.⁵⁸

3.47 Many reflected that the term 'trust' does not sit easily with people on low incomes. People associated trusts with wealth and large sums of money and did not consider them to be within their reach.⁵⁹ Ms Hughes, Chief Executive Officer of Carers Australia commented:

55 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 98.

56 Dr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 78.

57 Ms Emerson, FaHCSIA, *Proof Committee Hansard*, 29 July 2008, p. 112.

58 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 95.

59 See for example Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 12; Mr Buckley, Autism Aspergers Advocacy Australia, *Proof Committee Hansard*, 29 July 2008, p. 55; Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 86 and *Submission 21*, p. 11; Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 86; Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 95; Mrs McKerrel, *Submission 23*, p. 2.

...many families were absolutely overwhelmed when the previous government announced the notion of investing up to \$500,000 for the future care and accommodation of their family members. It just was not in the ballpark for many of these families. They just did not have the notion of that amount of money, even though they do believe very strongly that they do want to provide care and accommodation and quality of life options for their sons and daughters.⁶⁰

3.48 Submitters suggested changing the name of the trusts, for example to 'disability savings plans', to increase their appeal to those in the target group and capture the idea of gradually putting private funds aside for the long-term support of their family member. Mr Walter noted that this would be particularly applicable if the government provided co-contributions to the plans.⁶¹

Committee comment

3.49 The committee is of the view that while fundamental issues with the operation of SDTs, such as the eligibility requirements, tax implications and restrictions on the uses of the trusts have been major disincentives to their take-up, lack of awareness and promotion of the trusts has not helped. The committee considers it particularly important that the trusts be newly promoted following adoption of the recommendations made in this report.

3.50 In particular there is a need for a designated agency to take the lead and be held responsible for promoting SDTs. The committee is also of the view that there is a definite and pressing need to improve awareness of SDTs among those groups that provide the detailed advice that families need in planning for the future of a member with disability. Consideration should also be given to renaming the trusts to a name that is more generally relatable and appealing to those likely to establish a SDT.

Recommendation 12

3.51 The committee recommends that Centrelink be designated as the agency responsible and accountable for ensuring that special disability trusts are promoted and understood among families caring for members with disability.

Recommendation 13

3.52 The committee recommends that the Department of Families, Housing, Community Services and Indigenous Affairs in partnership with industry bodies and peak carer organisations develop a training package for financial and legal advisers focussed on future planning for carers of people with disability, including special disability trusts.

60 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 12.

61 Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 86.

Recommendation 14

3.53 The committee recommends that the government consider changing the name of special disability trusts, for example to disability support trusts.

Other supports for families caring for dependents with disability

3.54 The Hon Dr Patterson noted that SDTs were intended to be one of a number of measures, not the only measure, to assist families in planning and providing for the needs of sons and daughters with disability.⁶² Witnesses to the inquiry highlighted a range of other supports and assistance that are required.

Government co-contribution schemes

3.55 An issue raised by some submitters was that governments could increase their support to those making private financial provision for the care of family members with disability, by providing co-contributions to savings schemes. Some suggested that co-contributions could be made into SDTs, others called for different kinds of schemes completely. Ms Hughes of Carers Australia, commented:

If we have a lot of money out there being put into special funds, it seems to me that there is a great urgency to have some sort of care fund. In the disability area, people are talking about disability insurance schemes. I would like to broaden that notion and look at some sort of care scheme that people could pay into that the government could add to, because at the moment we have so many systems struggling.⁶³

3.56 Submitters suggested that a superannuation style co-contribution scheme could apply for disabilities.⁶⁴ Mr Pattison, Executive Director of the National Council on Intellectual Disability, commented:

It is similar to people putting aside money for their retirement. Their retirement is their care and support when they get old and need all those sorts of things. In this instance, we have people with a disability who are going to need ongoing care and support.⁶⁵

3.57 Mr Pattison agreed that such co-contributions could be capped, at a level similar to superannuation. Unlike superannuation, beneficiaries would need to be able to access the funds earlier in their life as their care and support needs are ongoing. Mr

62 The Hon Dr Patterson, *Proof Committee Hansard*, 29 July 2008, p. 1.

63 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 19.

64 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 96; Mr Marks, *Submission 34*, p. 2; Mr Spicer, *Submission 19*, p. 12.

65 Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, p. 22.

Pattison suggested that early access to funds could be restricted by placing a limit 'on the type of disability of a person that was able to access it before the age of 18'.⁶⁶

3.58 Mr Walter argued that a co-contribution scheme should be facilitated as a modification of the existing SDTs, rather than creating further complications by having two schemes.⁶⁷ Mr Weir also argued that the SDTs should be kept, but thought that these would come under the broader 'umbrella of the savings plan'.⁶⁸ He noted that it would be important to retain a trust and trustee to secure the funds for the person with disability, but that marketing could be based in the concept of a savings plan and that anyone could contribute to the plan right from the outset.

3.59 A model put forward for consideration by Mr Weir and other witnesses is the Canadian Registered Disability Savings Plan (RDSP).⁶⁹ The RDSP was introduced by the Canadian Government in 2007 and is intended to help parents and others to save for the long-term financial security of a child with a disability by allowing funds to be invested tax-free until withdrawal. Anyone can contribute to the RDSP, until the Plan reaches the cap of \$200,000 or the beneficiary reaches 59 years of age. The Canadian Government will also contribute to the RDSPs of some medium and low income families through matched contribution grants and through bonds that are not contingent upon contributions. There are no restrictions on when the RDSP funds can be used or for what purpose.⁷⁰

3.60 Mrs Breheny was less supportive of the Canadian plan, considering that it is too broad in scope.⁷¹ However she was supportive of a disability savings plan that parents could contribute too throughout their lives, similar to superannuation, and that may be able to feed into a SDT.⁷²

Succession planning

3.61 Several submitters and witnesses emphasised that financial considerations, such as setting up SDTs, are only one element in the family planning that needs to happen as people with disability move through life and their carers age. The

66 Mr Pattison, National Council on Intellectual Disability *Proof Committee Hansard*, 29 July 2008, p. 33.

67 Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 83

68 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 96.

69 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 97; Activ Foundation, *Submission 9*, p. 3; Mr and Mrs Walter, *Submission 21*, p. 11.

70 Department of Finance, *The Budget 2007*, 19 March 2007, pp. 83-84, www.budget.gc.ca/2007/pdf/bp2007e.pdf, accessed 15 September 2008. See also www.cra-arc.gc.ca/tx/rgstrd/rdsp/menu-eng.html and www.cra-arc.gc.ca/agency/budget/2007/rdsp-e.htm, accessed 10 September 2008.

71 Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 84; see also comments by Mr Walter, *Proof Committee Hansard*, 29 July 2008, p. 92.

72 Mrs Breheny, *Proof Committee Hansard*, 29 July 2008, p. 84; *Submission 24*, p. 3.

complexity of the future planning tasks faced by some families with a member with disability, including legal, financial, housing, psychosocial other support networks, can be daunting and time consuming. Families need to be supported in their 'life planning' and 'succession planning'.⁷³ Ms Hughes of Carers Australia noted:

If we go down the path of loosening up the guidelines for special disability trusts and forget that family members also need support with relinquishing care and looking at other care options for their family member, as well as for themselves, then you end up having what I call a very splintered system because you are looking at just one element of care, rather than looking at the whole aspect of care.⁷⁴

3.62 Ms Hughes mentioned some of the different issues that need to be taken into account, such as wills, estates and trusts, and having agreed care plans and advanced care directives in place. Ms Hughes commented that while carers' associations give families a lot of information about life planning, the associations are in touch with a small number of families and such information sometimes 'does not get out to those that are most in need'. Ms Hughes recommended that this type of information needs to be available from a whole range of places, such as disability groups, legal centres and Centrelink.⁷⁵

3.63 Mr Ward, Manager Pave the Way, Mamre Association Inc, described the kinds of supports needed for families to engage in succession planning:

In the work we are doing we are trying to provide opportunities through some fairly in-depth experiences by taking families away over a number of days, preferably two people from each family, and allowing them the head space and the frameworks within which to clarify what it is they really want, and then work out how they are going to plan to achieve that and who they are going to invite to share the journey with them and then look at how much money are we going to need to do this, what sort of funding might we need and how can we use the estate planning mechanisms to our best advantage and to the best advantage of our family members?⁷⁶

3.64 Similarly, Mr Weir described the Planned Living Advocacy Networks (PLAN) program in Canada, which the Planned Individual Networks in Australia is based upon. PLAN Canada provides a facilitator to help parents put together a network or a circle of friends around the person with disabilities. Mr Weir explained:

The idea is to have a group who will look out for that person when the parents are no longer able to do so. That is the key. But before we start that there is a huge issue around future planning and estate and financial planning

73 Mr Pattison, National Council on Intellectual Disability, *Proof Committee Hansard*, 29 July 2008, p. 31; Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 69; Pave the Way, Mamre Association, *Submission 14*; National Disability Services Ltd, *Submission 15*, p. 6.

74 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 12.

75 Ms Hughes, Carers Australia, *Proof Committee Hansard*, 29 July 2008, p. 17.

76 Mr Ward, Pave the Way, Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 65.

that needs to be in place. It is a holistic program where the family and the person with a disability can see a pathway for the future for the rest of their life.⁷⁷

3.65 The committee notes the importance of these wider supports to assist carers and families in planning for the future of a member with disabilities. The committee has recommended the government review funding for the development of long-term planning above at Recommendation 9.

Adequacy of existing Government support

3.66 Several submitters commented on inadequacy in government support for people with disability and their carers in a range of areas beyond SDTs. Mr Buckley, Convenor of Autism Aspergers Advocacy Australia suggested that the very existence of the SDTs points to inadequacies in government provided support:

...we keep getting stuff from governments, especially from state governments, that say we meet the basic needs and the trusts are there to meet basic needs, they are not to provide extras.⁷⁸

3.67 If care and accommodation needs were met adequately by government, SDTs as they are currently regulated would serve no purpose. The National Council on Intellectual Disability noted that, as things currently stand, most families provide financial support as 'the Disability Support Pension does not cover a person's living expenses (board and lodging) plus transport, day services and therapy costs'. The Council emphasised that it is important that SDTs are not used as a substitute for government responsibilities by diverting family support for 'extras' to essential care.⁷⁹

3.68 Mr Spicer noted that there is no incentive for families to set up SDTs, if support services and programs are not available in the community for people with disabilities to use. He said:

...it is no good for families to establish a trust and make funds available for non-existent services. The whole-of-life services that are there have got to be in place and available really before people are going to be terribly excited about establishing trusts to provide funds to enable people to access them.⁸⁰

3.69 Some of the particular concerns raised by submitters about government support for people with disabilities included:

- scarcity of government funded disability services Australia-wide;

77 Mr Weir, Planned Individual Networks, *Proof Committee Hansard*, 29 July 2008, p. 99.

78 Mr Buckley, Autism Aspergers Advocacy Australia, *Proof Committee Hansard*, 29 July 2008, p. 56; see also National Council on Intellectual Disability, *Submission 11*, p. 5.

79 National Council on Intellectual Disability, *Submission 11*, p. 4; see also Mrs Pretsel, *Submission 35*, p. 2; Mr Spicer, *Submission 19*, p. 15.

80 Mr Spicer, *Proof Committee Hansard*, 29 July 2008, p. 72.

- the need for 'whole-of-life' services, such as social activities, sporting activities, recreational activities and vocational activities;
- scarcity and cost of supported accommodation;
- costs of services such as respite care;
- the need for funding for support and accommodation for people with disability to be at a level that enhances community participation and an 'ordinary life';
- the need for more financial assistance, such as tax deductions for contributions made towards support costs, equipment and special needs items and transport needs of people with a disability;
- the need for uniform 'statutory wills' legislation across Australia for people who lack the capacity to make a will; and
- the need for simple mechanisms to facilitate the purchase of real estate by people with disability.⁸¹

3.70 Mr Buckley, Convenor of Autism Aspergers Advocacy Australia, noted in particular that SDTs seemed 'utterly remote' to carers of people with autism spectrum disorders. Other issues were a much higher priority for them.⁸² Some of these issues included:

- the need for early intervention services for people with autism spectrum disorders;
- exclusion of people with autism from services for treatment and rehabilitation;
- lack of education and employment for people with autism; and
- lack of funding for autism advocacy and support groups.⁸³

3.71 The committee acknowledges that a wide range of supports and services are needed to assist people with disabilities and their carers in both the short and long term. While this inquiry has been focussed specifically on SDTs, the committee recognises the importance of ongoing government attention to these wider issues.

81 Mr Ward, Pave the Way Mamre Association, *Proof Committee Hansard*, 29 July 2008, p. 64 and *Submission 14*, p. 8; Mr Baker, National Disability Services, *Proof Committee Hansard*, 29 July 2008, p. 75; National Council on Intellectual Disability, *Submission 11*, p. 5; Mrs McKerrell, *Submission 23*, p. 2; Mr and Mrs Sexton, *Submission 41*, p. 2; Mr Spicer, *Submission 19*, p. 5.

82 Mr Buckley, Autism Aspergers Advocacy Australia, *Proof Committee Hansard*, 29 July 2008, pp. 55–56.

83 Mr Buckley, Autism Aspergers Advocacy Australia, *Proof Committee Hansard*, 29 July 2008, pp. 55–56 and *Submission 2*.

Relevant Government initiatives

3.72 FaHCSIA noted that the Australian Government has several projects underway which are relevant to the private provision of support to people with disabilities. In April 2008, the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten MP, announced the establishment of a Disability Investment Group to 'explore innovative funding ideas from the private sector that will help people with disability and their families access greater support and plan for the future'. As part of its work the group will look at SDTs, including reasons for the low uptake and how the trusts might be modified to be more attractive to families.⁸⁴

3.73 FaHCSIA has also commissioned the Allen Consulting Group Pty Ltd to 'examine private financial provisions and future planning initiatives that exist internationally for carers and people with disability, how these compare with those available in Australia and how other options might be feasible in Australia'. FaHCSIA noted that the group will focus on 'structural mechanisms such as superannuation, insurance, tax incentives, matched savings funds and/or social support schemes'. The consultant is due to provide a final report to FaHCSIA in October 2008.⁸⁵

3.74 In May 2008 the Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon Jenny Macklin MP, asked the House of Representatives Standing Committee on Family, Community, Housing and Youth to inquire into and report on better support for carers. The inquiry covers a range of issues around the role and contribution of carers and measures to assist carers. Broader strategies to increase the capacity of carers to effectively plan for the future will be considered as part of the Inquiry.⁸⁶

Committee comment

3.75 The committee is pleased to note that the government is giving increased attention to finding ways to support people with disabilities and their families plan for the future. It looks forward to the outcomes of these reviews leading to better government support to people with disabilities and their families. In particular the committee notes that issues around succession planning and government

84 FaHCSIA, *Submission 13*, p. 18; Ms Emerson, FaHCSIA, *Proof Committee Hansard*, 29 July 2008, p. 103.

85 FaHCSIA, *Submission 13*, p. 19.

86 FaHCSIA, *Submission 13*, pp. 18-19.

co-contribution schemes warrant further attention and should be included in these reviews. The committee notes that the Disability Investment Group will consider SDTs but emphasises that the work of the group should not delay the adoption of the recommendations made in this report. The committee considers that the government should introduce the legislative changes required to give effect to the recommendations in this report as a matter of urgency.

Senator Rachel Siewert
Acting Chair
October 2008

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS, TABLED DOCUMENTS AND ADDITIONAL INFORMATION AUTHORISED FOR PUBLICATION BY THE COMMITTEE

- 1 Crouch & Co Solicitors (QLD)
- 2 Autism Aspergers Advocacy Australia (ACT)
- 3 Disability Services Commission (WA)
- 4 Planned Individual Networks Inc (PIN) (WA)
- 5 O'Hart, Mr Brian (WA)
- 6 Winacom Association Inc (VIC)
- 7 Public Trustee of Western Australia (WA)
- 8 Kew Cottages Parents' Association (VIC)
- 9 Activ Foundation (WA)
- 10 Booth, Mr Stephen (NSW)
- 11 National Council on Intellectual Disability (NCID) (ACT)
- 12 People With Disabilities (WA) Inc (WA)
- 13 Department of Families, Housing, Community Services and Indigenous Affairs (ACT)
- Supplementary information*
- Responses to questions on notice from hearing 29.7.08, received 2.9.08
- 14 Pave the Way (QLD)
- 15 National Disability Services Limited (ACT)
- 16 Trustee Corporations of Australia (NSW)
- 17 Office of the Protective Commissioner (NSW)
- 18 Carers Australia (ACT)
- Supplementary information*
- Additional information following hearing 29.7.08, received 26.8.08
- 19 Spicer, Mr Ian (VIC)
- 20 Department of Veterans Affairs (ACT)
- 21 Walter, Mr Ray and Mrs Wendy (WA)
- Supplementary information*
- Additional information received 30.7.08

- 22 Public Trustees of the States and Territories, and State Trustees Limited (VIC)
Supplementary information
- Additional information following hearing 29.7.08, received 26.8.08
- 23 McKerrell, Mrs Jo (NSW)
- 24 Breheny, Mrs Phillis (WA)
Supplementary information
- Copies of correspondence and emails concerning limitations of Special Disabilities Trusts, received 30.7.08
 - Comments following hearing 29.7.08, received 28.8.08
- 25 Stern, Professor Walker and Mrs Maida (WA)
- 26 Broughton, Mr B L and Mrs E J (VIC)
- 27 Battrick, Mr Matthew (WA)
- 28 Kiefel, Mrs Wendy (VIC)
- 29 Mortimer, Ms Stephanie (VIC)
- 30 Drever, Mr Col (NSW)
- 31 Raine, Mr Alan and Mrs Barbara
- 32 Smale, Mr Paul and Mrs Erica (WA)
- 33 West, Mr Colin (WA)
- 34 Marks, Mr Russell (WA)
- 35 Pretsel, Mrs Liz (WA)
- 36 Breheny, Mr Frank (WA)
- 37 Dalli, Ms Lucy
- 38 Guthrie, Mr L J and Mrs E J (WA)
- 39 Walker, Mrs Leonie (WA)
- 40 Kleber, Ms Robyn (WA)
- 41 Sexton, Mr Tony and Mrs Rosalie (WA)
- 42 Hughes, Mr Patrick (WA)
- 43 Patterson, The Hon Dr Kay (VIC)
- 44 McGarry, Mrs Olive
- 45 Johnstone, Ms Valerie (VIC)
- 46 Sunnyfield Independence (NSW)
- 47 Hawkevale Trust Inc (WA)

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARING

Tuesday, 29 July 2008

Parliament House, Canberra

Committee Members in attendance

Senator Claire Moore (Chair)

Senator Judith Adams

Senator Cory Bernardi

Senator Sue Boyce

Senator Rachel Siewert

Witnesses

Dr Kay Patterson *via teleconference*

Carers Australia

Ms Joan Hughes, Chief Executive Officer

National Council on Intellectual Disability

Mr Mark Pattison, Executive Director

Trustee Corporations Association of Australia and Public Trustees of the States and Territories, and State Trustees Limited

Mr Tony Fitzgerald, Managing Director, State Trustees Limited, and National President, Trustee Corporations Association of Australia

Mr Alistair Craig, Senior Corporate Lawyer, State Trustees Limited

Winaccom Association Inc *via teleconference*

Mr Ian Gresswell, Honorary Treasurer

Autism Aspergers Advocacy Australia

Mr Bob Buckley, Convenor

Pave the Way *via teleconference*

Mr Jeremy Ward, Manager

Mr Ian Spicer *via teleconference*

National Disability Services Limited

Dr Ken Baker, Chief Executive

Mr Ray Walter and Ms Phillis Breheny *via videoconference*

Planned Individual Networks *via videoconference*

Mr Harry Weir, Funds Development Director

Department of Families, Housing, Community Services and Indigenous Affairs

Ms Lee Emerson, Branch Manager, Carer Branch

Ms Angela Hope, Section Manager, Carer Policy

Ms Alanna Foster, Branch Manager, Seniors and Means Test Branch

Mr Sam Cavalli, Section Manager, Financial Markets Section, Seniors and Means Test Branch

Department of Veterans Affairs

Mr Stuart Kennedy, Director, Income Support Policy Development and Advice