

## 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.<sup>1</sup>

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'.<sup>2</sup> 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?<sup>3</sup>

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

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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.<sup>4</sup> 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?<sup>5</sup>

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.<sup>6</sup>

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.<sup>7</sup>

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.<sup>8</sup> 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.<sup>9</sup> Mr Booth suggested that simplification of the SDT rules including

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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

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

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.<sup>11</sup>

### ***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.<sup>12</sup> National Disability Services also noted the 'currently onerous compliance burden of reporting and auditing'.<sup>13</sup> 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.<sup>14</sup>

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

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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'.<sup>15</sup> 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.<sup>16</sup> 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.<sup>17</sup>

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.<sup>18</sup> 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'.<sup>19</sup> 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.<sup>20</sup>

### ***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.<sup>21</sup>

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

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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.

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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.<sup>22</sup>

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.<sup>23</sup> 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.<sup>24</sup>

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.<sup>25</sup>

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.<sup>26</sup>

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.<sup>27</sup>

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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.<sup>28</sup> 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'.<sup>29</sup> Mrs Breheny felt that immediate families contributing to a trust should be entitled to a review.<sup>30</sup> 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.<sup>31</sup> 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.<sup>32</sup>

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.<sup>33</sup>

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.<sup>34</sup>

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

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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.

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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.<sup>35</sup> 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.<sup>36</sup>

### ***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**

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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.<sup>37</sup>
- 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.<sup>38</sup>
- The need for a list of approved service providers to assist parents in determining what are considered eligible expenses.<sup>39</sup>
- 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.<sup>40</sup>
- 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.<sup>41</sup>

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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.<sup>42</sup>
- 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.<sup>43</sup>

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.<sup>44</sup> The Hon Dr Patterson noted that information booklets had been sent out about the trusts,<sup>45</sup> 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

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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 McKerrill, *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.<sup>46</sup>

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.<sup>47</sup> 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.<sup>48</sup>

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.<sup>49</sup>

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

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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.

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

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.<sup>51</sup>

***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'.<sup>52</sup>

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.<sup>53</sup>

3.42 Mr Spicer considered that disability organisations and carer organisations could have more of a role in promoting the trusts.<sup>54</sup> 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.

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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.<sup>55</sup>

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.<sup>56</sup>

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'.<sup>57</sup>

### ***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.<sup>58</sup>

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.<sup>59</sup> Ms Hughes, Chief Executive Officer of Carers Australia commented:

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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.

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...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.<sup>60</sup>

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.<sup>61</sup>

### *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.**

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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.<sup>62</sup> 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.<sup>63</sup>

3.56 Submitters suggested that a superannuation style co-contribution scheme could apply for disabilities.<sup>64</sup> 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.<sup>65</sup>

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

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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'.<sup>66</sup>

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.<sup>67</sup> Mr Weir also argued that the SDTs should be kept, but thought that these would come under the broader 'umbrella of the savings plan'.<sup>68</sup> 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).<sup>69</sup> 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.<sup>70</sup>

3.60 Mrs Breheny was less supportive of the Canadian plan, considering that it is too broad in scope.<sup>71</sup> 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.<sup>72</sup>

### ***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

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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](http://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](http://www.cra-arc.gc.ca/tx/rgstrd/rdsp/menu-eng.html) and [www.cra-arc.gc.ca/agency/budget/2007/rdsp-e.htm](http://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'.<sup>73</sup> 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.<sup>74</sup>

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.<sup>75</sup>

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?<sup>76</sup>

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

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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.<sup>77</sup>

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.<sup>78</sup>

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.<sup>79</sup>

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.<sup>80</sup>

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;

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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.<sup>81</sup>

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.<sup>82</sup> 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.<sup>83</sup>

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.

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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 McKerrrell, *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*.

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### ***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.<sup>84</sup>

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.<sup>85</sup>

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.<sup>86</sup>

### ***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

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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