

# **SUCCESSION PLANNING FOR CARERS**

## **REPORT ON CONSULTATIONS**

**January 2007**

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## EXECUTIVE SUMMARY

*“When it comes to succession planning for our son, the only certainty we have at present is the fact we are going to grow old and in our declining years our son is going to become more and more vulnerable.”*

The Australian Government’s Discussion Paper on Succession Planning for Carers and its request for submissions and information from families and organisations on issues to help plan for the future care and support needs of a person with disability, clearly struck a chord with ageing carers, family members and services. The responses demonstrated that this is a complex and challenging issue for families, the people they care for, service providers and governments; and one that is becoming increasingly urgent to address.

More than 100 submissions were received from families (59) and organisations (58) in response to the Discussion Paper. Consultations were also held in each capital city. Whilst each approach produced slightly different information; the results of both have been compiled into one report. The key cross-cutting themes from each of the approaches are presented in this summary and more detail is provided in the body of the report.

Many respondents indicated that planning for the future is a very difficult proposition for many families and carers. The key **barriers to planning** included:

- Families don’t know where to start; who to go to; where to find information or what to do.
- The costs of disability and caring are such that many parents may not have accumulated many assets in their lifetime and may not be able to financially provide for their child’s future, without significant government assistance.
- Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information.
- A planned transition is not considered feasible whilst services and governments continue to place only those people with disabilities in crisis or emergency situations.
- Many carers are too busy or tired from day to day responsibilities to be able to find the energy to undertake the complex and time-consuming task of planning for the future.
- Many ageing carers may not have expected their son or daughter to outlive them and may have unrealistic expectations around what governments, services and family members can provide when they need to relinquish care.
- Future planning is an extremely complex issue, across state, territory and Commonwealth law and regulations covering financial, legal, property, taxation and government support issues. Circumstances will change between any plan and its implementation, and establishing support networks is hard work.

Whilst the introduction of the Special Disability Trust (SDT) was welcomed as an early indicator that the Government was aware of the needs of ageing carers; it was widely reported that the SDT was suited mostly to middle-high income earners and was not particularly relevant to many low income earners or pensioners. After years of care, many carers find themselves on pensions and/or without assets. Some concern was also expressed around the possibility that governments could change the rules at any time.

With regard to the **Special Disability Trust** a number of **issues** were raised and **options** for improvement suggested including:

- Limiting the SDT to the provision of accommodation and care makes it too narrow (people don't want to have to set up and run two trusts; an SDT and another for day to day living expenses).
- The definition of severe disability is considered too limiting, and many people with mental illness and other disabilities would not meet the criteria.
- Undistributed income should not be taxed, but retained as capital accumulation.
- The cap of \$500 000 (indexed annually) is too low – it does not recognise the full cost of care and would not be enough to fund support for a long period of time; either the money will run out or not enough care can be provided. The cap should be raised to around \$1 million.
- The Capital Gains Tax and Stamp Duty paid on sale of primary place of residence when placed into the SDT is a negative and needs to be resolved.
- Donations to the SDT should be tax-deductible.
- Contributions to the SDT should be able to be made pre-tax by salary-sacrificing into the SDT.
- Some form of co-contribution to an SDT would be welcomed (along the lines of low- income superannuation with the government matching family contributions).

Throughout their submissions and at consultations, in addition to commenting on the SDT, carers, families of people with disabilities and organisations also raised a **broad range of general issues** facing families as they plan for the future care of a person with disability. The key general issues raised were:

- Future accommodation needs to be more than “just any place”. It needs to be a home that takes account of social, emotional, health and personal care needs. It needs to be local and familiar and with people they want to live with.
- Funding bodies are currently focussed on crisis and emergency management – they do not focus on planning for the future.
- Families don't know what options they have for future planning.
- Supplying accommodation can often be managed – it's funding the ongoing support that prevents planning (some examples were provided of where houses have been offered to governments or NGOs and rejected due to legal and other technicalities).
- There is no single contact point to help with planning and information.
- Families recognise the limited capacity of siblings, with their own families, careers and mortgages, to take on the level of care that parents have provided over many years.
- Many professionals (accountants, lawyers) are not experienced in disability issues;
- Respite care is important in helping families continue to care and find time to plan and more is needed.
- Planning for future accommodation and support must recognise that one size does not fit all; and that variety and choice are needed by individuals.
- Concern that focussing on private provision and succession planning assumes parents have full responsibility for future care arrangements and that governments are relinquishing responsibility.
- Governments are not building enough public accommodation and some approaches appear ideologically opposed to families' preferences for small scale congregate care settings.

In response to these general issues, a number of **suggestions** were made that would help families plan more effectively for the future including:

- Providing funding for planning services which are regionally based and can provide advice, information, planning support and review, counselling, and referral services to families and which involve family to family sharing of experience and option development.
- Establishing a centre of expertise such as a website and/or a toll-free information line providing advice, information, support and referral services around future planning.
- Starting the transition process now. By increasing access to respite, paid care in the home, independent living skills or accommodation places now, families would be able to reduce dependence now and prepare for the time when they have to relinquish care, enabling a smooth transition to new arrangements.
- Providing more accommodation support now to enable families to begin to transit to new arrangements and to give some sense of certainty to their planning. Families should be able to explore the full range of accommodation support options and develop models that best suit their family member and their situation.
- Having governments shift their focus from crisis to long-term planning and starting now.
- Encouraging services to help families establish and sustain “Circles of Support” or “Circles of Friends”.

Submission respondents were less clear about how to encourage private provision within families, or about informal arrangements or schemes to help parents provide for their child with disability over time. Similarly little information was supplied around innovative models of accommodation that would assist parents and families make provision for their child with disability. However, a number of good accommodation models and proposals were referred to (see **Appendix A**); but in most instances information and detail was limited. As a result, these areas would appear to remain open for further research and investigation.

## **BACKGROUND<sup>1</sup>**

On a positive note, many people with disabilities are enjoying a longer life-span and overall better health. However, for those who are cared for by parents or other informal carers, this often means they will outlive their carer, or live to an age where their carer is no longer able to provide the level of care required. There is relatively little information or data (either Australian or international) that clearly identifies what the needs and priorities of this group are in relation to succession planning.

Understandably, many parents and carers are concerned about what will happen when they are no longer able to provide care. Evidence is emerging in Australia and other countries that indicates few parents and carers have made comprehensive plans for future care, accommodation and support, and that they are reluctant to engage in such planning<sup>2</sup>. The reasons for this reluctance and/or lack of planning are varied. Some carers report that 'coping with the present' is difficult enough, others believe they are going to live longer than their children, and a number of carers experience frustration and confusion about the lack of information and services when trying to undertake planning<sup>3</sup>, whereas others are willing to contribute financially but don't know how to start to plan, or are discouraged by complexities in the social security and taxation systems.

## **THE CONSULTATION PROCESS**

### **PURPOSE**

The Australian Government Department of Families, Community Services and Indigenous Affairs (FaCSIA) sought information about the needs of parents and immediate family planning for the future care and support of a person with disability. Information collated from this consultation process may be used by the Department to assist in developing future policy including identifying areas where further research may be required on the needs of carers.

### **PROCESS**

The consultation process was divided into two parts (submissions and consultation meetings). A Discussion Paper "*Succession Planning for Carers*" was made available on the FaCSIA website and advertisements were placed in major newspapers on 4 November 2006 requesting submissions from family members or groups by 15 December 2006. The Discussion Paper was also sent to all major disability and carer peak organisations who were asked to circulate the paper amongst their members.

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<sup>1</sup> Department of Families, Community Services and Indigenous Affairs, *Succession Planning for Carers, Discussion Paper*, November 2006.

<sup>2</sup> See Bigby, C "*Transferring Responsibility: the Nature and Effectiveness of Parental Planning for the Future of Adults with Intellectual Disability who Remains at Home until Mid-life*". Australian Society for the Study of Intellectual Disability Inc, 1996 p296. This reluctance is also noted in other countries, see O'Grady, Reilly and Conliffe "*Facilitating future planning for ageing adults with intellectual disabilities: using a planning tool that incorporates quality of life domains*" *Journal of Gerontological Social Work*, Vol 37 (3/4) 2002, p105.

<sup>3</sup> Keyzer, Carney and Tait "*I hope he dies before me" caring for ageing children with intellectual disabilities and against the odds: parents with intellectual disability*". A review of legal service and options for people who lack competency and their carers, report to the disability services sub-committee, August 1997, p 36 – 37.

In November and December 2006, consultations (focus groups and in-depth interviews) were also held in each capital city.

The purpose of the Discussion Paper and the consultation meetings were aligned but each process had a slightly different focus, resulting in a broad range of information being collected with some overlap between the two parts of the process.

Submissions in response to the Discussion Paper canvassed a diverse range of views on general issues and concerns but provided only a limited number of direct responses to the four questions posed. Less than a quarter of submissions (26) directly responded to the questions, with widely varying degrees of detail. The consultations involved more detailed discussion of the Special Disability Trust (SDT).

#### **THE DISCUSSION PAPER**

The Discussion Paper referenced a number of government measures and highlighted some key issues for families in planning for the future. In particular it asked four questions:

- What prevents parents and families from planning for the future?
- What could be done to encourage private provisions within families?
- Are other informal arrangements or schemes needed to assist parents or carers who wish to provide for their child with a disability over time?
- Are there innovative models of accommodation that would assist parents and families make provisions for their child with disability?

Most (78%) of the 117 submissions received in response to the Discussion Paper and advertisements did not use the four questions to frame their responses; rather they raised general issues and concerns around being an ageing carer and planning for the future. Forty five submissions (38%) commented on the SDT and 23 submissions (19%) provided suggestions around the SDT.

A small number of submissions (13) made comments about the accessibility of the Discussion Paper and the timing for submissions. Most expressed concern about the relatively short timeframe for comments, the timing of comments being at the busiest time of the year (just prior to Christmas and school holidays); the limited advertising of the call for submissions; and that the Discussion Paper was only available on the Internet which some ageing carers noted they could not access or use. This may account for many family submissions addressing general issues only and not specifically the questions raised in the Discussion Paper.

Of the 117 submissions received, just over half (51%) came from family members, 29% came from advocacy or support groups and 16% came from service providers. The remainder came from government agencies (2%), University (1%) and unknown (1%).

FAMILY	ADVOCACY	PROVIDER	GOVERNMENT	UNIVERSITY	UNKNOWN
59	34	19	3	1	1

Submissions were received from all states and territories with the exception of the Northern Territory. NSW provided around one-third of those received (30%) with WA (17%) and QLD and VIC (16% each) the next highest. The ACT provided 10%, which could be considered relatively high for its population base.

ACT	NSW	NT	QLD	SA	TAS	VIC	WA	UNKNOWN	TOTAL
12	35	0	19	10	1	19	20	1	117

### THE CONSULTATION MEETINGS

Invitees to the consultation meetings held in each capital city included individual carers, representatives from carer and disability organisations, state and territory governments, service providers, public trustees and advocacy and support groups. The program for the meetings consisted of an introduction by Ian Spicer AM, a presentation on the Special Disability Trust (SDT) by Allan Swan (of Moores Legal) and an opportunity for questions and answers on more general matters regarding succession planning.

A significant part of each consultation meeting was taken up by the presentation on the SDT: where it came from; what it did; how it fitted with other measures; and what it did not do. The presentation also provided information on All Needs Protective Trusts, will drafting, the Disability Support Pension (DSP) and the impact of the means test. As a result, much of the discussion at these consultations centred on understanding the details and potential implications of the SDT.

### DETAILS OF THEMES THAT EMERGED FROM THE PROCESS

The two approaches in the process produced slightly different information and on slightly different issues. As a result, the information is presented in three parts. Part 1 provides the detailed information from the submissions that was general in nature and *not* in response to the four questions posed in the Discussion Paper. Part 2 captures submission responses to the four questions posed in the Discussion Paper. Part 3 provides detail of issues raised in the eight consultation meetings.

### PART 1. SUBMISSIONS – ISSUES RAISED NOT IN DIRECT RESPONSE TO THE FOUR QUESTIONS POSED

NOTE:                    Italicised quotes are direct from submissions.  
                              Numbers in brackets refer to the number of submissions that made reference to this issue.

#### Special Disability Trust issues raised in submissions

*“You cannot have it both ways: unpaid care for decades and financial provision for the future by carers.”*  
*“...the new disability trusts cannot pay for services that do not exist or are of grossly insufficient volume and flexibility.”*  
*“The definition of severe disability...should be torn up.”*

#### KEY SDT ISSUES (FROM SUBMISSIONS)

- Low income earners could not afford to contribute \$500 000; the cost of disability and care responsibilities over many years reduce income and prevent savings (33)
- The Government is to be applauded for recognising that planning for the future is an issue and taking this first step (18).
- Limiting the SDT to the provision of accommodation and care makes it too narrow (people don't want to have to set up and run two trusts; an SDT and another for day to day and living expenses) (13).
- The definition of severe disability is too limited (6).

- Undistributed income from the SDT should not be taxed, but retained as capital accumulation up to the SDT limit (4).
- The cap of \$500 000 is too low – it does not recognise the full cost of care and would not be enough to fund support for a long period of time; either the money will run out or not enough care can be provided (3).
- The Capital Gains Tax and Stamp Duty paid on sale of primary place of residence when placed into the trust is a negative (3).

#### SINGLE ISSUES

Other issues raised in individual submissions included: the use of the Secretary's delegated powers in so many areas creates uncertainty; the fact that the beneficiary cannot contribute to the fund; the need for clarification regarding ownership of property in the SDT– can it be in conjunction with another SDT?; can ownership be in conjunction with another individual?; what protections exist against challenging a will that establishes a SDT?; and will there be a tax burden on the parent/carer if the person with disability dies?

### **Suggested responses to Special Disability Trust issues raised in submissions**

#### KEY SDT SUGGESTIONS (FROM SUBMISSIONS)

- Need to broaden the SDT to cover all areas of life not just care and accommodation (11).
- Increase the cap from \$500 000 to around \$1 million to allow funds to last longer and/or purchase more care (5).
- Enable the SDT to be like low-income superannuation – allowing co-contributions from government and families from early on in the life of a person with disability and the care cycle (5).
- Allow unspent SDT income to be transferred tax-free into the base until the limit is reached (then above the limit could be taxed) (4).
- Allow donations to a SDT to be tax-deductable to encourage other family members and friends to contribute (4).
- Exempt income from the SDT from tax until the death of the person or they become ineligible to have a trust (2).
- Make SDT contributions an option for salary sacrificing (2).

#### SINGLE SUGGESTIONS

Other options raised in individual submissions included: allowing the beneficiary to contribute to the SDT; allowing for an advocate to keep in contact with the beneficiary and independently assist them as needed; make it possible to do weekly or fortnightly transfers into the fund; create a five year roll over period to allow income/expenditure to even out; do an ACAT-type assessment rather than the definition of severe disability; and use different tests for smaller funds.

### **General issues raised in submissions**

*“Families wish to ensure that their sons and daughters with disabilities are able to have a good life that involves family and friends, a place to call home, economic security, a sense of purpose and opportunities to participate and contribute to the community.”*

*“The processes that would enable our organisation to accept offers and use them flexibly and creatively are just not in place.”*

*“...need a Philadelphian lawyer to wade through it all.”*

#### KEY GENERAL ISSUES (FROM SUBMISSIONS)

- Accommodation needs to more than “just any place”. It needs to be a home that takes account of social, emotional, health and personal care needs. It needs to be local and familiar and with people they want to live with. (29).
- Funding bodies are focussed on crisis and emergency management – they do not focus on planning for the future (25).
- Families don’t know what options they have for future planning (23).
- Supplying accommodation can often be managed; it’s funding the ongoing support that prevents planning (some examples were provided of where houses have been offered to governments or NGOs and rejected due to legal and other technicalities) (23).
- There is no single contact point to help with planning and information (22).
- Families recognise the limited capacity of siblings, with their own families, careers and mortgages, to take on the level of care that parents have provided over many years (22).
- Respite care is important in helping families continue to care and plan and more is needed (16).
- One size does not fit all and different supports and accommodation are needed by individuals (13).
- There are no suitable accommodation places available – unmet demand (11).

#### LESS FREQUENTLY RAISED GENERAL ISSUES (FROM SUBMISSIONS)

- Concerns were raised regarding the quality of care provided in accommodation services (7).
- “Succession planning” assumes it’s the responsibility of the parents to organise and arrange ongoing care – what is the role of society and government? (6).
- Planning requires Commonwealth-State cooperation (5).
- Some families could feel so desperate they contemplate murder-suicide (4).
- Don’t trust state governments to do the right thing (3).
- Who can be the executor of their will and the guardian? (3).
- Concerns were raised about who will advocate on behalf of the person with disability and “keep the services honest”? (2).

#### SINGLE ISSUES

Other issues raised in individual submissions included: many families with people with disabilities in institutional care make no provision for them in their wills; and the impact on family relationships of the extent of the inheritance going to the person with a disability.

#### **Suggested responses to general issues raised in submissions**

*“In many cases it is not planning by families that is needed, but planning by governments to ensure that essential supports are available when needed.”*

*“It needs to be someone with whom you have a relationship and who you can trust. Trust takes time to develop.”*

*“Someone who will respect our decisions, even if they don’t like our choices.”*

#### KEY RESPONSES TO GENERAL ISSUES (FROM SUBMISSIONS)

- Fund services like PIN to provide free information, counselling and future planning workshops and supports for families (39).  
(See **Appendix B** for a list of planning tools, services and models mentioned in submissions)
- Need to start transition to new accommodation and support arrangements now – this can be helped by increasing hours of paid care, increasing use of respite, increasing the amount of live-in care, and developing independent living skills (36).
- Develop small-scale congregate care settings like aged care hostels and self-care units (23).
- Governments need to fund more accommodation and support to meet unmet demand (11).
- Build up and sustain circles of friends or circles of support to help with transition (9).

#### LESS FREQUENTLY REPORTED RESPONSES TO GENERAL ISSUES (FROM SUBMISSIONS)

- Fund organisations to re-establish family support networks (6).
- Should be able to claim additional costs of disability and care as a tax deduction (5).
- Allow private, not for profit investment in supported accommodation by introducing an accommodation bond (4).
- Give people with disabilities direct funding to purchase their own care (attendant care model) (3).
- Develop a guaranteed care plan which the government must commit to implementing (2).
- Maintain a register of people with disabilities and their carers and review it every two years to determine what support is needed (2).
- Re-invigorate dying country towns by converting them to villages for people with disabilities (2).
- Allow people on DSP to withdraw and use any superannuation they have before age 60 to help with care costs given their lower life expectancy (2).
- Increase the Medicare levy to pay for accommodation and care costs (2).
- Develop innovative savings schemes for families and people with disabilities (2).
- Provide more counselling services (2).

#### SINGLE RESPONSES

Other suggested responses raised in individual submissions included: abolishing the means test for Carer Payment; increasing the amount able to be earned on DSP before it starts reducing; establishing a department in Centrelink to help carers plan for the future; funding creative housing research; transferring supported accommodation to the Australian government; and enabling provision in wills to purchase a room or place in supported accommodation and fund it from the proceeds of the house sale.

#### **PART 2. SUBMISSIONS – ISSUES RAISED IN DIRECT RESPONSE TO THE FOUR QUESTIONS POSED**

Only 26 of the 117 submissions (22%) directly responded to the four questions posed in the Discussion Paper. Due to this small number, the number of submissions referring to a theme has been included rather than the number referring to a particular measure or idea.

NOTE: Italicised quotes are direct from submissions. Numbers in brackets refer to the number of submissions that made reference to this theme.

### **Question 1. What prevents parents and families from planning for the future?**

This was the most comprehensively answered of the four questions. Many submissions articulated clearly and succinctly why planning for the future is difficult for families caring for a person with disability. Personal experience shone through many of the responses, providing detail and understanding.

#### KEY ISSUES IN RESPONSE TO QUESTION 1 (FROM SUBMISSIONS)

##### The lack of accessible information prevents effective planning (16)

- There is a lack of knowledge and awareness of ways to provide for future care. Many carers are unaware of what they can do, and don't know how to start, who to go to and when to start.
- There is no central information point.
- Many older parents and carers have been broadly independent from the service system for much of their life – they have done it themselves and “just got on with it” – and therefore may have little or no contact with services or know very little about what the options are likely to be.
- CALD carers can face particular issues such as difficulties accessing services, limited culturally-sensitive services and diminished support networks.  
*“You don't know who to speak to”*

##### Limited finances and the cost of care (16)

- The costs of disability and caring are such that many parents may not have accumulated many assets in their lifetime and may not be able to financially provide for their child's future, without significant government assistance.
- Equity in the family home may be needed to provide care for ageing parents rather than for a child with disability.
- Migrants with disability, including their carers, have to wait ten years before they are eligible for any income support. This means financial resources are often substantially curtailed.  
*“Without finances you cannot plan you can only hope. In any case there are no options in place for us to plan for.”*  
*“A significant barrier to families is their limited financial standing, particularly for aged parents who have over many years borne the brunt of the financial burden in caring for their disabled son or daughter.”*

##### Future planning raises sensitive issues (13)

- Future planning requires people to face and discuss their own mortality – many people are not comfortable discussing death and dying, and will put it off.
- For people with episodic illnesses or disability (eg schizophrenia) succession planning can seem “disloyal” by virtue of it confirming that you believe there will be “a next time”, undermining faith in treatment and the ability to manage the illness or disability.
- It requires family members to identify and discuss issues that are sensitive, private or confidential, for example the real value of assets, the unspoken assumptions of family members regarding inheritances and care responsibilities.

- For some CALD families not providing care within the family may be seen as “shameful” and “letting the family down”. Female relatives, a mother or sister, may take on the role of carer as a duty more than a choice.  
*“Even talking about this makes my wife anxious.”*  
*“A lot of the information that needs to be discussed is personal, it’s hard.”*

#### No long term places available – only for crisis (13)

- A planned transition is not considered feasible whilst services and governments continue to place only those people with disabilities in crisis or emergency situations.
- Without places available locally and some sense of certainty about where the person with the disability may end up it is too difficult to try to establish networks of support and to determine what different roles or support may be needed.  
*“But we can’t get any (respite), because the respite beds are all taken up with people in crisis waiting for permanent accommodation.”*

#### No time and no energy to spend on planning (10)

- Many carers do not have the time or energy to undertake planning due to the ongoing day to day pressures of caring. Planning is viewed as important rather than urgent and dealing with the here and now care and support for a family member takes precedence.  
*“Thinking about the bigger picture is hard when we cannot get today’s needs met.”*  
*“Exhaustion from long term caring with inadequate support, inadequate respite and (often) lack of acknowledgement.”*

#### Unrealistic expectations and unspoken assumptions (10)

- Many families may have been told at the time of birth or diagnosis that their child would not live to a very old age, so many parents expected to outlive their son or daughter. Planning for the future has been a low priority.
- Many parents contributed to the establishment of service organisations and hold an expectation that these services will provide for their children when they are gone; despite changes to funding arrangements and government policies.
- Some parents assume that a sibling would take over the care and responsibility for their brother or sister with a disability and that things will continue “as normal” without ever checking this assumption with their other children.  
*“We’ve seen what Mum goes through – no way.”*

#### Planning for the future is complex (7)

- Developing a succession plan is a complex task. It is a lot more difficult than writing a will. It takes a lot of time to tease out and address sensitive issues and can seem daunting to many families.
- Many carers believe that all sorts of circumstances will change between the planning and the implementation of any plan; which can make all the effort seem worthless.
- Developing a support network to oversee and sustain a plan seems like an insurmountable obstacle. Fear of asking for support and being rejected or having lost a broad social network due to care responsibilities can mean that establishing and sustaining such a network requires a delicate balance and extensive effort and resources.

- There are many obstacles in attempting to implement a plan – financial, legal, property and insurance systems all make it hard to implement a plan that replaces the extensive care provided over many years.

*“Planning too early is also difficult as rules and regulations change as well as what is available.”*

#### SINGLE ISSUES

Other issues raised in individual submissions included: philosophical differences between families and policy makers around congregate care; and the quality of accommodation services.

#### **Question 2. What could be done to encourage private provisions within families?**

The concept of private provision did not appear to be well-understood. Most of these responses provided information about what would enable family members to continue to care in the present without burning out; rather than focussing on the future.

#### KEY SUGGESTIONS IN RESPONSE TO QUESTION 2 (FROM SUBMISSIONS)

##### Develop planning and information services (14)

- An information/consultancy service to help guide families through the maze of planning; including counselling for family members as they deal with sensitive and challenging issues. Services should be practical, easy to understand and tangible.
- Connect families thinking about succession planning up with other families who have already started or undertaken the process.
- Legal advice on tenancy and other support issues.
- Education and training for carers covering the complexity of succession planning. *“...a funding strategy aimed at supporting vision-driven, family focused, succession planning initiatives.”*

##### Special Disability Trust (9)

- The SDT was considered a good example of how to encourage private provision. *“the SDT ...is a great beginning.”*

##### Provide financial planning and support (7)

- Offer budgeting and financial management skills and training to families with children with disabilities as an early intervention option.
- Initiating an innovative savings scheme like the Benevolent Society’s Saver Plus could encourage private provision by providing incentives to save.
- Some arrangement whereby families could put aside funds throughout their life to provide future care for the person with a disability, including through salary-sacrificing.
- A Superannuation-type scheme.

##### There should be no expectation of private provision (3)

- Governments should not assume that families have the capacity make private provision; nor should they move away from their responsibilities to people with disabilities. *“The government is just relinquishing delegation of duty (sic).”*

### More capacity for hybrid models (3)

- Ways need to be found to enable families to provide funding and to have services match this for example by providing accommodation whilst services provide ongoing support.
- Other hybrid models to consider include services which manage transition – whereby some time is spent in the service and some at home; easing the transition process.  
*“Getting the house is the easy part. But where does the support come from?”*

### SINGLE ISSUES

Other issues raised in individual submissions included: relaxing immigration provision to allow extended family members to enter as carers; enabling earlier access to services and support for Visa holders; more independent living skills schemes; a shift from crisis management to long-term planning needs to occur within agencies; tax-breaks for people directly contributing to care and support provided by a charitable organisation; and a Parliamentary Inquiry to examine impediments to families making private provision.

### **Question 3. Are other informal arrangements or schemes needed to assist parents or carers who wish to provide for their child with disability over time?**

This question did not appear to be well understood and many “informal” arrangements were strongly linked to, or dependent on, government funding. A number of submissions indicated that informal didn’t work – given the multiple demands on other family members and the often geographic distance between them. Others highlighted that given the time and other constraints on ageing carers, that even informal supports may need some formal guidance and/or supervision. As with Question 2 above, many suggestions were linked to improving the lives of carers now; rather than planning for the future.

### KEY SUGGESTIONS IN RESPONSE TO QUESTION 3 (FROM SUBMISSIONS)

#### Better planning information and support (13)

- The booklet “Planning for the Future – People with Disabilities” is considered a valuable starting point, but there was a general view that very few families could manage the process on their own with only the booklet as a guide.
- Financial and legal advice and information should be more readily available and accessible in easily understood formats.
- Case manager roles should have more hours to be able to dedicate to this function.
- Seed funding for schemes such as PLAN (Planned Lifetime Advocacy Networks) and PIN (Planned Individual Networks). The models used do not require recurrent government funding. Once they are well-established, families can own and maintain them.  
*“...for example an information/consultancy service to advise people on what they could do and to guide them through the maze of future planning.”*

#### Encourage transition support including hybrids (8)

- Encourage greater independence through flexible respite care (regular and increasing), enabling the person with disability to make more contacts and establish other support systems.
- Brokerage or direct client funds with flexible guidelines to purchase care and support could enable more informal arrangements.

- Services that allow family involvement to continue – hybrids that can accommodate private provision alongside government-funded support.

#### Increase family supports (6)

- Funding should be provided for “family to family” information and support services or family support groups.
- Families need access to a facilitator who can help them develop a life plan and help review the plan regularly. Part of this plan could help families develop informal support networks that complement and strengthen formal support services.
- Circles of Support or Circles of Friends are welcomed; and whilst they are “informal” networks of a kind, they probably need some sort of guidance or facilitation to become established and to sustain them. This is in part due to carers’ reduced social networks, the time and effort needed to coordinate such a group, and many carers’ preference not to ask for outside help.  
*“...provide the means to set up Circles of Support and networks around the children.”*

#### Financial changes (4)

- Increase Carer Allowance, ensuring that more family income is available for savings and wealth creation.
- Change the superannuation rules to allow superannuation to be released early for the support of a person with disability.
- Enable people to salary-sacrifice (pre-tax) into a future accommodation fund.
- Costs of disability should be tax-deductible.
- Bond/entry fees to accommodation services should be treated the same as aged care accommodation contributions.

#### There should be no assumption of ongoing informal support (4)

- Whilst there should be room for families to continue to play a role and provide support, governments should not assume that siblings, other family members or friends are willing or able to provide full-time care.  
*“The provision of future planning for the care of a family member with a disability should not involve the expectation that another family member take over the personal and financial responsibility or the care and support of the person.”*

#### **Question 4. Are there innovative models of accommodation that would assist parents and families make provisions for their child with a disability?**

Responses were disparate, diffuse and not clearly focused on making future provision. Eighteen submissions provided the names of accommodation services and/or models which they considered innovative (see **Appendix A**); but not all of these would assist parents make future provision.

#### KEY SUGGESTIONS IN RESPONSE TO QUESTION 4 (FROM SUBMISSIONS)

##### Accommodation needs to be local, flexible and available (9)

- The most common request around accommodation was that it be local, flexible and available.
- Flexibility is vital in response to individual needs and also changes in circumstances. It is also needed to assist with transition periods.
- Being in a familiar community with as many local, social and community support as possible is far better than being removed and isolated from these supports.

*“The need for supported accommodation is NOW, not when we can no longer provide care”  
“Desirable models of accommodation incorporate choices – variety of accommodation available, flexible services, choice of location, choice of service provider.”*

#### Cluster Housing (8)

- Small individualised living units in a secure estate with onsite nursing/ care personnel are considered desirable.
- Retirement villages for 20-30 people with on-site support.
- Families and organisations are investigating or have developed cluster-housing models where several houses or units are built on one site and support staff move between units to provide services.  
*“Cottages with central services and adequate 24-hour staff, on call even for independent clients.”*

#### Co-Residency (4)

- Shared rental or co-residency options where the person with the disability shares the premises with another person who can provide support to meet the individual’s needs (the person with the disability owns or leases the property).  
*“Volunteer housemate model = housemate lives in rent-free.”*

#### Living “independently” in the community (4)

- The best option for some respondents was for people with disabilities to be living in their own home in their own community; and not being encouraged to join some form of communal, cluster or shared accommodation.
- A willingness to explore the possibilities and options was preferred so families were not forced to choose from the existing “menu” of accommodation support services.  
*“...models / approaches that build a life for the person with a disability that is congruent with ordinary lives in the community.”*

#### Hybrids – accommodation provided, ongoing support purchased (3)

- Families building a separate residence or granny flat on the family property for the family member to live an independent life - needs support of local government and state government planners for subdivision applications. Ongoing support funding is also needed.

#### Attendant care models (3)

- The allocation of funds to an individual to enable them to purchase the type, quantity and variety of support needed would enable many to stay in their own home.  
*“People have an entitlement and the ability to buy their own support.”*

#### SINGLE ISSUES

Other issues raised in individual submissions included: forums for families to creatively explore options; establishing co-operatives; and reimbursing the costs of visiting when someone is placed away from their home.

### **PART 3. OUTCOMES OF THE CONSULTATIONS**

Much of the discussion at these eight meetings centred on the SDT; however more general issues were also raised at each session.

NOTE: Numbers in brackets refer to the number of consultations where reference was made to this issue.

### **Special Disability Trust**

- The focus on the provision of care and accommodation only is too narrow (5).
- Don't trust governments – could change the rules at any time (5).
- Doesn't apply to low income earners – it's only for the wealthy or middle class (4).
- There are problems with taxation – capital gains and stamp duty (4).
- The cap of \$500 000 is too low – not enough to buy care and money will run out before the person with disability dies (3).
- Donations to SDT should be tax-deductible (3).
- Would be good to have some sort of co-contribution scheme (3).
- Should be able to pay family members (2).
- Too complicated and too much legal jargon (2).
- Should be able to lease or rent from a family member eg a granny flat (2).

### **Definition of Care**

- Very complex – doesn't look at the person's life as a whole (5).
- Should include lifestyle costs (3).
- Should include day to day costs – maintenance, rates, insurance etc (2).

### **Definitions of Severe Disability**

- Excludes many people with mental health issues (3).

### **State/Territory government issues**

- Respite is needed to help people cope now (2).
- Need to provide accommodation and support so that people with a SDT can actually purchase it (2).

### **Accommodation Support**

- Develop models along the lines of aged care – self-care, hostel, nursing home (2).
- Concern that the introduction of SDT was encouraging a cost-shift from governments with a responsibility for providing accommodation and support to individuals and their families (2).

### **Barriers to Planning**

- Uncertainty about the availability of and access to services and resources – especially what could be around in the future (6).
- A lack of information about what is available and a lack of assistance to guide through the process (6).
- The complexity of the planning system and its many dimensions (financial, legal, property, taxation, government support etc) (5).
- Professionals (accountants and lawyers) do not understand disability issues (5).
- Carers are too tired and exhausted from their daily responsibilities (5).
- Government agencies work on a crisis-intervention approach and not on a planned approach (3).

- Inconsistencies between states and within regions – fear of moving and going to the bottom of waiting lists (2).

### **Options to improve planning**

- Help families and individuals establish a circle of friend or circle of support for the person with disability (6).
- Begin transition arrangements early – increasing independent living skills; enabling more time spent away from the parents, moving into a new home whilst family members are still around and can visit (4).
- Establish a centre of expertise where legal, financial and emotional support is available (including a website) (4).
- Share innovative accommodation models and options with families (2).

### **POSSIBLE AREAS FOR FURTHER WORK**

- Explore the potential for modifications to the SDT – increasing the cap, working with state/territory governments to exempt homes from CGT and Stamp Duty, allowing tax-deductibility of donations; enabling income to be re-invested not taxed; enabling salary-sacrificing into an SDT and the possibility of developing some form of co-contribution scheme.
- Undertake research into innovative models of accommodation support and care in Australia and overseas, collate the information and make it widely available to governments, services, families and planners.
- Undertake research into best practice models for developing and sustaining “Circles of Support” or “Circles of Friends” as options to enhance private provision and make the information widely available.
- Explore how to remove impediments to hybrid models of accommodation and care – a) where funds or assets held by families can be joined with service resources to provide a package of care; and b) where the person with disability can move into supported accommodation but return home each weekend or for a night or two during the week as part of a transition process.
- Consider providing funding for planning services which are regionally based and can provide advice, information, planning support and review, counselling, and referral services to families and which involve family to family sharing of experiences and the opportunity to explore options.
- Explore the possibility of establishing a website and/or a toll-free information line providing advice, information, support and referral services around future planning.
- Consider providing funding to existing accommodation services or Carer Respite Centres to enable them to establish family/carer support groups.
- Explore schemes to encourage budgeting, saving and financial planning as an early intervention measure for families and carers with young children with disabilities.

## APPENDIX A

### EXAMPLES OF INNOVATIVE ACCOMMODATION SERVICES & PROJECTS

Eighteen (15%) submissions made reference to particular accommodation services, models or projects. In many instances limited detail was provided; but this appendix collates the names of the services or projects mentioned, and where possible their location, to enable further investigation.

Service or Project	Location	Description
Association for Children with a Disability	NSW	Ten Point Plan to provide accommodation support including: increasing government spending; families pay annual fee for maximum 10 years; accommodation rebate to families; Commonwealth subsidy to each service (like Aged Care); resident contribution of 85% of DSP; and a birth levy.
Campbelltown UnitingCare Hurley House	NSW	Parent and church-funded house for 5 intellectually disabled people; support funding from NSW government.
HomeShare model – Benevolent Society and Wesley mission	NSW	Links older people with younger people to provide assistance and company (vigorous interviewing and reference checks). Could be adapted to disability.
Shared Living Program – Hornsby Challenge	NSW	
Endeavour Foundation	Queensland	Proposal with Brisbane Housing Company providing housing and Endeavour Foundation providing support; seeking funding from DSQ.
Homes West	Queensland	A Family-centred collective with a paid coordinator where care and support arrangements are shared between paid support and families and friends of people. Each individual has some funding and 10 people are supported in a home of their own.
Young Care Village at Sinnamon	Queensland	
Affordable Housing Innovations Unit, Department of Families and Communities	South Australia	Potential for reverse mortgages to help finance trusts (?)
Community Accommodation and Respite Agency (CARA)	South Australia	Shared-care service, transition model with some time spent at home each week.
Community Living Project	South Australia	
Haven Foundation	Victoria	To provide housing and assistance for people with mental illness.
Jeshimon House –	Victoria	Several units on one property; each owned by

Camberwell		person with mental illness with a communal facility and carer support.
Mental Illness Fellowship – Ripponlea	Victoria	Block of 9 flats, each unit purchased by person with mental illness.
Mixed Equity Program	Victoria	Government funding for home purchase by person with a disability (?)
WinAccom	Victoria	Provides long term accommodation for young adults with mild intellectual disability; family or individual purchase property; support funding from Vic government and fundraising.
HOPES Cooperative Living Concept	Tasmania	Proposal for small cluster of independent units surrounding a common house; sharing support hours and funds; volunteer and peer group support; cooperative “ownership” of common house; people with acquired brain injury or cognitive impairment.
Alternate Family Care, Perth Home Care Services	Western Australia	Person with a disability lives in the home of an alternate family. The alternative family carer receives a carer reimbursement for care & support provided and respite is provided monthly and annually.
Hawkevale Trust	Western Australia	Volunteer visitation service to see person with a disability is well looked after; advocacy role; fee for service.
Innovative Accommodation Grants	Western Australia	Up to \$200 000 non-recurrent, to develop service models and strategies not reliant on recurrent State funding.
Subiaco and Western Suburbs Independent Housing Group (SWSIHG)	Western Australia	Eight two-bedroom units for people with intellectual disability; with plans for six two-bedroom units with a four bed-sit cluster and communal facility.
Support Accommodation Support Group (SARG) (sic)	Western Australia	Proposal for Activ Foundation to provide carers for 10 young people with disabilities and Foundation Housing Limited provide the property; group submission for funding.
Cromhurst Foundation’s proposal for an “intentional community”		
L’Arche community	www.larche.org.au	People with a disability and a support team live and work alongside each other – a community of mutuality and life-sharing.
Rougemount Intentional Community	Canada	

## APPENDIX B

### EXAMPLES OF PLANNING SERVICES, PROJECTS AND TOOLS

Thirteen (11%) submissions made reference to particular planning tools or to service models and projects which provide future planning support for families and carers of a person with disability. In many instances limited detail was provided; but this appendix collates the names of the services, projects or tools mentioned, and where possible their location, to enable further investigation.

Service, Project or Tool	Location	Description
Pathways Program	ACT	Helps with planning.
Stepping Stones for Life	ACT	Supports planning, identifies options.
Lifeways	Queensland	Helps develop individual plans and networks; helps maintain networks; provides seminars and information.
Parent 2 Parent	Queensland	Empowers parents to actively participate in the planning process.
Pave the Way – Mamre Association	Queensland	Provides workshops and information, helps develop plans; helps establish networks.
Positive Futures Program	Queensland	Strengths-based, family facilitator provides information and guides planning process.
Planning for Retirement	South Australia	ACROD-sponsored report written by David Albrecht to be launched in February 2007.
Caring into the Future	Western Australia (?)	
Families for A Good Life Futures Planning for People with Disabilities	Western Australia (?)	
Geraldton Lifetime Advocacy Development Group	Western Australia (?)	
Peel Advocacy Lifetime Network	Western Australia (?)	
Planned Individual Networks (PIN)	Western Australia	Provides orientation sessions, planning seminars, planning workshops; helps develop individual plans; provides family to family support; helps establish networks.
Time Off and Planning (TOP), Perth Home Care Services	Western Australia	Helps with a range of flexible services to enable carers to have time off and plan for the future.
Planned Lifetime Assistance Network	USA	Mental health focus.
Personal Advocacy and Lifetime Services	Boston USA	
Planned Lifetime Advocacy Network (PLAN)	Canada	Develops a personal plan; develops a personal network; provides advice about service models; monitors quality of services; advice re guardianship and home ownership;

		and advocates for law and policy reform.
Permanency Planning	Texas USA	Focus on financial planning (?)
Person Centred Planning tools (eg Helen Sanderson's)		Tells the life story of the person, includes information about likes and dislikes and what support different people provide.
Planning Alternative Tomorrows with Hope (PATH)		A visual, person-centred planning tool which uses simple drawings and words to represent goals and the 8 steps leading to them. The PATH is flexible and changes often.