Australian Government

Department of Families, Community Services
and Indigenous Affairs

SUCCESSION PLANNING FOR CARERS: SUMMARY REPORT ON CONSULTATIONS

July 2007

The Department of Families, Community Services and Indigenous Affairs commissioned the N-Carta Group to undertake a consultation process across Australia in late 2006 and to provide this report.

DISCLAIMER: N-Carta Group prepared the information in this publication about succession planning for carers. It draws on information, opinions and advice provided by a variety of individuals and organisations, including the Commonwealth of Australia. The Commonwealth accepts no responsibility for the accuracy or completeness of any material contained in this publication. Additionally, the Commonwealth disclaims all liability to any person in respect of anything, and of the consequences of anything, done or omitted to be done by any such person in reliance, whether wholly or partially, upon any information presented in this publication.

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.

BACKGROUND[1]

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[2]. 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[3]; 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

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.

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

---

[1] Department of Families, Community Services and Indigenous Affairs, *Succession Planning for Carers, Discussion Paper*, November 2006.

[2] 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.

[3] 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.

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, and 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 families to provide privately for their family member with severe disability?
- Are other informal arrangements or schemes needed to assist parents or carers who wish to provide for their family member with disability over their life stages?
- Are there innovative models of accommodation that would assist parents and families make provision for their child with disability?

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

THEMES THAT EMERGED FROM THE PROCESS

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

The lack of accessible information prevents effective planning

- Families don't know where to start; who to go to; where to find information or what to do.
  "You don't know who to speak to."

Limited finances and the cost of care

- 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.
  "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

- Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information.
  "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

- A planned transition is not considered feasible whilst services and governments are perceived to place only those people with disabilities in crisis or emergency situations.
  "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

- 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.
  "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

- 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.
  "We've seen what Mum goes through – no way."

Planning for the future is complex

- Future planning is seen to be an extremely complex issue, across state, territory and Commonwealth law and regulations covering financial, legal, property, taxation and government support issues. Circumstances may change between any plan and its implementation, and establishing support networks is hard work.

> *"…need a Philadelphian lawyer to wade through it all."*
> *"Planning too early is also difficult as rules and regulations change as well as what is available."*

Whilst participants welcomed the introduction of the Special Disability Trust (SDT) as an indicator that the Government was aware of the needs of ageing carers, many commented that the SDT would be suited mostly to middle-high income earners and not 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 as follows:

- 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).
- 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 the sale of the primary place of residence when placed into the trust 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).

In addition to commenting on the SDT and barriers to planning, 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 a disability. The key general issues raised were:

A home not simply a bed

- 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.
  "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."

You have to be in crisis

- Funding bodies seem to be focussed on crisis and emergency management – they do not focus on planning for the future. This makes it difficult for families to plan and to know what the real options are.

Options aren't clear

- Families don't know what options they have for future planning in terms of community-based support, accommodation models and places, and legal and financial options.

Partnering should be possible

- 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).
  "The processes that would enable our organisation to accept offers and use them flexibly and creatively are just not in place."
  "Getting the house is the easy part. But where does the support come from?"

No single contact point for planning

- There is no single contact point to help with future planning and to share information. Families have to work with lawyers, Centrelink, accountants, service providers, state and local governments to find a way through the maze.

Family members may not be able to take on responsibility

- 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; and it should not be expected that they will take on this role.
  "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."

Lack of experienced professionals

- Many professionals (accountants, lawyers) are not experienced in disability issues and are not experts in guardianship, trusts, social security payments etc.

Respite helps families keep caring

- Respite care is important in helping families continue to care. It could also allow them to find time to plan. More respite would help meet the care and planning needs of families.

One size does not fit all

- Planning for future accommodation and support must recognise that one size does not fit all; and that variety and choice are needed by individuals.

Governments should not shift responsibility to families

- Concern was expressed that focussing on private provisions and succession planning may assume that parents have full responsibility for future care arrangements and that governments may be relinquishing responsibility.
  "The government is just relinquishing delegation of duty. (sic)"

There aren't enough accommodation places

- Participants commented on a shortage of public accommodation and that some approaches appear ideologically opposed to families' preferences for small scale congregate care settings.

> *"Desirable models of accommodation incorporate choices – variety of accommodation available, flexible services, choice of location, choice of service provider."*

In response to these general issues, the following **suggestions** were made to help families plan more effectively for the future including:

Funding for planning and information services

- Provide funding for planning services which are regionally based and can provide advice, information, planning support and review, counselling, and referral services to families which involve family to family sharing of experience and option development.
  "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."

A one-stop shop

- Establish 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.
  "…for example an information/consultancy service to advise people on what they could do and to guide them through the maze of future planning."

Start the transition process now, not at crisis point

- 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.

Provide more accommodation places now

- More accommodation places are needed 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
  "The need for supported accommodation is NOW, not when we can no longer provide care."

Governments should shift from crisis to planning

- Governments need to begin long-term planning now, providing a more stable backdrop against which families can make decisions about their future.
  "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."

Help establish Circles of Support or Circles of Friends

- Encourage services to help families establish and sustain "Circles of Support" or "Circles of Friends"
  "…provide the means to set up Circles of Support and networks around the children."

Submission respondents were less clear about how to encourage future planning within families, and provided few suggestions 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.

Respondents also provided examples of good planning models, tools and projects which could be considered and this list is provided at **Appendix B**.

APPENDIX A

EXAMPLES OF INNOVATIVE ACCOMMODATION SERVICES & PROJECTS

Eighteen 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 – Camberwell	Victoria	Several units on one property; each owned by 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.
Cromehurst 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 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.