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# Planning options and services for people ageing with a disability and their caring families

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Submission to the Senate Community Affairs Committee

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# 1. Introduction

The focus of this submission concerns the need for planning options and planning support services for ageing people with a life long or acquired disability and their caring families. Its particular but not exclusive emphasis is people with long term decision making disabilities who are currently particularly disadvantaged. People with a disability who ‘have capacity’ have access like most adults to existing mechanisms to appoint Enduring Attorneys or Guardians to make financial, medical and lifestyle decisions. They can put in place Advanced Care Directives to indicate their wishes for the future.

The needs of people with long term decision making disabilities and their families are of particular concern to Carers Victoria. This is a consequence of the significant gaps in the availability of services they need, the lack of mechanisms and services to assist them with planning for the future and the significant risks they face in the event of changes to their health and well being.

We have chosen not to address issues concerning planning options and services for people acquiring a disability or chronic illness after 65 years and their families although our recommendations may be relevant to their planning needs. Older people are more likely to have accumulated assets and savings, and to have made provision for future substitute decision makers if these are required. In addition, as advised[1], we have confined the focus of our submission to the services which are needed to assist families and people with a disability with future planning. We are aware that the Productivity Commissions Inquiry into Disability Care and Support will consider the key services and supports that are needed for the lifelong care of people with a disability and their families and how they can be financed.

## 1.1 Definitions

For the purposes of this submission, we have defined disability broadly as inclusive of people with physical, sensory, intellectual and psychiatric disabilities which were acquired in childhood or adulthood and which are accompanied by decision making disabilities. Family carers are defined as unpaid family members or friends who provide care and support for the person with a disability. They may be parents, siblings, offspring, other relatives and friends. Many parent carers and other relatives of people with lifelong disabilities are themselves ageing.

## 1.2 Demographic Context

Throughout Western countries, including Australia, the ageing of the population will be accompanied by:

- Increasing life expectancy for people with a developmental or an acquired disability (Australian Institute of Health and Welfare 2003a, 2003b)[2], particularly people with severe and profound disabilities who with advances in health care, are living into adulthood and ‘old age’

- Increasing numbers of people with a pre-existing disability entering the aged care system at 65 as well as increases in the numbers of younger people with a pre- existing disability who develop age related conditions such as early dementia. The numbers of ageing people with a pre existing disability will increase further due to the effect of the baby boom population bulge.
- A steady increase in the number of ageing people with a severe or profound disability accompanied by deceases in the availability of unpaid care. It is anticipated that increasing numbers of older parents and other relatives will be unable to continue their direct caring role. They are increasingly likely to be outlived by their adult children.
- Increases in widowed parent carers of ageing people with a disability, some who will have a disability or chronic illness themselves.
- Increases in the numbers of relatives or friends who are obliged to provide substitute care as parent carers die or become infirm.

## 2. Data about ageing people with a ‘pre existing’ disability and their families

There is currently no reliable and comprehensive data concerning the needs and circumstances of ageing people with a disability and/or their caring families. Existing data sets have limitations; many separate services systems are involved in the provision of care and support. Many older people with a disability and their families remain hidden.

### 2.1 Ageing people using services funded through the National Disability Agreement

The CSTDA Minimum Data Set[3] notes that in 2008-9 there were 11, 845 users of CSTDA funded services who were aged 65 or older, a total of 4.8% of all services users. A further 62, 536 were aged between 45 and 64 years and represented 25% of services users and a growth rate of 5% since 2003. This indicates the ageing of people with a disability. It is noted that:

- Intellectual, physical and psychiatric disabilities represent the highest proportion of total CSTDA services users.
- Within CSTDA services users who access supported employment, employees are ageing significantly[4]. In 2007, 47% were older than 40 years; and 277 were older than 65.
- 16% of CSTDA services users have little or no effective communication.

### 2.2 ‘Hidden’ ageing people with a pre existing disability

Unknown numbers of people with a pre-existing disability are not users of services funded under the National Disability Agreement (or CSTDA). However, they will be in need of planning options and services to address their changing needs and the needs of their families. Most will not have accumulated assets and savings and will be reliant on income security payments.

‘Hidden’ ageing people with a pre existing disability include:

- People (often with either an intellectual or psychiatric disability or acquired brain injury) who were ‘deinstitutionalised’ in earlier decades to live in Supported Residential Services (SRS) or Boarding Houses. In Victoria there are around 2,000 people with a pre existing disability living in pension level SRS’s. They have a mean age of 58 years[5]. It can be anticipated that their need for support and assistance will increase as they age. It is likely that equivalent numbers of ageing people with pre-existing disabilities are inappropriately housed in other states. Many may not have access to the continued support of informal family care.

- Ageing people with a psychiatric disability. Their numbers are likely to be grossly under estimated as a consequence of limited community support services and limited data. The National Disability Agreement in Victoria, Queensland and Western Australia provides funding for community support services for some people with a psychiatric disability (and thus some identifying data). However, many clinical, acute and sub acute services for people with a psychiatric disability are funded under the Health Care Agreement in these and other states and territories and there is no clear data about their circumstances.

- It is known that people with an intellectual or psychiatric disability or an acquired brain injury are over represented in homelessness and prison services[6].

## 2.3 CSTDA services users with unpaid family carers

CSTDA data about whether or not services users have a family carer has a degree of unreliability as a consequence of definitional and collection issues. In 2008, 46% of services users (around 112,293) had an informal family carer.[7] A further 45% of services users did not have an unpaid carer: this has serious implications concerning access to formal advocacy and support.

About 7% of unpaid family carers of people using CSTDA services continued to provide advocacy, support and assistance to their relative who was living in supported accommodation.

Of the 10,500 services users with unpaid carers aged over 65 years, 7,500 were older parent carers. Of these 57% were providing care to a son or daughter between 45 and 64 and were mostly mothers. This indicates a substantial and increasing number of very long term older parent carers. Their numbers will increase exponentially in the coming decades.

## 2.4 ‘Hidden’ ageing parents of people with a pre existing disability

- Many ageing parents of people with pre existing disabilities do not access CSTDA services; a consequence of unsuitable or unavailable services in past years, or withdrawal as a consequence of negative experiences.

- They may re enter the services system as a consequence of a family crisis or increases in their need for support.
- Many families from culturally and linguistically diverse backgrounds do not access formal services but provide informal support to family members with a disability. CSTDA services users are less likely than the total Australian population to be born outside Australia (11% compared with 22%)

## 3. The circumstances of ageing parents

Practice experience tells us that ageing parent carers are:

- Diverse in their individual characteristics and needs, and caring for a diverse range of individuals with a disability.
- Often single and mostly mothers who live with the person for whom they care. Some provide substantial ongoing support to a relative who lives elsewhere. Some have the support of other family members.
- Positively adapted to caring. Their caring expertise is not easily replicated in substitute care arrangements.
- Anxious about the future of their son or daughter when they die; in particular their need for housing and ongoing support.
- Often reluctant to plan for the future of their son or daughter; a consequence of the lack of formal planning mechanisms; difficulties in facing their own mortality; awareness of issues in the quality of available services and the knowledge that they face an ‘unanswerable question’. Few are believed to have plans for the future in place.
- Sometimes reluctant to discuss their concerns about the future with other family members.
- Either hoping for a planned transition for their son or daughter to care outside the home, or wanting to maintain home care and interdependence for as long as possible.
- Sometimes struggling with health issues or frailty and needing packages of in home and other assistance to continue to care.

Parents and families can legitimately lay claim to knowing much about the history, strengths, shortfalls, preferences and wishes of the person with a decision making disability. However, disability rights policy and current representation arrangements tend to bypass or reject the reality of family relationships. They fail to express a positive role for parents and ignore the role they play in nurturing, protecting, enabling and deciding with or for the person with a disability.

The needs of ageing parents and the people for whom they care can change rapidly as a consequence of a family crisis, a breakdown in the health of the parent or the health and support needs of their son or daughter, or parent death.

# 4. The circumstances of ageing people with a decision making disability

Ageing people with a disability can be equally anxious about what will happen when their parent or relative dies or is unable to continue with their care and support. This applies equally to those who live with their family, and those who live elsewhere but who enjoy ongoing family advice, support and assistance. There are many anecdotes about people with a disability who experience painful dislocations from family friends and familiar services when their parent dies. They also loose their key supporters.

While disability rights frameworks assume autonomy, and self determination for adults, some people with decision making disabilities are not self determining or able to make major and daily life decisions. They need the support and assistance of their families and others.

Relationships with family members are a significant and enduring aspect of their lives. Shared living, parent support, guidance and nurturing, reciprocity and mutual support and assistance are important. Some parents act informally as substitute decision makers; others support the decision making processes of their son or daughter.

Many people with a disability who ‘lack capacity’ are unable to put in place arrangements for their estate or for their future support and representation.

# 5. What is needed in planning for the future?

## 5.1 For parent carers or other family members

Within a framework of early and timely intervention, ageing parents and ageing people with decision making disabilities need a variety of support services to assist them in planning for the future. This will prevent as far as possible, inappropriate crisis responses. It will contribute to the avoidance of dislocation of the person with a disability from family and friends. Planning for the future in a way that engages other family members and friends will be needed.

Planning for the future is multifaceted and involves most families needing to marshal a wide variety of information and outside assistance such as Wills, substitute decision making provisions such as Enduring Powers of Attorney, and a variety of optional trust arrangements. Families may need an understanding of formal guardianship and financial administration systems. Encouraging relatives and friends to continue their involvement with the person with a disability may also be required and the development of emergency plans can be important. These are complex tasks.

Future planning tasks include:

- The development of Wills and Estate plans to define how property and assets should be distributed.

- Appointing Powers of Attorney and Enduring Powers of Attorney or Guardianship or developing an Advanced Care Directive. (For the parent only)
- Considering the establishment of trusts such as a Discretionary Trust or a Special Disability Trust.
- The development of emergency care plans in case of sudden parent illness or death and sharing these with the person with a disability and other key people.
- The development of Succession Plans or arrangements for medical, financial and lifestyle representation. This will ensure that a trusted person can oversee the ongoing care and support needs of the person with a disability, and advocate for housing and support services consistent with family wishes. Such plans will also be interpreted to the person with a disability.
- Creative use of respite and recreation programs to explore and practice eventual separation.
- Transition planning to housing and support outside the family home will also be required.

### 5.2 For people with a decision making disability

In the same way as other community members, people with a decision making disability need support to undertake the following.

- The development of a Will to define the distribution of their property and assets.
- Participation in decision making about their on going support and representation – financial, medical and lifestyle. Many people with a decision making disability have always sought the support of their family or friends in making significant decisions about their lives or have needed to rely on the decisions made by others.
- Participation in emergency care plans and how they are to be actioned.
- Participation in decision making about private alternative housing arrangements.

People with a decision making disability who live separate to their family are likely to require advice and assistance about their future as they age.

## 6. Current barriers to future planning for people with decision making disabilities in Victoria

There are many legal and other barriers for planning for the future in Victoria. These may be paralleled in other states.

### 6.1 No mechanism for appointing successors (the anticipatory appointment of Enduring Attorneys (medical and financial) and Enduring Guardians) for people with a disability

Current mechanisms for citizens to appoint substitute decision makers in Victoria, such as Enduring Powers of Attorney and Enduring Guardians are not accessible to people with decision making disabilities. They are regarded as lacking capacity. Legal capacity is defined as the knowledge or understanding necessary to commit to a legal contract; capacity is seen as defining whether or not the person can make a valid decision about the matter at hand.

Parents or significant others cannot make anticipatory appointments on behalf of, or in consultation with their son or daughter. Many wish to ensure that a person, usually a trusted family member or friend will organise, oversee and safeguard the affairs of their offspring. In addition, they are unable to make a current appointment which can be activated to allow them to step back from financial and lifestyle decision making when they are frail or tired. Some ageing parents wish to pass responsibility for substitute decision making to other family members prior to their illness or death to allow an adjustment period.

In Victoria, requests to appoint a (future) Guardian or Administrator for a person with a decision making disability, chosen by the family, are rarely supported. While the Victorian Civil and Administrative Tribunal, under the Guardianship and Administration Act (1986) can appoint substitute decision makers, it:

- Is crisis focused and rarely makes anticipatory orders.
- Operates under the principle of the 'least restrictive alternative' with Guardianship and Administration to be used as a last resort[8]. It has a strong preference for reliance on informal family arrangements unless there is family conflict or breakdown.
- Makes limited (partial) orders which are short term or confined to a single decision.
- Is concerned about Guardianship as an incursion on civil liberty and regards Guardianship of adult children with decision making disabilities as unnecessary for parents. It is considered (unwisely) that parents have informal authority and their counsel, advice and consent will be sought[9] in matters concerning their son or daughter.

The operation of the Guardianship and Administration Act 1986 in Victoria has a protective focus rather than an enabling focus for people with a decision making disability and their families. This is believed to be paralleled in other states. There is a reliance on the informal arrangement of the 'person responsible' which works well for decision making in health care, but has no legal or policy standing in other areas. As a consequence of Privacy Regulation and increasing numbers of risk averse organisations, frustrating problems arise for families who act as informal representatives in relation to legal and financial matters. These include operating bank accounts, dealing with utility companies, Medicare, Centrelink and the Australian Tax Office or liaising with services providers.

Many ageing parents will loose capacity or die with the anxiety of having no formal succession plan in place and no clear arrangements for ongoing care and support to discuss and share with their offspring. There is little to encourage them to engage a commitment from others in the ongoing care of their relative as such arrangements cannot be formalised. While they can nominate a person (usually a family member) to be appointed as Guardian and or Administrator in their Will, appointments are made by VCAT usually in crisis situations. Usually limited appointments are made

Those parents who make applications to VCAT to formalise their status as advocates and concerned persons may be appointed Guardians for a brief not ongoing period; Administration is usually a three year appointment with yearly reviews. Family members who are appointed Administrator by VCAT report that they only way they can get out of Administration is to appoint the State Trustees, whose services are both costly and impersonal. Those who want to formalise a future role for a son or daughter in the ongoing care and support of the person with a disability are unsuccessful.

It is understood that in Victoria and other states efforts are being made to streamline and simplify Powers of Attorney to allow citizens to plan for their future financial, lifestyle and health care needs, and to clarify powers granted by the donor. However, there is no apparent focus on the development of substitute decision making mechanisms to allow ageing parents and people with a decision making disability to plan for the future.

### 6.2 Poor access to future planning mechanisms by people with a decision making disability

Currently all adult citizens with capacity can appoint Enduring Powers of Attorney or Guardianship, set up discretionary trusts; make a Will and put in place Advanced Care Directives. Most adults will look for support from others in making such choices and decisions. Interdependence is common and some people need more assistance than others.

People with a decision making disability, regarded as lacking capacity, have no access to these mechanisms; no rights in the current legal framework. However, for many, supported decision making processes which involve family and friends could assist them to make valid life decisions[10] such as nominating people they trust as Enduring Attorneys, (financial, medical and guardianship) or developing a Will. Supported decision making is currently being considered in the Victorian Law Reform Commission Review of the Guardianship and Administration Act.

Other people with decision making disabilities require substitute decision making – where others take on a role with daily and major life decisions as well as with implementing these decisions.

### 6.3 Inflexibility and limitations of Special Disability Trusts

Special Disability Trusts (SDT's) were established to encourage families of people with a disability who are in a position to do so, to make private financial provision for the current or future accommodation and care of people with a severe or profound disability. They provided a means of making financial provision without impacting on the beneficiary's entitlement to the Disability Support Pension or other income security payment. The mechanism is overly restrictive.

The Senate Standing Committee on Community Affairs has previously and successfully recommended modifications to SDT's to increase their flexibility and attractiveness to families.[11] Some modifications have been made in terms of taxing arrangements for SDT's, in allowing part time employment for beneficiaries, and in an expansion of allowable uses of trust funds to include day to day living expenses; medical expenses; property maintenance and other discretionary items.

However, many barriers to the use of SDT's remain, including:

- An overly restrictive eligibility focus on severe disability which excludes many people with an mild or moderate intellectual disability or a mental illness who are likely to require ongoing financial support for housing affordability and maintenance and day to day living costs.
- Family access to low cost legal and financial advice which is disability sensitive and supports them with accurate information and dialogue about the complex planning issues they face.

## 7. Needed reforms

Many areas of reform are needed to ensure that there are appropriate mechanisms in place which allow ageing parents and ageing people with a disability to develop plans for the future when parents can no longer care.

### 7.1 Simple, accessible, low cost and nationally consistent mechanisms for the ongoing representation and support of people with a decision making disability

The Senate Standing Committee can take a significant role in encouraging state and territory jurisdictions, where necessary, to modify existing mechanisms for the appointment of substitute decision makers. Modifications should accommodate the needs of people with a decision making disability and their families and allow them to:

- Put in place current or anticipatory long term representation arrangements for financial, medical and lifestyle decisions concerning their son or daughter. There is potential to expand Enduring Power mechanisms to allow:
    - Parents and family members of people with very severe decision making disabilities to nominate substitute decision makers for their son or daughter;
    - Parents and family members to work with a person with a disability through participatory supported decision making. This will give weight to the views of the person with a disability and assist them to make valid decisions. This can allow either:
        - Parents or significant others to make current or anticipatory arrangements for Enduring Attorneys for their offspring in collaboration with them and involving people with whom they have a long standing relationship and who they trust, or

- Supporting the person with a decision making disability to understand and make such nominations themselves.

Information and capacity building programs for nominated Attorneys around their role and responsibilities will also be required.

Mechanisms such as representation agreements in British Columbia where meeting the capacity test is easier, the supported decision making agreements in the Yukon, and supported decision making orders and co decision making orders used in Alberta could be explored and modified to suit[12]. There is potential for a greater investment of decision making for those unable to make their own decisions in trusted family members and friends, with appropriate protective mechanisms for situations of relationship breakdown, abuse or neglect.

Concurrently, Tribunals need to incorporate principles of supported decision making into guardianship and administration legislation, and ensure appropriate workforce development in its practice.

## 7.2 Expand eligibility for Special Disability Trusts

As discussed above.

## 7.3 Ensure the availability of low cost legal and financial advice for people with a disability and their families.

Family carers are overrepresented in the lowest 2 income quintiles; many are unable to afford private legal and financial advice. Others have found it both very expensive and difficult to access the advice and support they need to plan for the future. Access to low cost, well informed legal and financial advice which is disability sensitive is essential. It will support people with a disability and their families with accurate information and dialogue about existing planning mechanisms and the complex planning issues they face. This is currently not readily available.

There is potential for:

- Workforce development within Community Legal Centres to ensure the availability of legal and financial advice to assist families.
- The development of fee subsidies for Community Legal Centres as an incentive for parents to engage in legal and financial planning.
- These mechanisms can be supplemented by on line access to information and advice about legal and financial planning tools for families and professionals (note QICPPP)[13]

## 7.4 Development high quality and informed family workshops and information tools about planning for the future

Many families of people with a decision making disability want to make plans for the future when they can no longer care. However, financial and succession planning is difficult and complex and there are many barriers. There is a poor level of understanding of available legal and other tools, their application and limitations. Families need access to quality information and advice in determining what steps to take.

FaHCSIA has developed training modules which outline the complex operation of Special Disability Trusts as well as an information booklet- Planning for the Future. In addition, professionals working with ageing parents deliver education workshops which vary in quality and content. The development of high quality workshop modules in each jurisdiction which can be consistently delivered through specialist or generalist non government organisations is needed. Content could include for example, information tailored to each jurisdiction about wills, trusts and estate planning, Powers of Attorney, succession planning, Guardianship and Administration and the development of emergency care plans.

### 7.5 National Register of ageing parents and outreach support

Within a framework of early and timely intervention with ageing people with a disability and ageing parents, the development of a national register of ageing parents accompanied by outreach support to individual families is needed.

Nationally there is a paucity of planning data. Little is systematically known about ageing parents and ageing people with a disability, the make up of the care situation, carer age, health and capacity to continue to care. Little is systematically known about the expressed future needs and preferences of ageing parents and the people for whom they care. Information is separately managed within each jurisdiction; family circumstances and needs are not adequately recorded within the CSTDA Minimum Data Set; and data collection about family carers has definitional and collection problems.

A National Register of Ageing parents would:

- Be nationally coordinated but operate on a state wide basis,
- Reassure ageing parents that their needs and those of the person they care for were known to ‘the system’.
- Identify and register key information about ageing parent carers (with their permission) on a centralised database, through outreach by nominated key workers. The Register would maintain consistent planning data about the age, needs, circumstances and future preferences of ageing parents and ageing people with a disability. These could include preferred future housing and support arrangements, emergency and succession plans, and financial plans such as wills and trusts.
- Ensure that families have access to a defined key worker who regularly maintains contact with the family, monitors and reviews their health, wellbeing and needs and makes referrals for additional support as required. Key workers may be drawn from:
    - Case managed support programs (government and non government)
    - Day programs managed by NGO’s
    - Specialist programs for ageing parents

    - Respite and support programs
- Key workers would be appointed according to family preference, and through collaborative agreement between agencies who may be involved with the family. They would be named on the register. Their allocation would aim to minimise the current duplication of workers involved with some families and reduce the overlap between agencies.
- They would encourage ageing parents, their family and significant others to plan for the future as outlined above.
- Their outreach and monitoring work would be guided by policy framework governing program operation, protocols and procedures, as well as key performance indicators.

## 8. The critical importance of increased investment into housing and support

Clarification of the terms of reference of the Inquiry into Planning Options and Services for People Ageing with a Disability and their Families has resulted in the inquiry being focused on the services that need to be developed to help families with future planning[14], rather than needed housing, support and other services. This is a consequence of the Productivity Inquiry into Disability Care and Support, and an assumed wish to avoid duplication.

It is our view that the housing and support needs of people with a disability and their ageing parents must urgently be addressed. There are significant gaps between demand and supply of housing and support services in all jurisdictions; all housing services are crisis driven; there are long waiting lists and the needs of many people with a disability and their families are ‘under the radar’.

There is huge diversity in family perceptions about what is possible and needed by their son or daughter. Some have strong views about shared supported accommodation being the only option; others lack a clear understanding of the pro’s and cons of options such as individual support packages, private, public and community housing and other innovations which lack visibility.

Ageing parents and ageing people with a disability need:

- Opportunities and informed support to plan the transition of their son or daughter to care outside the home, within a context of significantly increased financial investment by the Commonwealth Government.
- Access to empowering processes of exploration and discussion of housing and support options, in collaboration with the person with a disability and other significant people. Based on the choice of families about where the person with a disability should live, in what sort of housing and with whom, it would include consideration of:
    - Shared supported accommodation options;
    - Shared and mixed equity housing;
    - Improved support in the family home;

  - Private and public housing arrangements accompanied by packages of support (individual, couple or group).
  - The potential to combine family and public resources.
- A guaranteed commitment of funding for support packages to accommodate family crises and to provide time for longer term plans.

The Productivity Commission will explore the cost and funding of a long term Disability Care and Support Scheme, the services required by eligible people etc. However, commencement of the implementation of a National Disability Care and Support Scheme is unlikely for 7-10 years.

***In the interim, the most pressing need is housing and support for ageing parents and ageing people with a disability. There is a crisis looming!***

The consequences of any failure of government to direct a significant amount of funding for housing and support for ageing family carers and ageing people with a disability will be:

- Significant increases in waiting lists for housing, support and other services in the disability and mental health sectors.
- A continuation of disorderly crisis driven access to services and its accompanying social and emotional costs rather than planned transitions to needed housing and support.
- Decreased access for people with a disability or mental illness to social housing as a consequence of inadequate supply and access barriers.
- Bed blockages in acute hospitals and psychiatric hospitals: 46%of acute inpatient psychiatric beds are blocked (BCG 2006)[15]. There is pressure on emergency departments and bed blockages in facility based respite services for people with a disability (AIHW 2007)[16].
- Increasing over representation of people with a disability in homeless services which are ill equipped for their management and care. For the period 2001-05, 20% of SAAP clients were in receipt of Disability Support Pension (AIHW 2007)[17].
- Increasing numbers of people with a mental illness living in rooming houses. In the years 2001-06, there was a 43.2% increase in these. (DHS, 2008b)[18]. This form of accommodation is arguably the least secure and regulated in the state.
- An unacceptable and growing number of people with a disability or mental illness are street homeless.
- Increased numbers of frail and ageing parents have no choice but to continue to care and are unable to retire from caring role.
- A continuing trickle of murder / suicide by desperate and disillusioned families.

## 9. Summary

The following actions are essential:

- A program of continued investment in public, community and shared supported housing for ageing people with a disability or mental illness.

- Development of a register of ageing parent carers so they can be identified and support can be targeted towards them.
- Investment in programs to assist ageing parent carers and ageing people with a disability to make plans for the future.
- Investment in increasing the availability of support packages to allow the planned transition of people with decision making disabilities to their own homes, as well as increased in home support for ageing parents.
- Development of simple, accessible, low cost and nationally consistent mechanisms for the ongoing representation and support of people with a decision making disability.

## References

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[1] Boyce, Senator S. (May 2010) Clarification regarding inquiry terms of reference

[2] AIHW (2003a and 2003b)

[3] AIHW (Dec 2009) Disability Support Services 2007-8. Cat no. DIS 56

[4] FaHCSIA (2007) Australian Government Disability Services Census.

[5] DHS (2009) 2008 Supported Residential Services Census, Summary Report, Residents.

[6] Australian Institute of Health and Welfare (2000) Disability and Ageing, Australian population patterns and implications

[7] AIHW (Dec 2009) Disability Support Services 2007-8. Cat no. DIS 56

[8] Dearn, L. 2010 Too much Guardianship? Office of the Public Advocate

[9] Cocks, E (1982)

[10] Carter, B. (2009)Supported Decision Making: Background and discussion paper, Office of the Public Advocate, Victoria

[11] Senate Standing Committee on Community Affairs (2008) Building trust: Supporting families through disability trusts.

[12] Chesterman, J (2010) Supported Decision Making: Options for Legislative Recognition, Office of the Public Advocate, Victoria and

Carter, B. (2009)Supported Decision Making: Background and discussion paper, Office of the Public Advocate, Victoria

[13] See http://www.qicppp.org/

[14] Boyce, Senator S (June 2010) Communication from the Principal Research Officer.

[15] Boston Consulting Group (2006) Improving mental health outcomes in Victoria: the next wave of reform.

[16] Australian Institute of Health and Welfare. (2000) Disability and Ageing, Australian population patterns and implications.

[17] Australian Institute of Health and Welfare. (2007) Current and Future Demand for Specialist Disability Services.

[18] Department of Homan Services (2008b) Because Mental health Matters: a new focus for mental health and well being in Victoria.