



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

**Submission to the Senate Community Affairs
Committee**

Carers WA

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1. About Carers WA

Carers WA is the recognised peak body for carers in Western Australia. Since 1996 Carers WA has provided systemic advocacy and grassroots support to the more than 307 000 family members and friends in WA who provide the overwhelming majority of care and support to those who need assistance to live in the community.

2. Carers in Western Australia

A family carer is someone who provides care and support to a parent, partner, child, relative or friend who has a disability, is frail aged or who has a mental or chronic illness. Carers cut across all aspects of West Australian society: from ages 5 to 95 years of age, they can be from any ethnic group; they live in both urban and rural communities within the state; they care for people who live with the whole spectrum of illness, disability or age-related frailty; they comprise almost 307 000 West Australians. They are your neighbours, friends and relatives and they are unpaid.

Western Australia was the first State in Australia – and only the second government in the world – to legislate an Act recognising carers. The WA Carers Recognition Act 2004 has been a significant and positive step forward in the recognition of the important role that carers play in our society.

3. Future planning for people with decision making limitations in WA

Carers WA supports the overarching submission prepared by Carers Australia which provided information regarding the broader issues impacting on the ability of carers to make future plans to support care recipients with decision making disabilities. As stated in that submission, the issue of access to suitable housing that supports families through life transitions is critical to all other planning processes.

This submission will focus on the needs of family carers who are caring for people with long term decision making disabilities and focuses on state based arrangements for guardianship and trusteeship/administration.

Formal planning mechanisms

Family carers are often assumed to be able to make decisions by virtue of their role as family members. In practice, this is not always feasible and family members do not have legal rights over an adult person with a disability unless an order has been made to this effect.

In Western Australia, family carers may need to work with a number of separate state agencies at various stages in order to formalize and/or make changes to their decision making responsibilities and arrangements. These agencies and their responsibilities in this regard are:

Public Trustee

- Enduring power of attorney

- Trust management

 - Public administration of compensation trusts

 - Private administration - examination of accounts

Office of the Public Advocate (OPA)

- Enduring power of guardianship

- Public guardianship

- Community guardianship

State Administrative Tribunal (SAT)

- Orders and applications relating to the appointment of public or private administrators, guardianship, and reviews of assessments made by the Mental Health Review Board

Courts

- Orders regarding the appointment of administrators and the expenditure of trust funds

Access to information and advice

Each agency has a website and is willing to post printed information. Each offers some assistance over the phone. SAT offers a phone and email information service but carers who seek services through SAT may also require independent legal advice. The OPA offers a statewide telephone advisory service during business hours which covers many of the services offered by the Public Trustee, the SAT and the court system. The Public Trustee's Support Team gives advice to people appointed as private administrators. The Public Trustee and the OPA together offer training to people who undertake the role of private administrator. There is a charge to participate in this training.

Carers Queensland provides individual advocacy for family carers involved in guardianship and trustee matters. Carers WA is not funded to provide this service.

Putting in place and amending planning arrangements

Courts make orders about the expenditure of compensation funds held in trust. The Public Trustee allocates funds accordingly. These orders do not always reflect the needs of the family caring for the person with disability. The goal of the order should be to support the person with disability to participate as fully as possible in family and community life. A family-centred approach to assessing the use of trust funds is required. Carers have reported feeling guilty about asking for funds to allow the care recipient to join the family on holidays. The allocation of funds should also be determined in a culturally appropriate way to ensure the person with disability can contribute and participate in the same way as other family members to meeting shared family costs. In some cultural settings for example, adult family members share the funeral costs of elders.

Once an order has been made regarding expenditure of trust funds, the Public Trustee administers the fund according to the order. If family carers need to alter these orders, they must take action through the court system or through SAT. Both processes require an understanding of legal procedures. This is a barrier to the ability of carers to provide for the changing needs of the care recipient over their life course.

Transitions occur that have the potential to create confusion and further administrative burden for family carers. When the person with disability turns 18, their family carers have no

legal decision making rights with regard to the care recipient unless they have sought to be appointed guardians and/or administrators through SAT. Family carers require support through this process due its technical nature but also because of the sense of guilt some family members feel when pursuing this process. Carers wish to ensure that neither the family nor the care recipient feels punished or diminished by the process. Another transition point relates to adults with mental illness whose decision making capacity may vary over time. The investigation process to determine capacity can cause trauma to all concerned. A supportive and family centred approach is required which acknowledges the needs of both the care recipient and the family carers and which then allows flexibility should the carer need to move in and out of the guardian/administration role.

Another transition point is the death, or loss of capacity, of the primary carers, usually the ageing parents. For the family carers, there is no straightforward means of appointing future guardians and administrators. Ageing parent carers are unable to use an Enduring Power of Attorney or Enduring Power of Guardianship to make future provision for their adult child with disability. Ageing parent carers who still have capacity but wish to be relieved of their guardianship or administration role must seek a review from the SAT. They can propose a new person to take on the role of guardian and/or administrator. However, SAT will decide whether the parents can be relieved of the role and whether someone else can be appointed and who that person is.

If the parent carer loses capacity and is not coping, it is often a service provider attending to either the parent or the adult child who first becomes aware of the situation and takes action. By this stage, both the carer and care recipient may be in difficulty. In practice, for ageing parent carers, there is limited scope for future planning of guardianship and administration. Instead it is system driven by events such as the death of the carer.

Emerging issues - the move to self directed funding in mental health and disability

In Western Australia, the Mental Health Commission has made reference to the introduction of self directed funding.ⁱ The Productivity Commission also canvassed this model in the recent inquiry into the long term care needs of people with disability.ⁱⁱ This model, while welcomed by many family carers, is likely to place more financial and other decision making

responsibilities on carers. This increased responsibility needs to be recognised both in terms of the requirement for appropriate education and information, but also for the need for increased respite for family carers.

4. Recommendations

- The WA Carers Recognition Act 2004 to be extended to all government agencies with responsibilities relating to planning for people with decision making disabilities.
- Training for family carers appointed as private administrators to be provided at no charge.
- Develop a centralized information resource to support carers seeking services and advice in their planning for people with a decision making disability.
- Family carers to participate in and be consulted throughout during the process of making orders for the expenditure of trust funds.
- Community Legal Centres be funded to support families who participate in legal processes related to future planning on behalf of a person with a decision making disability.
- No-cost information, financial counselling and mediation services be made available and promoted to family carers when making financial and other decisions on behalf of the person with a decision making disability.
- Develop and implement a family-centred approach to the investigation and assessment of decision making capacity and when appointing guardians and trustees/administrators.
- Investigate means through which family carers can implement succession planning for guardianship and trusteeship/administration.
- Fund a pilot program to determine the benefits of providing advocacy to family carers pursuing guardianship and trustee matters through the SAT and the court system.

5. Sources of information

Carers Queensland

<http://www.carersaustralia.com.au/?/qld/section/17:services-we-provide/6>

Mental Health Commission WA.

http://www.mentalhealth.wa.gov.au/Initiatives_and_Projects/towards_2020_consult.aspx

Office of the Public Advocate

<http://www.publicadvocate.wa.gov.au/default.aspx>

Productivity Commission Inquiry into Disability Care and Support

<http://www.pc.gov.au/projects/inquiry/disability-support>

Public Trustee

http://www.publictrustee.wa.gov.au/A/about_us.aspx?uid=5108-9129-6171-1189

Private Administrator Training

http://www.publictrustee.wa.gov.au/_files/administrator_training.pdf

State Administrative Tribunal

<http://www.sat.justice.wa.gov.au/>

ⁱ Mental Health Commission 2010. WA Mental Health Towards 2020. Consultation Paper. Available online at http://www.mentalhealth.wa.gov.au/Initiatives_and_Projects/towards_2020_consult.aspx

ⁱⁱ Productivity Commission, 2010. Inquiry into disability Care and Support. Available online at <http://www.pc.gov.au/projects/inquiry/disability-support>