

Disability Services Commission

Submission to the Inquiry into Planning Options and Services for People Ageing with a Disability

Terms of Reference

Access to planning options and services for people with disability to ensure their continued quality of life as they, and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their families.

Introduction

The Disability Services Commission was established in December 1993 under the *Disability Services Act 1993 (WA)* to be the Western Australian State Government agency responsible for advancing opportunities, community participation and quality of life for people with disability. The Disability Services Commission provides a range of direct services and support, and also funds disability sector organisations to provide services to people with disability, their families and carers.

The general ageing of the Australian population as the baby boomers age, along with the increased longevity of people with life long disability, such as intellectual disability, and the similar ageing of this population group, is creating additional stress on the disability sector¹. Although not a large proportion of the ageing population, there are additional issues that face people with disability who are ageing² and impact on their ageing family carers, as well as the disability sector organisations that provide them with care and support.

Some people with disability experience premature ageing as a result of their disability. Examples include early onset dementia for people with Down syndrome and the loss of functioning experienced by people with Cerebral Palsy over time. This may involve issues at the interface with the health system.

People with disability in the care of ageing family carers may face a crisis, such as the death or serious illness of the carer and require emergency support. Shortages of accommodation placements or delays in finding suitable options may add to the person's distress. Where some of these people have medical needs, as well as disability support needs, they may enter residential aged care where they may be the only younger person with a disability in the facility. They may be lonely and isolated in the facility dealing with the loss of their parents, friends and their usual activities. They may also find no natural peer group within the facility and be ostracised by the much older co-residents who do not understand their disability.

Bigby describes the life-long disadvantages that people with disability have experienced. They are often dependent on carer support or services to support their participation in the community and to assist them with lifestyle planning.

¹ Australian Institute of Health and Welfare (AIHW) 2000. *Disability and ageing: Australian population patterns and implications*. AIHW cat. No. DIS 19. Canberra: AIHW (Disability Series).

² Bigby, C. 2004 *Ageing with a lifelong disability*. Jessica Kingsley Publishers, London.

Many people with disability do not marry and do not develop informal support networks outside of their family networks; most have had limited participation in the workforce and therefore have restricted incomes and limited access to wealth; few people with disability have had access to private health services³; and many have received poor diagnosis and treatment when their symptoms are ascribed to the disability and not investigated.

Current policies on ageing provide support for ageing in place where services support the person to remain in their home and in the community for as long as possible. To provide support to people with disability to 'age in place' is sometimes difficult because of the complexity of their care needs.

The Disability Services Commission provides services and funds disability sector organisations to provide a range of services focused on both planning and service provision. Ageing carers are a priority in allocating funding and for many of the services. Key initiatives are outlined below.

Count Me In: Disability Future Directions

The Disability Services Commission in Western Australia has launched a long term future plan for disability in Western Australia following extensive consultation with all stakeholders and a review of contemporary literature on future economic, environmental and social trends. 'Count Me In: Disability Future Directions' has a strong emphasis on families with a focus on the needs of ageing family carers as an important priority area.

Local Area Coordinators

Local Area Coordinators assist people with disability to plan, organise and access supports and services which enhance their participation in and contribution to their local community.

A core function of Local Area Coordination is planning with individuals and their families and carers; including future planning for people with disability who are ageing and their carers. The object is to prevent crisis through long term planning, particularly with ageing carers.

Local Area Coordinators are located across the Perth metropolitan area and throughout all regional areas of Western Australia. Each Local Area Coordinator works with between 50 and 65 people with disability, to provide individuals and families with timely information and access to supports and services that may assist them, especially in critical periods such as transition planning.

³ Bigby, C. 2008 Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 33(1): 76-86

Community Living Initiative

The Community Living Initiative aims to establish a broader range of alternative community living arrangements for adults, which are sustainable, culturally appropriate and outside the traditional models of accommodation. Each community living arrangement is 'person-centred' and emphasises key elements of a 'home' in the community and 'a good life' such as valued relationships, choice, contribution, security for the future and challenge. A community living option is an arrangement of individually tailored supports that are carefully planned and put in place to support a person with a disability to have their own home in the community and to live a good life. The supports (which may be funded) complement and supplement the assistance and support provided by family/carers, friends and social and community networks.

The Disability Services Commission has developed resources to support the Community Living Initiative: 'Looking Forward to Community Living' and 'Information Resource for the Community Living Plan' that provide guidance on planning and developing successful community living opportunities.

'All in a Life's Design: Planning Independent Living' is another resource handbook for parents with an adult family member with disability moving out of home.

Family Trusts

The Western Australian Government has, through a succession of measures, sought to strengthen support for families making private provision for a family member with a disability. The State Tax Review identified a number of barriers to such support and the Revenue Laws Amendment Act 2008 and Duties Act 2008 have granted:

- changes to the definition of disabled beneficiary in both the Land Tax Assessment Act and the Rates and Charges (Rebates and Deferments) Act that requires only eligible for the Disability Support Pension or Carers Allowance Child. This will make Land Tax Exemption available for families providing independent housing for their family member with a disability and provides access to water and local government rates' concessions provided under the Rates and Charges (Rebates and Deferments) Act 1992.
- the need to transfer a property to a trust to qualify for these benefits has been abolished. This had been a major barrier for some families who will pay Capital Gains Tax on any transfer of ownership, including the transfer of ownership to a trust.
- the requirement that no income or rent can be obtained from the property will be abolished. This is a more generous provision than is allowed in Special Disability Trust arrangements.
- stamp duty will not be payable when a property is transferred to a Special Disability Trust; and
- unlike the Australian Government provisions, any person will be able to gift a property to a trust.

These changes have removed many barriers for families making private provision for family members with a disability.

Statewide Specialist Services

- Statewide Specialist Services provides a range of person centred specialist services to people with an intellectual disability and their carers and families. They aim to support the active participation of people with disability in the life of their community to maximise their independence and quality of life. Statewide Specialist Services staff members also work collaboratively, consult and provide advice to professionals working in the community, local hospitals, schools and other services.
- Statewide Specialist Services' social workers provide future planning for ageing carers referred to them with a focus on long-term care and maintaining independence.
- Statewide Specialist Services' psychologists provide assessments and management strategies to carers where there are challenging behaviours and occasionally conduct dementia assessments of people with Down syndrome who may be exhibiting the first stages of early onset dementia.
- The Adult Therapy Team provides services to people in the Disability Services Commission's provided accommodation services and to disability sector organisations. Team members have identified that the number of complex assessments being undertaken by individual team members has increased due to the increasing age demographic of people in the Commission's accommodation services.

Disability Services Commission Funding Process

The Combined Application Process is the method used by the Disability Services Commission to offer individualised funding on the basis of priority need. There is a strong focus on older carers through this process, which is an important access point for funding for accommodation support, intensive family support and alternatives to employment.

Family Support Services

A broad spectrum of support services are provided to older carers including in-home support, out of home care support, accommodation support, host families, holidays and camps. These services are provided through a number of service providers throughout Western Australia.

Accommodation

The Disability Services Commission both provides and funds accommodation for people with intellectual disability and funds accommodation support options for people with a broad range of disability types for people who meet the eligibility criteria on the basis of priority and critical need. Where people with disability are ageing, the accommodation services will monitor their condition to ensure that adjustments are made to their care arrangements to accommodate their changed care needs. Medical and psychological investigations will be arranged where necessary to maintain the person's health and functioning within the house.

The Disability Services Commission has set up a Nursing Team consisting of three nurses:

- Hospital Liaison Nurse;

- Mental Health Liaison Nurse; and
- Palliative and Aged Care Coordinator.

These roles are to work with residents, staff and families and other service providers in managing the care for a person with disability, managing admissions and discharges of residents to and from hospital, setting up equipment and care when they return to their home, arranging pain relief and management of palliative care through available health services. They also set up future planning for residents and their family members and prepare staff for the journey ahead.

Referrals to Aged Care

The Disability Services Commission in Western Australia has developed two protocols with the State Government Department of Health in relation to referrals to aged care services:

- Protocol between the Department of Health, Aged Care Assessment Program and the Disability Services Commission: People with Disabilities Transitioning from the Disability Services Commission's Accommodation Services to Residential Aged Care
 - This protocol guides the provision of referral information to the Aged Care Assessment Teams to demonstrate that a person is ageing prematurely and requires the type of care available in residential aged care.

- Protocol between the Department of Health and the Disability Services Commission: Joint Protocol to Guide the Assessment and Support of Younger People with a Disability
 - This protocol manages the referral of younger people with disability, under the age of 65, when they are referred for aged care services to ensure that all appropriate disability options have been exhausted before aged care services are considered. The Disability Services Commission has set up a Disability and Aged Care Coordinator to manage the referrals between the health and disability sectors.

Other examples of supports available to assist with future planning include the following:

Planned Individual Networks

Future planning for families based on the Canadian model 'Planned Lifetime Advocacy Network' that supports families to plan a safe, secure and fulfilling future for their family member with disability when they can no longer care for them.

Time Off and Planning

The Time Off and Planning Program, provided through Perth Home Care Services, gives priority to older carers and provides comprehensive family support in addition to talking with older parent carers about planning for the future care needs of the family member with disability.

Ageing Carers Program

This program is run by Hills Community Support Group and targets older carers with a focus on families developing ideas about future options and arrangements.

Gaps/Needs Identified

The ageing of the population is having an impact on the provision of services to people with disability who may not, in the past, have expected to live into old age.

As a cohort people with disability:

- are often financially disadvantaged and have less money than their peers;
- together with their carers, are more likely to live in areas of most disadvantage;
- have poorer health outcomes than people with greater economic and social resources; and
- people with intellectual disability (including dementia) who also have profound core activity restrictions are less likely to be cared for at home as they age than people with profound core activity restrictions who do not have an intellectual disability⁴ (Australian Bureau of Statistics 2006).

People aged 65 years and over are more likely to have a disability than younger people, and the likelihood of acquiring a disability increases with age. The severity of disability also increases as people get older. Consequently, as people age, they tend to need greater assistance with health-related and day-to-day activities, and greater access to health and community services. With the increasing number of people living to older ages, and the prospect of the 'baby boomer' cohorts reaching older ages, questions of how best to meet the needs of greater numbers of older people with disability are becoming more acute. This issue is compounded where people have life-long disability and decision-making disabilities.

The matter of guardianship is an emerging issue as people with disability, particularly people with an intellectual disability or long-term cognitive disability, are ageing. Following the least restrictive alternative, family members – usually parents – have assumed 'guardianship' of their adult family member with impaired decision making capacity. Application for a formal guardianship order has only been pursued where a person with disability interest's are being compromised. As parent carers are ageing, and their capacity is diminishing, so the requirement for formal guardianship for their family member is emerging.

The disability sector supports the concept of ageing in place for people with disability in order to maintain existing relationship within their homes. This places stress upon existing accommodation options where staff may not have the skill set, where staff ratios may not support the changed needs and where housing stock may not have been designed to cope with the equipment needed for transfers and other care.

Residents, their families and staff may wish the person with a disability to remain in the accommodation option; however, without the capacity to adequately care for the person, this may not be possible. Funding these changes may mean that less accommodation options are available to meet the increasing demands for accommodation within the disability sector. One of the factors slowing the development of additional accommodation options has been the lack of suitable housing stock.

⁴ Australian Bureau of Statistics 2006, Older People with Disability 1301.0 - Year Book Australia.

For people who have been living in the community with family, they may be faced with the increasing frailty or ill health of their carers and the lack of available support to assist them, particularly when this is required urgently.

Conclusion

Additional resources are required to allow for the continuing care for people with disability as they age and to support their families.

- This requires changes to be made to housing stock, using the principles of Universal Design to ensure that it is designed to meet the needs of people with disability who are ageing.
- Staff working with people with disability who are ageing need to be educated to deal with the changed needs of the people for whom they provide care.
- Some people with disability may have difficulty in accessing appropriate health and aged care services, such as memory clinics and diagnostic assessments. There can be issues with diagnosis as deteriorating health may be viewed as part of the disability resulting in delays in commencing treatment for reversible conditions. Some people with major psychiatric and physical illnesses go untreated because of the lack of training of health professions about the impact of disability. There is a need for training for medical staff in dealing with people with disability who are ageing.
- There is a need to have a dedicated resource that will allow a quick response to specialised equipment needs related to ageing.
- The cost of home modifications, and of increased care costs, may put pressure on organisations in terms of their viability, or if these changes are made from existing funding, this may result in less new placements becoming available to meet the growing demand for accommodation services.

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