Submission No. 043
(Dementia)
Date: 02/05/2012

National Disability Services

NDS Submission

Inquiry into Dementia:
early diagnosis and intervention

National Disability Services

May 2012

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About National Disability Services

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes over 750 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

Introduction

In 2008–09, 19,048 (6.8 per cent) of the 279,374 users of National Disability Agreement funded services were aged 65 years or over.[1] Apart from people with sensory disabilities, this current cohort of people with disability who are ageing is the first to have survived into 'old age' in significant numbers since data have been collected. Greater longevity of people with severe disability will see this figure grow markedly over coming decades.

Generally, the prevalence of disability increases with age. The average male (in 2003) can expect to experience 18.6 years of life with a disability (5.4 of which are expected years of life with a severe or profound disability). Females can expect 20.7 years of life with a disability (8.3 years with a severe or profound disability).[2] Indeed, in 2010 an estimated 705,200 people aged 65 and over live with severe or profound core activity limitation and this figure will more than double over the next two decades.[3] Of these, some will have lived with severe disability since their early years; others will have acquired disability as a result of ageing.

The correlation between ageing and disability highlights the need for the interfaces between disability services and health, allied health and aged care services to be workable for older Australians with disability. Supporting people ageing with disability requires cooperative action across governments and across departments because administrative responsibility for health, aged care and disability services is split.

NDS members, particularly those providing accommodation support to people with disability—in their own home, in group homes or in institutions—but also those supporting people to participate in the community or employing them in supported environments, increasingly report they are supporting people who have signs of dementia. Improving the supports available to this group are needed.

A significant focus of this submission will be on people with intellectual disability, particularly those with Down syndrome, for their needs require special attention. Evidence indicates that people with intellectual disability have an increased risk of developing dementia as they age. While research reports different rates of one type of dementia—Alzheimer's disease—for people with Down syndrome, most report that about 50 per cent of will have this disease by the age of 60 years.[4]

People with other learning disabilities also seem to be at greater risk. Alzheimer's Society in the UK suggest that this population group have a risk of developing dementia that is about three to four times higher than the general population and estimate the rates as:

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[1] Australian Institute of Health and Welfare 2011, *Disability Support Services 2008-09*, Canberra: AIHW, Table 3.1, p. 13.

[2] AIHW 2006, 'Life expectancy and disability in Australia 1988-2003'.

[3] AIHW 2008, 'Australia's Welfare 2009', Table A4.2.

[4] Alzheimer's Australia, Down Syndrome Australia and the Centre for Developmental Disability, *Down syndrome and Alzheimer's disease*, http://www.fightdementia.org.au/understanding-dementia/down-syndrome--alzheimers-disease.aspxviewed 1 May 2012, p. 4.

- 1 in 10 of those aged 50 to 65;
- 1 in 7 of those aged 65 to 75;
- 1 in 4 of those aged 75 to 85; and
- nearly three quarters of those aged 85 or over.[5]

NDS welcomes the opportunity to provide input to this important Inquiry.

Diagnosis issues

While the diagnosis of dementia in someone with an intellectual disability should follow the same process as for other people, special challenges arise from the fact that people with intellectual disability have pre-existing difficulties with tasks that involve thinking, remembering and daily living skills. They, therefore, do not perform well on the standard tests used for the general population. This makes it critically important that clinicians have good information about a person's abilities before any deterioration was noticed. Currently, this information will not always be well documented.

People with disability have poorer health than the general population. When investigating possible dementia it is important that a full health assessment occurs to rule out preventable conditions (such as depression or problems with vision and hearing which are more common in people with intellectual disability and may present with symptoms similar to dementia)[6]. Brain scans from this group may also be difficult to interpret.

Recommendations

As people with intellectual disability often do not perform well on standard tests, families, carers and disability service providers should be encouraged to work in partnership to collect (and date) information about the individual over their life. This will help diagnosis by informing clinicians about the person's abilities before changes were noted.

The electronic health record should be developed in such a way as to make this type of data recording possible.

Future planning

Many families of people with disability find planning difficult, but as people with disability are living longer there is a pressing need for families to consider future support arrangements for their family member with disability. Concerns about possible dementia will escalate this need. Older carers, in particular, need support to undertake this future planning task—involving legal, financial, housing and support, and guardianship decisions.

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[5] Alzheimer's Society UK 2011, *Factsheet 430 Learning disabilities and dementia*, p.2.

[6] Ibid., pp. 3–4.

While the booklet developed by the Department of Families, Housing, Community Services and Indigenous Affairs, *Planning for the future: people with disability*, provides useful advice to assist families make arrangements, some require additional informed support and have difficulty in identifying such assistance.

The historical practice of primarily directing government funds in response to crisis situations fails to give due recognition to the need for future planning. Older carers of people with disability need:

- encouragement and support to undertake future planning;
- handing-over options: that is, substantial care packages and a range of accommodation and support options to assist them to withdraw from their primary care role;
- flexible consumer and carer-driven services and supports; and
- access to (usually episodic) case management services when necessary.

The key elements of any future planning initiatives ought to include:

- a dual focus that ensures the needs and desires of the person with disability, as well as those of the carers and other family members, are included in planning processes;
- engagement with the service system; and
- both future and emergency planning.

As the key aim of future planning is often to facilitate transition to alternative accommodation and support arrangements when the person with disability is no longer able to live with the family, it is important to encourage early engagement with the disability and/or aged care systems that will ultimately have a role in providing support.

Some carers, particularly those who have not used support services, will need to establish confidence in the ability of others to provide quality support for their family members. They may require time to build this trust. Consideration should be given to gradually building the range of services accessed by the person with disability, including:

- in-home support;
- community access and participation (which may include transport assistance);
- day programs;
- leisure and holiday services;
- aged care services; and
- respite.

Planning should also consider options that would be available for the provision of emergency care, whether it is for a temporary period until the family can return to usual support arrangements or an interim period while alternative arrangements are sought.

Recommendation

Affordable access to financial, legal and guardianship advice for parents of people with disability should be part of any future planning services. Case management, particularly to assist during times of transition, should also be available.

Implement appropriate responses to changing support needs

As people with disability age their support needs often increase. Current responses by state and territory governments to these changing needs are inadequate. All governments must put in place processes that allow the support arrangements for people with disability to be re-assessed and adjusted as required (regardless of the person's age). This is crucial when there a signs that a person with disability is developing dementia. Where appropriate, this should include the provision of advice and/or assistance from skilled aged care professionals.

Where a person with disability is developing dementia while in supported employment, priority must be given to assisting them to transition to new support arrangements.

Currently, Aged Care Assessment Teams are the gateway to aged care services but extensive anecdotal evidence suggests these teams frequently struggle with providing adequate assessment of the needs of older people with disability. Indeed, it is not infrequent that NDS hears reports that older people with disability are refused assessment. These problems occur even when there are concerns that a person with disability is developing dementia.

Recommendations

All governments should commit to improving processes to reassess support needs, as necessary, as people age. This is critically important to enable people with disability who develop dementia to be adequately supported.

Assistance should be given to increasing the sharing of skills and knowledge between the disability and aged care sectors. Information on dementia would assist disability organisations to provide high quality support in existing arrangements for longer; information on disability would also assist aged care providers to support a person with disability who develops dementia. Encouraging the inclusion of ageing competencies in disability training packages, and disability competencies in aged care training packages, would be one way of doing this. People with disability—particularly those with intellectual disability—would then be better supported if they developed dementia.

Supported employees who develop dementia should be prioritised for assistance (with adequate levels of funding) to transition to new support arrangements.

Improved assessment protocols for people aging with disability need to be negotiated as a component of the National Health and Hospitals Network Agreement reforms.

Information provision

Families caring for a person with disability, particularly an intellectual disability, need to be provided with easy-to-understand information on dementia. While general information is available on dementia websites, it would be rarely accessed by this population.

Specialist disability providers would also benefit from targeted information on dementia to encourage them to document abilities over time, to help them identify changes and, importantly, on strategies to improve support. Once again, while this information will be available on dementia websites it will not be widely accessed by disability support workers.