

## **NDS Submission**

# **Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)**



**National Disability Services**



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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 820 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.

At some point during the course of the disease, many people with dementia will experience behaviours that need specific management. A proportion of these will have behaviours that families, carers and workers find extremely difficult.

NDS, therefore, welcomes the inquiry by the Senate Community Affairs References Committee. The focus of this submission will be on people with younger onset dementia and how the interface between the aged care—which has specialist dementia knowledge—and disability sectors needs to be strengthened in order to provide appropriate care and support. This Inquiry is particularly timely as the Australian Government implements reforms to both aged care and disability (the latter through the introduction of the National Disability Insurance Scheme).

## What is the National Disability Insurance Scheme?

In July 2011, the Prime Minister released a Productivity Commission report into disability care and support with the recommendation to establish a National Disability Insurance Scheme (NDIS). Since this time, the Australian Government has worked with State and Territory Governments to design and implement the NDIS. It will launch in four sites in July 2013, with two more beginning the following year. Agreements have been reached for the full roll out of the NDIS in NSW, SA and the ACT following the launch period.

The NDIS will be aimed at those who are most in need. Long term supports (and early intervention services) will be provided to around 410,000 people who have a significant and permanent disability—that significantly affects their communication, mobility, self-care or self-management—before the age of 65 years

The NDIS will:

- provide supports and funding based on an assessment of need;
- take a lifelong approach to providing care and support;
- have a focus on early intervention;
- support choice for people with disability and their families and carers, and put people in control of the care and support they receive (including the option of self-managing funding for supports);
- provide support for families and carers; and
- develop a comprehensive information and referral service.

## Younger onset dementia and the NDIS

While dementia is more commonly associated with older people, it is estimated that there are more than 24,000 people in Australia with younger onset dementia (that is, diagnosed under the age of 65)<sup>1</sup>. Their dementia may be caused by a range of conditions including Alzheimer's disease, frontotemporal lobar degeneration, stroke, Parkinson's disease, Lewy bodies, multiple sclerosis and Huntington's disease.

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<sup>1</sup> The estimate has been provided by Alzheimer's Australia, 2013.

People with Down syndrome are also more likely to develop younger onset dementia than the general population.

The wide variation in the causes and types of younger onset dementia creates diagnosis, service planning and service delivery difficulties. A person's needs may be poorly met because they do not fit neatly into the health, mental health, aged care or disability sectors. In addition, when diagnosed they may still be in full time employment, have children living at home, and have significant financial commitments. People with younger onset dementia are commonly fit and strong; managing difficult behaviour can, therefore, be difficult. Given the particular challenges of younger onset dementia, other family members will frequently also need significant support.

The following issues need consideration and attention if the NDIS is to appropriately support people with younger onset dementia (and their families).

## **Assessment of dementia in people with disability**

Having a disability can complicate the assessment and diagnosis of dementia.

People with an intellectual disability may be misdiagnosed as having behaviours associated with dementia when they may actually result from another cause, such as depression or pain. Conversely, a diagnosis of dementia may not be considered when behaviour changes are noted.

Current aged care assessments which assess for dementia do not work well for sign language users. Dementia in people who are Deaf (meaning culturally Deaf) is often misdiagnosed or missed.

NDS requests that greater attention be given to determining the most appropriate methods of assessing dementia in some groups of people with disability. For people who are Deaf, consideration should be given to adopting the UK Cognitive Screening Tests which have been developed for sign language users.

## **Access to quality services**

Younger people with dementia will be a group that poses considerable challenges for the NDIS—in assessment, information provision, planning appropriate supports (for both the participant and other family members), regular adjustment of packages, the availability of appropriate services, and the interfaces with the health and aged care sectors.

These challenges become particularly acute when behaviours are difficult to manage.

Currently, people with younger onset dementia commonly end up being supported by the aged care sector, but those with particularly challenging behaviours struggle to receive what they need. When behaviours are challenging, families have difficulty organising in-home support services; respite options are almost non-existent;

residential aged care services refuse to accept the person. Families' lives are torn apart.

While this scenario has the potential to change under the NDIS, it is not 'a given'. These people—as they become participants under the NDIS—will have greater choice over the services they could receive, but organisations may not want to provide services to this group (this is often the experience of families).

The NDIS must give consideration to how it will encourage or support the existence of specialist services for people with very challenging behaviours. The aged care sector must do likewise.

## **Flexible support arrangements**

During the design of the NDIS, governments have acknowledged they must respond to the needs (and changing needs) of people with significant disability. Younger people with dementia will challenge this, not least because their (and their family's) support needs are likely to change significantly (and sometimes rapidly) over time and because current services often struggle to provide the support required.

Under the NDIS, this group of participants must be flagged as requiring significant monitoring and support. Rapidly changing support needs will require close monitoring; this must be done in conjunction with the monitoring of the well-being of informal supports.

Because many people with younger onset dementia enter residential care before the age of 65 years, they will (in the future) continue to be eligible to NDIS-funded supports until they turn 65. These supports that may best be provided by disability services. Consideration needs to be given to how to maximise the outcomes from supports that are provided across this interface.

## **Access to specialist supports**

Younger people with dementia may need to access specialist behaviour support services. Currently, for people with dementia, this is currently provided by the Dementia Behaviour Management Advisory Service (DBMAS). This service aims to improve the capacity of care workers, carers and service providers to respond to BPSD. Access to these specialist services must be funded by the NDIS.

## **Availability of respite**

Many younger families are providing support for someone with BPSD but it is never easy. No surprisingly, both planned and emergency respite services are in high demand. Unfortunately they are not always available.

### Alzheimer's Australia reports:

The main barriers to respite care include the lack of flexibility, availability and sufficient hours of care, concern that the service will not benefit the person with dementia and inability of most respite services to appropriately support individuals with BPSD.

The NDIS Launch Transition Agency must investigate and fund appropriate respite services for the families supporting these challenging participants. The needs of these families are high and urgent.

## Decreasing the use of restraints

Of increasing concern to disability services—across Australia—is the use of restrictive interventions; people with BPSD are particularly vulnerable to their use. While jurisdictions vary in how they are managing this issue, there is an overwhelming commitment to monitoring and reducing their use. This is a priority within the National Disability Agreement.

NDS is aware that the disability sector is working on a National Framework to reduce the use of restrictive interventions. Consideration needs to be given to how such a Framework will be interpreted and managed for younger people with BPSD who will also have greater choice and control over the supports they receive. These participants are unlikely to choose restrictive practices but without them they may be subject to more extreme practices and be unnecessarily restricted in their day-to-day activities.

## Workforce

Disability support work is changing. Responding to individual needs and desires is taking service provision increasingly out of facilities and into people's homes and communities. And this is not a model of service restricted to those who are easiest to support; it is becoming available to people with a diverse range of support requirements. People with very challenging behaviours—including BPSD—have the right to be active within their community.

This trend makes the skills of support workers harder to define or describe. Flexibility in what they do and how they do it is becoming a more important feature of their work. Service providers need to think creatively about job design (and re-design) and be prepared to do it often as the needs and desires of the individuals being supported change. Information and training for service providers on how to undertake job design may be useful.

NDS encourages initiatives to support the development of a skilled and committed disability workforce. The skills of disability workers must be sufficient to meet the requirements of the job and the needs of the people they support. This will require greater collaboration with the aged care sector (which has, for example, much greater knowledge of dementia and BPSD).

The importance of appropriately supporting BPSD cannot be ignored. A number of jurisdictions have increased the legislative and/or regulative requirements around behaviour management and the use of restrictive interventions. Workers need to be more highly skilled at assessing behaviours and understanding their triggers. They also need to be able to implement interventions that are the least restrictive.

Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities—and the need to regularly report on progress—will place greater expectations and requirements on support workers. The rights of people with disability must be respected as any challenging behaviours are managed. Workers also need to be able to manage any reporting requirements and be able to evaluate the effectiveness of the strategies they implement. These are complex skills for which many support workers are currently ill-equipped.



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