

National Disability Advocacy Program Review Team
Department of Social Services
GPO BOX 8920
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To Whom It May Concern

Review of the National Disability Advocacy Program

Alzheimer's Australia welcomes the opportunity to comment on the current Review of the National Disability Advocacy Program (NDAP).

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.¹

Alzheimer's Australia represents and supports the more than 353,800 Australians living with dementia, and the more than one million family members and others involved in their care². Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

Dementia involves progressive neurological decline, leading to serious cognitive disability. The number of Australians with dementia is growing, and while the onset of dementia is correlated with advancing age, the condition also affects some younger people. An estimated 25,100 Australians with dementia are under the age of 65. This number is expected to increase to 36,800 by 2050³. There are many causes of younger onset dementia (onset before the age of 65), with the most common being Alzheimer's disease, vascular causes, and fronto-temporal dementia.

For decades, people with younger onset dementia have fallen through the gaps between the disability and aged care sectors. Disability services often do not have a good understanding of dementia or the specialist services required to support people with younger onset dementia. Aged care services are often out of reach due to age limits or are not appropriate for this group.

¹ Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

³ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

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Alzheimer's Australia urges the Department of Social Services to ensure that the next iteration of the National Disability Advisory Program includes advocacy services targeted to people with younger onset dementia, who are often overlooked by disability services. We note that one reason for the review is to address the situation where "some types of advocacy are not available to a large number of people with disability". This is likely to include people with younger onset dementia.

People with a cognitive impairment should be able to access appropriate advocacy services which support them to maintain their independence, at the same time as ensuring formal and informal advocacy channels are in place.

People with younger onset dementia require appropriate advocacy services. Without advocacy and linkages to appropriate supports, these people often end up in the residential aged care system, which is not appropriate to their needs. In 2014, there were 6,400 people in residential aged care under the age of 65⁴. The vast majority of these have some type of cognitive impairment. Residential aged care, where the average age of residents is 84.5⁵ is not an appropriate environment for a younger person with dementia or cognitive impairment. Younger people in residential aged care often feel isolated, and the activities and services available often do not cater to their needs. At the same time, there are limited options outside of residential aged care for younger people with dementia who are in the later stages of the condition and require full time care and support.

There are precedents for the provision of effective individual advocacy (a model supported under the NDAP) for people with younger onset dementia. This kind of advocacy has been provided by Alzheimer's Australia through the Younger Onset Dementia Key Worker (YODKW) Program, a program which the Government has decided will be transitioned to the National Disability Insurance Scheme (NDIS). This program is a critical initiative in meeting the needs of people with younger onset dementia, who often "fall through the cracks" between the aged care and disability services sectors.

The YODKW program provides one-to-one support from diagnosis throughout the dementia journey. Under this program, the Key Worker acts as a primary point of contact for providing information, support, counselling, and advice; and links people with appropriate services. Key Workers link clients to early intervention supports and services and build capacity in families and clients to remain independent for as long as possible. The benefits of early intervention are well known and critical in ensuring the person living with dementia remains engaged, independent and maintains a good quality of life for as long as possible following a diagnosis. The Key Workers co-ordinate service access across the disability, aged care, and other sectors, and work within the service sector to develop dementia-specific services and supports. To date the program has assisted

⁴ <http://aihw.gov.au/aged-care/residential-and-home-care-2013-14/characteristics/>

⁵ <http://aihw.gov.au/aged-care/residential-and-home-care-2013-14/characteristics/>

1,586 people with younger onset dementia, and 1,866 carers. It has been recognised as highly effective in a recent independent review of dementia services.⁶

As the YODKW Program transitions to the NDIS, it is essential that consideration is given to how to continue to provide this important specialist linkage service. Mainstream, non-condition specific services will not meet the needs of people with younger onset dementia.

Alzheimer's Australia urges that through the NDAP, people with younger onset dementia and their cares should have access to individual advocacy services and other advocacy services which are fully inclusive, appropriate for, and targeted to their specific needs.

Thank you again for the opportunity to comment.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Carol Bennett'.

Carol Bennett
Chief Executive Officer
Alzheimer's Australia

⁶ KPMG (September 2015). *Analysis of dementia programmes funded by the Department of Social Services: Final report*, p 18.