

Nick Hartland
Group Manager, NDIS
Department of Social Services
Emailed to: disabilityadvocacy@dss.gov.au

Dear Mr Hartland,

**RE: CONSULTATION ON NATIONAL DISABILITY ADVOCACY
FRAMEWORK**

Alzheimer's Australia welcomes the opportunity to provide a submission to the National Disability Advocacy Framework (The Framework) Consultation Paper (the Paper). Alzheimer's Australia looks forward to commenting on the outcomes of this significant consultation and taking part in any future discussions relating to the National Disability Insurance Scheme (NDIS). This submission discusses the needs of individuals with Younger Onset Dementia (YOD) in relation to the Framework and provides general comment on the importance of ensuring independent, specialist advocacy support for consumers in developing the Framework.

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 overall, and will have an increasing impact on the health system due to population ageing.¹

Dementia poses a unique challenge for Australia due to increasing rates of prevalence, economic costs and social implications. Traditional models of care based on residential care are becoming unsustainable as a result of high and steadily growing service demands. In addition, changes in community expectations are creating greater demand for community based, consumer-driven models of support and a broader range of specialist services. The NDIS aims to address the unique needs of around 25,100 Australians with dementia who are under the age of 65, a number which is expected to increase to 36,800 by 2050². Clearly while the transition of people with younger onset dementia (YOD) to NDIS presents many opportunities, it also poses significant challenges.

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. Cat. no. AGE 70. Canberra: AIHW.

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Overall, Alzheimer's Australia supports the objectives of the Framework to advance the advocacy rights of people with disability, while maximising the choice and control over their lives. This objective should also be afforded to those with YOD, which would not occur under the proposed transition of the Younger Onset Dementia Key Worker (YODKW) Program into the NDIS in its current form.

Younger Onset Dementia and the NDIS

Alzheimer's Australia believes that it is paramount to consider that the needs of people with YOD span both the disability and aged care sectors and thus it is very important that the interface between, or transition between, the NDIS and the aged care system continue to be effective for consumers with YOD. As our experience across current trials in the ACT, Hunter and Barwon has shown us, not only is there a danger that without dementia specialist support, people with younger onset dementia will continue to 'fall through the cracks' of both systems, but there is a danger of a lack of continuity from one system to the other.

Alzheimer's Australia believes that people diagnosed with younger onset dementia should continue to receive seamless and equitable care and support throughout their life, regardless of the stage of life at which they develop care needs. The YODKW Program is built on the proven approach of ensuring greater choice, flexibility in service delivery and community participation for our consumers – all objectives which align with the Framework. This Program provides one-to-one support from early intervention and assistance in obtaining a diagnosis, to post-diagnosis support throughout the dementia journey, across all care settings.

The strength of the key worker role is the provision of person-centred care through a single point, long-term contact that can adapt to changing needs over time. The role mitigates against the current complex structures of disability, health and aged care that creates fragmentation, poor coordination and lack of collaboration between service providers. The key worker role responds to the unique needs of people with younger onset dementia and their families to have long term relationships of trust with a 'real person'.

Key workers also follow consumers and their families and carers and advocate for their unique needs as they seek assistance through all care settings: disability, aged and health care. This seamless continuity of care ensures that consumers always have the one trusted point of contact, and the key worker role plays a significant part in avoiding crisis driven and late presentations.

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While the focus on a re-ablement policy that the NDIS is based on is a good principle, this all too often fails to respond to the needs of those with cognitive impairment. It is clear that the needs of people with YOD can only be met with a holistic approach to service delivery and ensuring a continuum of care and support, from prevention and early intervention, to timely diagnosis, carer and client support in the community, to support for consumers as they need residential care.

Retaining YOD Advocacy

A robust Advocacy framework is a good starting point in ensuring that consumers have access to advocacy that supports their needs and requirements. This is particularly important for people with YOD, given the progressive nature of the condition which requires responsive, individually-tailored solutions from service providers that will evolve over time and with the individual's condition.

Overall, Alzheimer's Australia is encouraged to see that the Council of Australian Governments' Disability Reform Council acknowledges and recommends that systemic advocacy, legal review and representation should be funded outside of the NDIS. This should also include funding for dementia specialist advocacy services that currently assist people with YOD in navigating through complex aged care and disability sectors.

The essence of the YODKW Program provides specialist services that are designed specifically to meet the needs of people with YOD. The YODKWP provides one-to-one support from the point of diagnosis throughout the dementia journey and for those in the early stages of diagnosis, in particular, it is critical that this understanding is built into the system.

Alzheimer's Australia has provided submissions to the Senate Inquiry into the Adequacy of Existing Care Arrangements Available for Young people with Severe, Physical, Mental or Intellectual Disabilities in Australia³; its 2015-16 Federal Budget Submission⁴; and to the NDIS: Information, Linkages and Capacity Building Policy Framework consultation⁵. In these documents, we highlight the importance of appropriate and timely community supports for people with YOD and how the current plan to transition the YODKW Program into NDIS is likely to result in service delivery gaps for this group.

³ Alzheimer's Australia (2015). Submission to the Senate Standing Committee on Community Affairs on the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. Canberra.

⁴ Alzheimer's Australia (2015 b). Budget Submission 2015-16. Canberra

⁵ Alzheimer's Australia (2015 c). Submission to the NDIS on the Information, Linkages and Capacity Building Policy Framework. Canberra

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We take this opportunity to reiterate this point given that under the anticipated transition, many of the clients eligible for YODKW Program will become ineligible for the NDIS and the services and safeguards provided under the scheme once rolled out.

Alzheimer's Australia recommends that the YODKW Program continue to be funded outside the NDIS at least for a period of 2 years to ensure that specialist advocacy and representation for people with YOD is retained.

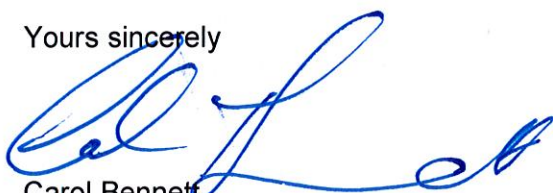
This recommendation is also supported by the Senate Standing Committee on Community Affairs, which recommended:⁶

“extend the National Younger Onset Dementia Key Worker Program (YODKWP) to all young people identified as being at risk of placement in residential care to provide collaborative case management. The key worker should be assigned before any placement commences”.

Conclusion

Thank you for the opportunity to provide a Submission to the National Disability Advocacy Framework Consultation Paper. Alzheimer's Australia recommends that the Advocacy Framework should support and protect the specialist needs of people living with YOD which can be met by the retention of important elements of programs such as the YODKW.

Yours sincerely



Carol Bennett
CHIEF EXECUTIVE OFFICER
Alzheimer's Australia
24 July 2015

⁶ Commonwealth of Australia 2015. Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. Canberra. Retrieved from: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Report

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