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**SUBMISSION TO THE NATIONAL DISABILITY
INSURANCE SCHEME (NDIS)
QUALITY AND SAFEGUARDING
FRAMEWORK**

April 2015

ALZHEIMER'S AUSTRALIA

Executive Summary

Alzheimer's Australia welcomes the opportunity to provide a submission to the NDIS Quality and Safeguarding Framework (The Framework) Consultation Paper (the Paper). Alzheimer's Australia looks forward to commenting on the resulting Decisions Paper and taking part in any future consultations relating to the 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 good governance principles 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 second for women, and will have an increasing impact on the health system due to population ageing. Currently there are 25,100 Australians with dementia who are under the age of 65. A number which is expected to increase to 36,800 by 2050¹.

It is paramount that NDIS clients receive high quality services and are protected by appropriate, effective safeguards. Alzheimer's Australia supports the objectives of the Framework to advance the rights of people with disability and minimise the risk of harm, while maximising the choice and control over their lives. For people with YOD, these objectives are particularly important 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 Paper acknowledges '*the need to recognise that every person is at a different stage along the way to independent decision making...*'. The essence of Alzheimer's Australia's Younger Onset Dementia Key Worker Program (YODKWP) echoes this philosophy to provide specialist services that are designed specifically to 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 Australia*²; its *2015-16 Federal Budget Submission*³; and to the *NDIS: Information, Linkages and Capacity Building Policy Framework* consultation⁴. In these documents we highlight the importance of appropriate and timely community supports for people with YOD and how the current plan to subsume YODKWP into NDIS is likely to result in service delivery gaps for this

¹ Australian Institute of Health and Welfare (2012). Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

² 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.

³ Alzheimer's Australia (2015 b). Budget Submission 2015-16. Canberra

⁴ Alzheimer's Australia (2015 c). Submission to the NDIS on the Information, Linkages and Capacity Building Policy Framework. Canberra

group. 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.

YOD experience in NDIS Trial Sites

Experience to date in the NDIS trial sites suggests that people with YOD have difficulty getting through the assessment process and those in the early stages of the disease are considered as not having a sufficient functional impairment to access services.

As we have detailed in our submission to the NDIS: Information, Linkages and Referral Framework⁵, people with younger onset dementia in the trial sites have indicated that they find the application process difficult and confusing with some consumers giving up because the process was too complex. Key workers are helping people with younger onset dementia in the trial sites apply for the NDIS, prepare for planning meetings and ensure they have appropriate support to implement their NDIS plan to receive services. This support would not be funded through the NDIS, and if the YODKWP is defunded, people with younger onset dementia would be forced to face the application process without support.

The administrative burden of enrolling into NDIS has also been a major barrier for our clients. Currently, the Evidence of Disability Form must be filled out by GP or specialist for each client. The completion of this form is dependent on the doctor having a thorough understanding of the functional capacity of the person with dementia. The Access Request Form must accompany the Evidence of Disability Form. Understanding the forms, and how to complete them is an area identified as a barrier to those with cognitive impairment. Key workers have helped clients transitioning from the YODKW. Considering that diagnosis is one of the biggest barriers that people with YOD face, this emphasis on providing evidence of 'functional disability' represents a considerable gap in the delivery of what should be consumer directed care, and should be addressed through the Quality and Safeguarding Framework.

The proposed transition will also result in many important features that the YODKW Program currently provides to YOD consumers being lost, such as support for family and carers, information for people with dementia and families and the building of capacity within the service sector.

Alzheimer's Australia is also concerned that the current emphasis on strengthening a participant's abilities to coordinate supports & participate in the community will clearly never meet the needs of clients with YOD. The premise of the NDIS here could work to support people with a disability, but is completely misaligned to the management of clients dealing with progressive neurological decline.

⁵ Available online at: <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Alzheimers-Australia-Response-to-NDIS-ILC-Policy-Framework.pdf>

People living with YOD and their families and carers already fall between the cracks of both the disability and the aged care sector. They have unique needs and it is essential that they have access to specialised dementia services which cannot be delivered by the mainstream disability sector, or even by the generalist Local Area Coordinators proposed under the NDIS.

A robust and effective quality framework thus needs to ensure that these consumers are not compromised by a mainstream approach to service provision and that the unique needs of YOD consumers are met through the delivery of specialist services. As the consultation paper itself notes, *central to the framework are developmental safeguards designed to make sure participants have the capabilities and supports to be able to choose quality supports and to build good and safe lives.*

Recommendation: Alzheimer's Australia recommends that the Quality and Safeguarding Framework should support and protect the specialist needs of people living with YOD which cannot be met through the provision of mainstream disability supports.

The Framework: Consumers' needs first

The questions raised in the Paper highlight the complexities in balancing the needs of clients, service providers and governments, while ensuring timely access to those services within a robust framework of consumer protections. However, irrespective of the industry, jurisdiction or sector, there are fundamental features that should be included in an instrument such as the Framework.

It is essential that the various instruments forming part of the NDIS rollout puts consumer needs ahead of expediting market access and accommodating commercial needs. The establishment of any framework should be underpinned by the principles of good governance: accountability, participation, predictability and transparency, as outlined by the Australasian Council of Auditors General.

Future iterations of the Framework should be developed to uphold these principles. These principles have been reflected through some provisions, for instance where the Paper notes that the Chief Executive Officer of the National Disability Insurance Agency (once the NDIS is fully rolled out) will have primary responsibility for deciding whether individuals and organisations meet the quality and safeguard standards for the NDIS, and will therefore be eligible to provide services to NDIS clients. This supports both the principles of accountability and predictability and will ensure that service providers do not simply self-certify of their ability to provide services to NDIS clients, and that service providers can rely upon the assessment criteria in making their eligibility claim.

In terms of accountability, Alzheimer's Australia considers that industry self-regulation of a complaints mechanism to be the least favourable option of those proposed in the Paper. This approach, which has been adopted by the prescription and complementary medicines industries, for example, shows that it is a system that benefits and protects industry rather than the consumer. Upholding the principle of accountability in the Framework would result in a complaints mechanism

that is independent of influence from the industry sector over which it has oversight, mitigating any actual or perceived conflict of interest in the complaints process.

Further relating to accountability, the Paper proposes an NDIS Code of Conduct as a possible approach to set out what the expectations for safe and ethical behaviour are, with breaches to be investigated by the NDIA or an independent authority. Alzheimer's Australia supports the establishment of universal standards expected of NDIS service providers but only supports a Code of Conduct if there are significant penalties for breaches, and if those penalties are enforced. Simply de-registering those who breach the Code, as proposed in the Paper, would not provide a sufficient deterrent, and needs to be strengthened by accompanying financial penalties. It is also essential to ensure that any new Codes developed across NDIS also reflect current accreditation, and licensing standards across similar industries such as aged and health care.

Establishing a registration, monitoring and enforcement regime has significant financial implications. Before a system of provider registration is further explored, consideration needs to be given as to the financial requirements for the system and whether the NDIA or the overseeing body has the resources to manage such a regime. It is also important to consider linkages to the health and aged care system to ensure continuity of care for participants within these systems. This needs to be determined as part of the Framework development process, and not occur after this is completed.

Conclusion

Thank you for the opportunity to provide a Submission to the NDIS Quality and Safeguarding Framework Consultation Paper.

Alzheimer's Australia supports the objectives of the Framework to advance the rights of people with disability and minimise the risk of harm, 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 YODKWP into NDIS.

Alzheimer's Australia recommends that the Quality and Safeguarding Framework should support and protect the specialist needs of people living with YOD which cannot be met through the provision of mainstream disability supports.

In developing the Framework, policy makers should at all times apply the principles of good governance, establishing an independent complaints mechanism for consumers, and developing a Code of Conduct that provides sufficient deterrent for breaches and in which the penalties are actively monitored and enforced.