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SUBMISSION TO THE
DEPARTMENT OF SOCIAL
SERVICES

NATIONAL DISABILITY
INSURANCE SCHEME (NDIS)
- CODE OF CONDUCT
DISCUSSION PAPER

JUNE 2017

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide a submission to the NDIS Code of Conduct (The Code) Discussion Paper (the Paper). This submission draws on the needs of individuals with Younger Onset Dementia (YOD) in relation to the Code and provides general comment on the importance of good monitoring and implementation processes in finalising the Code.

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 will have an increasing impact on the health system due to population ageing. Currently there are over 25,000 Australians with dementia who are under the age of 65. This number is expected to increase to over 42,000 by 2056.¹

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 Code to advance the rights of people with a 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 trajectory 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 *NDIS Quality and Safeguarding Framework*,² the *Senate Inquiry into the Adequacy of Existing Care Arrangements Available for Young people with Severe, Physical, Mental or Intellectual Disabilities in Australia*,³ its *2015-16 Federal Budget Submission*,⁴ the *NDIS: Information, Linkages and Capacity Building Policy Framework* consultation,⁵ and the *Inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities*.⁶ In these documents we highlight the importance of appropriate and timely community supports for people with YOD and how barrier that prevent the NDIS from currently achieving this.

¹ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

² Alzheimer's Australia (2015). Submission to Department of Social Services consultation NDIS Quality and Safeguarding Framework. Canberra.

³ Alzheimer's Australia (2015 a). 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

⁶ Alzheimer's Australia (2017). Submission to Inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities. Canberra.

It is currently proposed that the YODKWP will transition to the NDIS completely by 30 June 2018; however, our current experience of ongoing transition activities highlight that there are several areas of concern that need to be addressed before the transition can be successfully completed. We take this opportunity to reiterate this point given that, under the anticipated transition, many of the clients of the YODKWP will face challenges.

In this submission, Alzheimer's Australia includes comments areas which should be considered in further developing this Code and makes the following recommendations:

Recommendation 1: Embedding pre-planning support for people with a progressive neurodegenerative disease into the Code

Recommendation 2: Reference to a cohesive, structured and integrated national approach to disability education and training is needed, including minimum standards for education and training for those working with people with dementia.

Recommendation 3: The Code recognises and removes the inherent conflict of interest that arises from assessment and service delivery roles being provided by the same provider.

Recommendation 4: The Code be strengthened in order to limit and restrict instances of disability abuse. This should include mandatory Working with Vulnerable People checks across the Scheme, as well as mandatory reporting requirements for serious breaches.

BACKGROUND: DEMENTIA IN AUSTRALIA

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal condition that affects people's abilities and memories.⁷ It is surrounded by stigma and misunderstanding,⁸ isolates people living with dementia, their families and carers from social networks,⁹ and carries significant social and economic consequences.¹⁰

The care and support of people living with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 410,000 Australians living with dementia and nearly 300,000 people involved in their care; by 2056 there will be over a million people living with dementia.¹¹ Younger onset dementia develops before the age of 65, even as young as 35 years of age, and currently, there is an estimated 25,938 people with younger onset dementia in Australia, which is expected to rise to 29,375 people by 2025 and 42,252 people by 2056.¹²

A common misconception is that people diagnosed with dementia are older and live in residential aged care. The reality is that 70% of people with dementia are living in the community at the time of diagnosis and they may be receiving services through the National Disability Insurance Scheme rather than through the aged care system.¹³ Statistics also reveal that dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the fourth leading cause of disability burden overall.¹⁴

Dementia also has a profound social impact. People with dementia experience stigma and social isolation,¹⁵ and family carers often find it difficult to balance work, life and caring responsibilities.¹⁶

Many of us will be diagnosed with dementia over the years ahead, or have people we care about faced with a diagnosis. Some of us will be younger than 65 when we develop symptoms or receive a diagnosis, so it is vital that the NDIS Code of Conduct encompasses the needs of people living with younger onset dementia and addresses such themes as decision making support for people living with neurodegenerative disorders, accessibility, and service quality.

⁷ Mitchell, S et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

⁸ George D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-87.

⁹ Blay S. and Peluso E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

¹⁰ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

¹¹ The National Centre for Social and Economic Modelling NATSEM (2016). *Economic Cost of Dementia in Australia 2016-2056*.

¹² NATSEM, *Economic Cost of Dementia*.

¹³ AIHW, *Dementia in Australia*.

¹⁴ AIHW, *Dementia in Australia*; Access Economics (2009). *Keeping Dementia Front of Mind*.

¹⁵ Alzheimer's Australia (2014). *Living with Dementia in the Community: Challenges and Opportunities*.

¹⁶ Brooks D., Ross C., Beattie E. (2015). *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. Report for Alzheimer's Australia.

NDIS and People with Dementia

The Code of Conduct is a key component of the NDIS Quality & Safeguarding Framework, which seeks to outline the expectations for people delivering NDIS supports and services. It is anticipated that it will apply to all providers and workers doing work that is funded under the NDIS, including registered and unregistered NDIS providers, providers delivering partners in the community services, including local area coordinator (LAC) and early childhood early intervention (ECEI) services, providers delivering information, linkages and capacity building (ILC) activities, providers delivering Commonwealth Continuity of Support (CoS) Programme services and workers providing NDIS funded supports or services. The development of the Code of Conduct thus provides us with another opportunity to revisit some of the barriers people living with dementia face through the NDIS, and address them through building awareness of neurodegenerative diseases into the Code.

Alzheimer's Australia believes that the NDIS will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception. To date some NDIS participants have received plans that have had positive, life-changing impacts on their lives; however, many others have received insufficient plans that will adversely affect their quality of life and place some at risk of avoidable hospitalisation.

When the NDIS operates as it was originally intended, and participants have the opportunity to exercise 'choice and control' by actively participating in the development of their first NDIS plan, the plan outcomes generally have been positive. However, when the progressive and complex needs of people with neurodegenerative diseases like YOD have been overlooked due to lack of understanding of these diseases (for example, conducting planning sessions over the phone despite communication or cognition challenges, or creating plans that do not address key support needs), the outcomes have been overwhelmingly poor.

People with a progressive neurological disease like YOD can run counter to the 'traditional' trajectory of someone on the NDIS: that is, an ability to enhance independence and re-ablement through a more effective engagement of services. For someone with a neurodegenerative disease, however, care needs will inevitably increase over time, no matter how effective early interventions are. NDIS plans for this cohort need to acknowledge this and balance independent goal setting with advance care planning. Individuals with neurological diseases should also have pre-planning education and support to assist them as they consider future needs that go beyond the first year of their plan.

Consideration of YOD and anticipated progression should also be factored into planning meetings. People with cognitive or communication impairment require patience and understanding, limited distractions, clear speech, eye contact and non-verbal indicators which are difficult to achieve over the phone. Therefore, when NDIS planning sessions are conducted solely over the phone, many of which, our consumers tell us, have been conducted solely with the person's carer without the participant present (or the reverse), the plan outcomes are less than optimal and the participant (and their supporter) is deprived of choice and control.

Dementia Specialist Decision Making Support

People with a progressive neurodegenerative disease must consider a number of elements when preparing for NDIS plans. For many, they have only recently been diagnosed and are not yet completely aware of how the disease will progress and how their needs will change. It is essential that individuals have a clear understanding of their anticipated future needs

and how the progressive nature of the disease may impact them in the next 12 months (and the years afterwards) when preparing for an NDIS plan.

This is evidenced through reports of people with progressive neurodegenerative diseases advising their NDIS planner of their immediate needs (e.g. social interaction) without considering their greater needs (e.g. occupational or speech therapy) despite having a clear requirement for them.

The Productivity Commission (PC) itself has noted in its recent Position Paper¹⁷ that right now NDIS planners lack disability specialist awareness and that:

“Planners should, at a minimum, have a general understanding about different types of disability. The Commission recommends specialised planning teams for some types of disability, such as psychosocial disability. An alternative (or complementary) approach would involve leveraging expertise from within the industry, and getting specialist disability organisations or service providers more involved in the planning process.”

PC Position paper on NDIS Costs

Lack of pre-planning can result in ineffective plans which require an NDIS review and/or result in negative health impacts for people with a progressive neurodegenerative disease. Therefore, the Code should require either for expert organisations to provide support to people with a progressive neurodegenerative disease as they prepare for NDIS planning sessions or for targeted NDIS education to address the needs of people with a progressive neurodegenerative disease. This would significantly reduce the risk of inappropriate or insufficient NDIS plans and the need for unscheduled plan reviews.

Recommendation 1: Embedding pre-planning support for people with a progressive neurodegenerative disease into the Code

Dementia Specialist Education and Training for all providers.

To ensure quality dementia care, health care professionals and all care staff that provide services to people with dementia must be educated and trained in key aspects of dementia care including: person-centred care; the fundamentals of caring for people with dementia; psychosocial approaches to addressing unmet needs; pain assessment and management (particularly as people with dementia may be unable to verbalise their needs); and appropriate end-of-life care.

The Code should also ensure that learning pathways are available for care staff to develop knowledge, skills and emotional intelligence, from basic level to advanced practice level. This should be part of the mandate of the NDIA as well as the soon to be established NDIS Safety and Quality Commission. These organisations, as well as all NDIS funded service providers, have a shared responsibility to develop and fund education and career pathways for the disability workforce. Government must maintain a commitment to supporting ongoing education and training to develop and sustain a workforce skilled in dementia care in disability, and employers must also be committed and contribute to education and training.

The move to a market model of service delivery also points to the potential need for significant additional training requirements for registered providers, who will no-longer

¹⁷ Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra.

receive block-funding to cover these types of costs. There is a need to ensure relevant training is funded under ILC (or similar) to embed changes within the sector.

Education and training programs must also respond to the evolving characteristics of the workforce, including targeted education and training for the increasing proportion of the workforce which comes from culturally and linguistically diverse backgrounds.

Further, there is a need to ensure an outcomes focus to the provision of all education and training, and more so for dementia in particular. Lessons should be learnt from aged care, where currently education and training is essentially provided on the presumption that simply undertaking an activity or using a particular resource results in practice change; little review or analysis is given to whether this actually occurs. Practice change requires more than simply creating an awareness of knowledge; measures are needed to translate this to practice.

Dementia training should be linked to clear levels of competency and/or practice standards, so that the learning outcomes of all dementia education and training activities may be aligned with the competencies/practice standards. Ideally, the outcomes of each education and training activity would be assessed using a framework to ensure that they achieve the intended outcomes and lead to practice change.

<p>Recommendation 2: Reference to a cohesive, structured and integrated national approach to disability education and training is needed, including minimum standards for education and training for those working with people with dementia.</p>
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Removing Conflict of Interest between roles: Separating Assessment from Service Provision

Coordinators of Support play a vital role in negotiating support costs with providers, making arrangements for support delivery and providing information and ongoing support to providers regarding the specific needs of people with a neurodegenerative disease. These supports are therefore vital inclusion in the plans of people with dementia accessing the NDIS.

People with progressive neurodegenerative diseases like younger onset dementia are caught between a changing disability sector and aged care sector and there are limited options available to them within the marketplace. Without the support and advocacy of a Coordinator of Supports who understand a client's disease and journey, such as the YODKW, many people with a progressive neurodegenerative disease may fall through the cracks and be unable to access appropriate services.

It is important to note that coordination of supports is a specialist skill, which helps NDIS clients navigate a complex service delivery environment by understanding their unique needs.

It is inappropriate, and in fact a clear conflict of interest, to have roles such as an LAC assess an individual's needs for support co-ordination or support connection, and then provide the service themselves. This is becoming a frequent occurrence that can be observed across Australia, across which the NDIS have moved to a model where LACs are also undertaking the support coordination/connection role. This means that, in some instances, people with YOD are having support coordination/connection included in their plans, but the LACs are providing the service.

As we have noted earlier, LACs have limited to no knowledge of complex neurodegenerative conditions like YOD, which is inadequate from the perspective of needs assessment, but even more inadequate when it come to the provision of a specialist service such as co-ordination of supports for a person living with dementia.

Recommendation 3: That the Code recognises and removes the inherent conflict of interest that arises from assessment and service delivery roles being provided by the same provider.

Strengthening Code to limit and restrict disability abuse

Younger people with dementia and their family carers are often reluctant to access services because of the fear of the person with dementia 'not fitting' traditional disability care services. This perception can negatively impact family carers due to the increased guilt they may experience when they have to access services they believe are not adequately meeting the needs of their family member. For example, carers have conveyed to us their concerns about the lack of engaging and enjoyable activities in many community based services.

Over the past several years, people living with dementia have shared their experiences with us of poor quality care and the frustrations they have experienced in attempting to navigate a highly complex system that at times affords little transparency. These stories have ranged from the mismanagement of the behavioural and psychological symptoms of dementia (BPSD); chemical and physical restraint; care recipients being treated with a lack of dignity and respect; and psychological, physical and sexual abuse.

The stories shared by some of our consumers paint a disturbing picture of a care system under strain which is, in some cases, failing to meet the basic human rights of our most vulnerable citizens. This risk is due to a host of factors including cognitive impairment, depression, immobility, limited support and contact with the outside world and difficulties in accessing the appropriate channels through which to raise complaints, as well as fear of victimisation for doing so.¹⁸ Alzheimer's Australia has released a paper that shares these courageous consumer stories, and provides strategies about how we can begin to address the systemic issues that are leading to breakdowns in care. The paper also draws on international examples of initiatives where consumers play a key role in monitoring quality and determining accreditation of services.¹⁹

With the establishment of the NDIS Safety and Quality Commission and the development of a Process of Code of Conduct Investigation and Enforcement there are significant protections in place to assist in ensuring a minimum quality of care is provided to consumers through the NDIS. However, there is a need for further provisions in the Code to protect people living with dementia. There is a need for the Working with Vulnerable People check process to operate nationally, so that the scheme can also track workers who breach the Code in a significant manner, and possibly also report to the NDIS Safety and Quality commission.

In addition, self-regulation of unregistered providers could be problematic as there are no formal reporting requirements and no harsh penalties such as de-registrations for violations either. In terms of accountability, Alzheimer's Australia considers that industry self-regulation

¹⁸ Barnett and Hayes, 'Not seen and not heard'.

¹⁹ Alzheimer's Australia 2013. Quality of Residential Aged Care: The consumer perspective. Retrieved from:
https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

of a complaints mechanism can be quite ineffective. This approach, which has been adopted by the prescription and complementary medicines industries in Australia for example, shows that it is a system that benefits and protects industry rather than the consumer. Upholding the principle of accountability in the Code should 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.

Mandatory reporting requirements should be established for serious breaches to ensure that the most harmful breaches are addressed by the appropriate authorities in a timely manner. Reporting requirements also need to be bolstered by requisite penalties for failure to report in these situations. These are particularly important for the following points under the Code:

2. *Actively prevent all forms of violence, exploitation, neglect and abuse.*
5. *Raise and act on concerns about matters that may impact on the quality and safety of supports provided to people with disability.*
7. *Not engage in sexual misconduct.*

Recommendation 4: The Code be strengthened in order to limit and restrict instances of disability abuse. This should include mandatory Working with Vulnerable People checks across the Scheme, as well as mandatory reporting requirements for serious breaches.

ABOUT ALZHEIMER'S AUSTRALIA

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.

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care. 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.

Alzheimer's Australia is a member of Alzheimer's Disease International, the umbrella organisation of Alzheimer's associations across the world.

Our organisation advocates on the basis of evidence-based policy, promotes awareness of dementia, delivers national projects and programs under contract from the Commonwealth, and provides research grants to emerging researchers. We are committed to a strong consumer focus and have a number of consumer advisory mechanisms, which actively seek and represent the voice of people with dementia themselves, as well as carers. We participate on many Ministerial and Departmental Committees, and contribute to consultation forums and advisory groups. We are also involved with key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.