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SUBMISSION TO THE JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

INQUIRY INTO ACCOMMODATION FOR PEOPLE WITH A DISABILITY

March 2016

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to respond to the inquiry by the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) into accommodation for people with a disability. Our submission focuses on the need for access to appropriate housing and support for people with younger onset dementia.

Dementia involves progressive neurological decline, leading to serious cognitive disability. The number of Australians with dementia growing, and this is not only an issue affecting the elderly: more than 25,000 Australians have younger onset dementia (onset before the age of 65). For decades, people with younger onset dementia have fallen through the gaps between the disability sector and aged care. 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.

In 2014, there were 6,400 people in residential aged care under the age of 65[1]. The vast majority of these have some type of cognitive impairment. Residential aged care, where the average age of residents is 84.5[2]., 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 do not cater to the needs of younger people with dementia. 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.

People with younger onset dementia need access to affordable and flexible community housing options, particularly in the form of social housing. Like other people with disabilities, people with younger onset dementia usually want to reside in the community for as long as possible. When this is no longer possible, appropriate residential care services need to be available.

There is also a need to develop comprehensive supports for people who are homeless and have a cognitive impairment such as younger onset dementia. A significant proportion of the homeless population have cognitive impairment, including dementia, indicating high levels of unmet need for housing and support services.

As noted in evidence provided to the Committee Roundtable by the Australian Housing and Urban Research Institute[3], due to issues including scale and timeframes, a demand-side approach to ensuring access to housing for people with disabilities may not be effective. Well-designed supply-side approaches are more likely to be effective in meeting the housing needs and preferences of NDIS clients, including people with younger onset dementia.

[1] http://aihw.gov.au/aged-care/residential-and-home-care-2013-14/characteristics/
[2] http://aihw.gov.au/aged-care/residential-and-home-care-2013-14/characteristics/
[3] Report of Joint Standing Committee on NDIS October 2015 Roundtable: http://www.aph.gov.au/joint_ndis_accommodation

To meet the growing need, government will need to take the lead role in funding and co-ordinating the provision of appropriate social housing for people with disabilities, including those with younger onset dementia. As outlined by participants at the Committee Roundtable, there is also a role for charitable organisations, philanthropic funds, superannuation funds, and corporates to participate in funding and delivering social housing for people with disabilities, including through social impact bonds. However, this should be seen as additional to, rather than as a substitute for, government leadership and funding.

RECOMMENDATIONS

1) Government should ensure that the transition of the Younger Onset Dementia Key Worker Program to the NDIS does not result in a loss of the specialist advocacy, linkage and support services which to date have provided assistance in relation to housing, amongst other areas of concern, for people with younger onset dementia.
2) Government should continue to support efforts to reduce the number of younger people placed in residential aged care, including through alternative supported housing arrangements. This should include the use of dementia enabling environment design principles in housing for people with dementia.
3) Appropriate residential care services should be developed for people with younger onset dementia who cannot be supported in another setting.
4) Initiatives are needed to support partnership and collaboration between the homelessness sector, and the dementia, health, and aged care sectors, in order to improve access to appropriate, co-ordinated and seamless services for people with dementia who are homeless.

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 can impact a range of cognitive functioning including memory, language, and thinking.[4] It is cloaked in stigma and misunderstanding,[5] isolates people with dementia and their carers from social networks,[6] and carries significant social and economic consequences.[7]

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 350,000 Australians living with dementia and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people with dementia[8]. Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050[9].

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least $4.9 billion per annum[10]. Dementia also has a profound social impact. People with dementia experience stigma and social isolation[11], and family carers often find it difficult to balance work, life and caring responsibilities[12].

As our population ages, and as more people survive the diseases of mid-life, more of us – both in terms of raw numbers, and as a proportion of the population – will experience dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men[13]. The higher lifetime risk for women is mainly due to women's longer life expectancy.

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.[14] Provision of comprehensive community based support to enable people to live

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[4] Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine, 361*, 1529-38.
[5] George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet, 376,* 586-7
[6] Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry, 18*(2), 163-71.
[7] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*
[8] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*
[9] Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050.* Report for Alzheimer's Australia.
[10] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*
[11] Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*
[12] Brooks D, Ross C, Beattie E, *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers.* (2015) Report for Alzheimer's Australia.
[13] Sehadri S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al (2006). The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*, 37 (2):345-50; cited in Alzheimer's Association (USA) *2013 Alzheimer's Disease Facts and Figures* p 19. www.alz.org/downloads/facts_figures_2013.pdf
[14] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*

at home, and appropriate, high quality residential care are therefore both critical to meeting the needs of people living with dementia.

Given the high and ever-increasing prevalence of dementia, it is critical that people with dementia are able to participate fully in the community and to access appropriate accommodation and care services.

Younger onset dementia

An estimated 25,100 Australians with dementia are under the age of 65. This number is expected to increase to 36,800 by 2050[15]. There are many causes of younger onset dementia, with the most common being Alzheimer's disease, stroke, and frontotemporal dementia.

People with younger onset dementia face a unique set of circumstances compared to people who develop dementia in later life including different economic, family, workplace and social pressures. They can experience significant delays in diagnosis as dementia is often not considered as a likely diagnosis in a younger person. The majority of younger people with dementia live at home with their families. As the condition progresses, however, it can be difficult to access sufficient care services in the community to remain at home.

Many people with younger onset dementia end up moving to residential aged care services, as often there is no other place for support once their care needs exceed what is available in the community. For people with younger onset dementia who are single or live alone, and do not have an informal carer, getting access to adequate support is even more difficult.

In 2014, there were 6,400 people under the age of 65 in residential aged care and the majority of these had some form of cognitive impairment[16]. Residential aged care is often not appropriate for younger people and is unable to meet their care needs. Given that the average age of residents within residential aged care is 84.5[17]. services and supports are focused on an older population. Access to physical activity and meaningful social engagement opportunities for people with younger onset dementia are limited.

The lack of appropriate social engagement and care within the residential aged care environment can lead to an exacerbation of behavioural and psychological symptoms of dementia. Staff often respond to these behaviours by requesting that psychotropic medications be prescribed. As a result, people with younger onset dementia are often medicated to manage their response to an inappropriate environment.

Concerns about the appropriateness of residential care for younger people were highlighted in the 2015 Senate Committee Inquiry into adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. The report from that inquiry found that "RACF are designed for older Australians and are not funded to provide care for young people or people with severe disability. It is the committee's view that everyone is entitled to live in a home of their

[15] Australian Institute of Health and Welfare (2012). *Dementia in Australia.*
[16] http://aihw.gov.au/aged-care/residential-and-home-care-2013-14/characteristics/
[17] http://aihw.gov.au/aged-care/residential-and-home-care-2013-14/characteristics/

choosing."[18] The Committee also stated that, "the mental health of young people in residential care is often exacerbated or acquired because of the emotional and psychological impacts of an environment which is not age-appropriate. It is the committee's view that there must be specific attention given to ensuring good mental health and well-being of young people in care."

The National Disability Insurance Scheme (NDIS) will provide funding for support and services for people with younger onset dementia living in the community. The hope would be that this would reduce the need for placement within residential aged care facilities. However, NDIS has limited funding to provide housing for people with a disability. Due to the lack of housing in the community, residential aged care will continue to be the only solution for some people with younger onset dementia.

It is essential that people with younger onset dementia have access to appropriate and affordable accommodation, particularly in community settings where most people with dementia prefer to live as long as possible. This includes housing that is designed or adapted to use dementia enabling environment design principles, which better meet the needs of people living with dementia[19]. People with younger onset dementia should also have access to support services that are offered as an integrated package along with housing. Age appropriate residential care services must be developed for people with younger onset dementia whose care needs cannot be met in the community.

Dementia and homelessness

A recent literature review on homelessness and dementia in Australia[20] notes that while there is limited research evidence, it is apparent that rates of cognitive impairment and dementia are higher in the homeless population than in the general population. Available research indicates that approximately 10% of younger homeless people (aged under 65) are likely to have cognitive impairment, while around two thirds of older homeless people were found in one study to be cognitively impaired. Many of these people have not been formally diagnosed and have little access to services and supports. Cognitive impairment is often co-morbid with other conditions, including mental health problems, substance abuse issues, and physical health problems.

One of the major barriers to addressing homelessness amongst older persons is a lack of appropriate, affordable housing.. It is also well established that homelessness prematurely ages people, and so many may be physically "old" but chronologically too young to access the aged care system. Many of these people will be cognitively impaired. The evidence also indicates that many of the problems experienced by the homeless population can only be effectively addressed in an environment of stable housing, as it is difficult to provide care and resources to people who are living on the streets.

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[18] Community Affairs Reference Committee (2015). Adequacy of existing residential care arrangements for young people with severe physical, mental, or intellectual disabilities in Australia.

[19] http://www.enablingenvironments.com.au/

[20] Chenco C (2015). *Homelessness and Dementia in Australia: A Literature Review*, conducted on behalf of the Victoria and Tasmania Dementia Training Study Centre. http://dtsc.com.au/download/dementia-and-homelessness-report/

ACCESS TO APPROPRIATE AND AFFORDABLE ACCOMMODATION FOR PEOPLE WITH YOUNGER ONSET DEMENTIA

The Younger Onset Dementia Key Worker Program

Alzheimer's Australia's Younger Onset Dementia Key Worker (YODKW) 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.

Under this program, the Key Worker acts as a primary point of contact for providing information, support, counselling, and advice; and links people with services that are appropriate to their individual needs. Eligibility includes being under 65 years on first contact to the program; and includes all forms of dementia, including a person with symptoms of dementia that have not yet been diagnosed. Key Workers co-ordinate service access across disability services, aged care services, and other services.

This program has provided assistance and linkages to people requiring support in maintaining or securing appropriate housing. As this program transitions to 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.

Key Workers report a lack of housing options for people with younger onset dementia. To meet the needs of the 25,000 plus people with younger onset dementia, the NDIS needs to consider means of ensuring a supply of affordable, appropriate housing for this population, integrated with the supports provided through the YODKW Program and related programs.

A few cases studies are presented here to illustrate the impact of the program on addressing the housing needs of people with younger onset dementia.

Case study 1: Support to meet the complex needs of an Aboriginal client with Younger Onset Dementia

The YODKW program had a referral from a client who is Aboriginal but stated she does not wish to be identified as such on any record. She had no proof of identity and was subsequently at risk of homelessness. The Key Worker slowly built a relationship with the client and carer, who had proven to be resistant and suspicious of services as they had not worked out previously. The Key Worker gained a birth certificate for the client and placed her on a waitlist for housing to address the risk of homelessness. The client now gets enjoyment from attending a social program which had been rejected previously without the intervention of the YODKW.

Case Study 2: Assisting a client to transition from a High Care Residential Facility into the community

A client newly registered with the YODKW Program was living in a high care residential facility and becoming increasingly depressed. Her family had unsuccessfully tried to assist her to move to appropriate accommodation and the client left the facility and moved into the

studio apartment of one of her children, who has a disability. This arrangement broke down and the client was at risk of homelessness. The Key Worker partnered with another community organisation ("Partners in Recovery") which, together with the Key Worker, supported the client to move into her own apartment with support services in place.

Case Study 3: Assistance to successfully access respite care

The YODKW Program helped a client who was discharged from a community based respite facility due to changed behaviours causing risk of harm to self and others. A family breakdown resulted in urgent need of access to suitable, affordable accommodation. The Key Worker facilitated meetings between the client, carer and respite facilities to negotiate long-term respite options. The Key Worker also liaised with Commonwealth Respite and Carelink Centre to successfully access funded temporary in-home and residential respite while the carer sourced suitable accommodation and moved home for a second time in six months. The Key Worker facilitated a transition into the respite facility, which resulted in the first successful residential respite stay for the YOD client. The Key Worker continues to support the YOD client and the carer to access affordable, meaningful, long-term community based in-home respite.

Age appropriate care services

Most people with dementia reside in mainstream aged care facilities. However, some providers (eg Hammond, Brightwater, Youngcare) have developed age appropriate models of support for people with younger onset dementia. These specialised services often have long waiting lists and therefore are not available when needed for many people with younger onset dementia.

Further work is needed to ensure timely access to age-appropriate residential care for people with younger onset dementia who require it. There is a need for clear guidelines about best practice and an appropriate funding model to ensure that age-specific services have the resources to provide the additional support and services required.

Initiatives addressing homelessness and dementia

A recent review of the literature on dementia and homelessness notes the importance of seamless service delivery through effective co-ordination between aged care, health, and housing. The review concludes that "Ultimately, the best model for care of older homeless people is a one stop service that provides prevention, outreach, assessment and evaluation, all types of housing including crisis, transitional, community and residential, and support services such as mental health, addiction, etc; assistance with all aspects of daily living and continuity of care"[21].

A number of current initiatives addressing homelessness and dementia are described below but further work is needed to create a seamless coordinated approach.

[21] Chenco C (2015). *Homelessness and Dementia in Australia: A Literature Review*, conducted on behalf of the Victoria and Tasmania Dementia Training Study Centre. http://dtsc.com.au/download/dementia-and-homelessness-report/

Service Access Liaison

Commencing late 2010, Alzheimer's Australia Service Access Liaison Officer (SALO) roles, funded by the Australian Government through the Service Development Pathways Project, aim to improve access to dementia services for specific needs groups and to improve Alzheimer's Australia's capacity to further develop diverse, flexible and responsive services (Stevens et al, 2011). As part of this project, a number of initiatives were undertaken to address dementia and homelessness including:

- Alzheimer's Australia Queensland established partnerships and linkages with homelessness organisations. The Project includes capacity building through training and provision of resources and supporting the homeless sector to have a greater understanding of dementia and where and how to refer clients when there is a concern about cognitive functioning.
- Alzheimer's Australia NSW developed train-the-trainer approaches and resources that build capacity of service providers to deliver quality service responses to consumers with special needs who have dementia or are at risk of developing dementia.
- Alzheimer's Australia SA has been working to address access and equity issues of homeless people in relation to the provision of quality dementia care, support and services.

These initiatives built on existing services and led to cost-effective capacity building and support. It is essential that Government continue to fund specialised dementia services to reach special needs groups.

Assistance with Care and Housing for the Aged

Government has responded to the growing aged care needs of older Australians experiencing homelessness through the Assistance with Care and Housing for the Aged (ACHA) program, a Government program that aims to provide housing and support for incapacitated, low income older people who are living in insecure housing, at risk of homelessness, or already homeless. ACHA provides service coordination to assist with both housing and with linking a person to community based supports.

Aged Care Services

Wintringham Specialist Aged Care services in Victoria provides a non-conventional model of service to older homeless people based upon social principles of justice. Their innovative approach is towards dignified and respectful support that includes working with frail aged and dementia. Wintringham staff have in-house training, including face-to-face training with an internal behaviour management consultant as well as access to online delivery of behaviour management training[22].

[22] National Ageing Research institute Ltd (NARI)(2015). Dementia and Homelessness. Report to the Victoria and Tasmania Dementia Training Study Centre. http://dtsc.com.au/download/dementia-and-homelessness-report/

AnglicareSA Ian George Court, Adelaide, is an example of an ageing-in-place facility providing 40 beds to support disadvantaged frail aged care for those who are homeless or at risk of homelessness. Ian George Court staff have extensive knowledge in the connection between homelessness and dementia, particularly in people who are, or have been, long-term users of alcohol and who are presenting with an associated cognitive deficit.

As noted earlier however, people with younger onset dementia may lack access to programs and services delivered through the aged care sector. This means that specialised and integrated housing and supports need to be provided to this group through other channels, and the NDIS is likely to be the avenue for this.

Proposed future directions

The majority of people with dementia choose to live in the community for as long as possible, rather than entering residential care early; and the provision of affordable, appropriate, and secure housing for people with younger onset dementia, integrated with support service to enable them to live successfully at home for as long as possible, is vital.

As noted in evidence provided to the Committee Roundtable by the Australian Housing and Urban Research Institute (AHURI)[23], many people with disabilities are unable to access secure housing in the private market for a range of reasons, including but not limited to affordability. AHURI notes that social housing provides tenancies that are more secure and affordable. AHURI further notes that while supply-side approaches, such as providing housing subsidies for NDIS participants, may seem attractive and aligned to the individualised approach of the NDIS, in the absence of adequate supply, such subsidies may simply lead to higher housing costs rather than benefiting consumers. AHURI argues that due to issues of scale and timeframes, a demand-side approach to ensuring access to housing for people with disabilities may not be effective. AHURI argues in favour of supply-side approaches:

> "A well designed supply-side subsidy could facilitate new supply of housing designed to meet NDIS participants' needs and preferences. Supply needs to be dispersed and noncongregated. It needs to be adaptable or accessible. It needs to be located and designed to maximise health, employment, social inclusion and living affordability outcomes, and a proportion of housing needs to be designed to enable sharing."[24]

Alzheimer's Australia supports the contention that well-designed supply-side approaches are more likely to be effective in meeting the housing needs and preferences of NDIS clients, including people with younger onset dementia. To meet the growing need, government will need to take the lead role in funding and co-ordinating the provision of appropriate social housing for people with disabilities, including those with younger onset dementia. As outlined by participants at the Committee Roundtable, there is also a role for charitable organisations,

[23] Report of Joint Standing Committee on NDIS October 2015 Roundtable: http://www.aph.gov.au/joint_ndis_accommodation
[24] Report of Joint Standing Committee on NDIS October 2015 Roundtable: http://www.aph.gov.au/joint_ndis_accommodation

philanthropic funds, superannuation funds, and corporates to participate in funding and delivering social housing for people with disabilities, including through social impact bonds. However, this should be seen as additional to, rather than as a substitute for, government leadership and funding.

CONCLUSION

Dementia is one of the major chronic diseases of this century. With the continued ageing of the population and the growing numbers of people with dementia, including people with younger onset dementia, there is a need to ensure access to appropriate and affordable housing and support options.

There are over 25,000 people in Australia with younger onset dementia, and the number is growing. Accessing appropriate support services can be difficult for this group as they often fall between the cracks of the aged care and disability sector. In many cases, people with younger onset dementia end up being placed in residential aged care services, as there are no other appropriate services and supports. In addition, people with younger onset dementia, particularly those without an informal carer, are at a higher risk of homelessness.

The YODKW Program has provided essential services in supporting people with younger onset dementia including in regards to issues around housing. In many cases, the services provided by the key worker program assisted in finding alternatives to placement in residential aged care or prevented homelessness. It is essential that the NDIS consider how to provide support, linkages and advice to people with younger onset dementia as the funding for the key worker program transitions into NDIS.

We trust that the matters raised in this submission will be of assistance to the Joint Standing Committee on the NDIS, in the development of strategies to ensure the future availability of appropriate and affordable accommodation for people with a disability, including people with dementia.

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.[25]

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 care[26]. 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.

[25] Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013:* Cat no. 3303.0
[26] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*