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YOUNGER ONSET DEMENTIA

STILL SLIPPING THROUGH THE CRACKS

**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
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ACKNOWLEDGMENTS

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Alzheimer's Australia NSW respectfully acknowledge the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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CONTENTS

Acknowledgments	2
Abbreviations	4
Executive summary	5
Context	8
Younger Onset Dementia	10
Disability	12
Relationships	14
Accessing services and supports	16
The NDIS	19
Information, linkages and capacity building	21
Accommodation	23
Conclusion	24
References	25

ABBREVIATIONS

AANSW	Alzheimer's Australia NSW
ACAT	Aged Care Assessment Team
ADHC	Ageing, Disability and Home Care NSW
CCSP	Community Care Supports Program
CSP	Community Support Program
CHSP	Commonwealth Home Support Program
CRCC	Commonwealth Respite and CareLink Centres
GP	General Practitioner
HACC	Home and Community Care
ILC	Information, Linkages and Capacity Building
MAC	My Aged Care
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDSP	National Dementia Services Program
NSW	New South Wales
SDA	Specialist Disability Accommodation
YODKWP	Younger Onset Dementia Key Worker Program
YODKW	Younger Onset Dementia Key Worker/s
YPIRAC	Young People in Residential Aged Care

EXECUTIVE SUMMARY

Living with dementia is a traumatic reality for hundreds of thousands of Australians. For Australians under 65 years of age who are living with younger onset dementia, this experience is especially challenging. Being diagnosed in their 40s, 50s or early 60s in the midst of career and family life can be devastating to the person and their families and carers. That is why it is essential that there are services available to them that are of high quality, easily accessible, and responsive to their particular needs.

For many years people with younger onset dementia have fallen through the cracks of the disability and aged care systems, with both sectors seeing the other as better placed to respond. In 2012 Alzheimer's Australia NSW identified this in a report titled *Service and Support Requirements of People with Younger Onset Dementia and their Families*. In 2016, many of these issues continue to exist leaving the 25,000 Australians with younger onset dementia in a grey area of policy and service responsibility. Recent policy reforms in Australia that commenced in 2011 have confirmed a division of disability and aged care eligibility at 65 years of age. Whilst this has provided some clarity, it appears, for many consumers, to be an arbitrary distinction that creates a significant issue for people with younger onset dementia in attaining the supports they need.

Irrespective of the age when someone has dementia, it is a progressive neurological disability that reduces a person's capacity and functional ability to do things they could do previously. It is therefore more appropriate to think in terms of 'stages' than 'age' as the characteristic that influences the needs for services and support. This paper examines these issues in the context of the policy reforms underway and presents a number of case studies and experiences of consumers and professionals working in this area.

The Australian and State Governments have agreed to transform aged care and disability services with a focus on placing the care recipient/participant at the centre of the service system in order to provide individuals with greater choice and control as well as structuring the service to support prevention and early intervention strategies across the life course.

Although the drive towards individualisation and focus on the care recipient/participant has resulted in increased choice and control for people with dementia, it presents a number of concerns for Alzheimer's Australia NSW (AANSW). These include losing the current 'whole family' focus by reducing the involvement of carers in the planning and support process of the National Disability Insurance Agency (NDIA), the lack of clarity surrounding supports available to carers in the future, gaps in service provision for specialist minority disability types like younger onset dementia and the restriction or loss of broader-based community programs accessible to people with younger onset dementia.

With the commencement of the National Disability Insurance Scheme (NDIS) in NSW and a number of State Government programs being aligned to the NDIS policy framework, there are benefits for people with younger onset dementia to be covered under the NDIS. The Scheme aims to empower the scheme participant which is a laudable principle; however it is important to be fair in presenting the positive sides of the reforms for people with younger onset dementia. Our research for this paper confirmed that there have been many positive outcomes of the changes for people with younger onset dementia. The experiences of the NDIS pilot sites and Ageing, Disability, and Home Care (ADHC) individualised funding programs has been invariably positive and initial evidence suggests that the clients/participants are being empowered through greater direction, choice and control.

The purpose of this paper is therefore to build on these successes by highlighting issues with the policy design and implementation that can be improved based on the experiences of people with younger onset dementia and service professionals documented in this paper. Specific concerns include: low levels of understanding that the NDIS is for people with younger onset dementia; the reassessment period of 12 months may not be frequent enough; a reassessment after the age of 65 may trigger an inappropriate or unwanted move to residential aged care; the persistent lack of access to appropriate long-term accommodation and care options; and knowledge and understanding

EXECUTIVE SUMMARY CONTD.

of dementia by National Disability Insurance Agency (NDIA) staff, particularly support planners. The Younger Onset Dementia Key Worker Program (YODKWP) has been instrumental in responding to these issues and we hope the functions of the program will blend seamlessly into the NDIS in the future, however other responses are also needed.

It is also prudent to consider and reflect on the good things that happened in the past that may be lost in the reform process. For nearly two decades the former Home and Community Care (HACC) Program and Commonwealth Respite and CareLink Centres (CRCC) accommodated some needs of people living with younger onset dementia as they were designed to sustain the independence of people with a disability, the frail aged and their carers. In addition, the National Dementia Services Program (NDSP) has played a critical role for people with younger onset dementia by not presenting age restrictions to access its services. These three programs are particularly worth reflecting on as they responded to the needs of the person with dementia as well as their carer, reflecting the mutually interdependent nature of their relationships and support needs. It is essential that in future reforms these types of services are maintained.

Reports from the NDIS suggest that people with younger onset dementia who have accessed the NDIS are at a fairly advanced stage with significant functional loss, while those in the early stages of dementia have been directed towards some early intervention supports offered under the NDIS.

AANSW's main concerns for people with younger onset dementia arise from uncertainty over what resources and programs will be available for people 'pre-NDIS eligibility' and also whether the ongoing issue of lack of access to age and disability-type accommodation will be resolved in the future. Greater investment by State and Local Governments in creating dementia-friendly communities should help sustain participation and engagement in the pre-NDIS stage. Coupled with support from enhanced care coordination through the recently announced Healthier Medicare initiative for people with chronic conditions, people with younger onset dementia should remain supported

to live in the community. The use of residential aged care by people under the age of 65 has been problematic. Hopefully other more appropriate options will become available through the Specialist Disability Accommodation of the NDIS.

Recommendations

Australian Government

1. Continue the functions of the Younger Onset Dementia Key Worker Program through the National Disability Advocacy Program, Information Linkages and Capacity Building (ILC) and NDIS.
2. Alter the assessment and re-assessment processes implemented under the NDIS to be more responsive to people with a progressive neurological disability.
3. Increase and improve communication between the NDIA and users of the system to provide greater clarity regarding the continuity of services for people aged over 65.
4. Ensure that information about the NDIS is easily accessible, consistent across all states and territories, and communicated frequently to stakeholders.
5. Provide investment from the Specialist Disability Accommodation (SDA) funding to pilot dedicated residential options for people with younger onset dementia.
6. Prioritise people with younger onset dementia for the Health Care Homes packages to support them in having a care plan co-managed with their general practitioner (GP) that manages the progression of dementia.

NSW Government

1. Commit to making NSW a dementia-friendly State with subsequent funding to ensure this can happen.
2. Evaluate the experiences of people with younger onset dementia accessing disability supports in NSW and advocate for improvements to the NDIS in accordance with findings.



CONTEXT

Australia is undergoing radical transformations of both its disability and aged care services that are being reshaped around themes of empowerment, control, choice and individualisation for people receiving Government support. The processes commenced with two publications by the Productivity Commission released in 2011; *Disability Care and Support*¹ and *Caring for Older Australians*². Since they were published, the Australian and State Governments have adopted most of the recommendations of these two reports and set the sectors on two different pathways of reform.

For the purpose of this paper, the most critical policy decision was the decision to split the disability and aged care systems at the age of 65. In order to access support from the aged care sector, individuals need to be 65 years of age or older, while disability services are restricted to those aged under 65. Due to the often rapidly progressive nature of younger onset dementia, an individual under 65 years of age may sometimes find that services offered through the aged care sector are more appropriate in meeting their needs, but will have problems accessing these services as they are deemed 'ineligible' based on their age. Conversely, the disability services sector has had limited experience in supporting people with younger onset dementia in instances where it is a primary diagnosis, but has the capacity to offer services for them.

Both sector reforms are focused on the importance of placing the care recipient/participant at the centre of the service system in order to provide individuals with greater choice and control as well as structuring the service to support prevention and early intervention strategies across the life course. The NDIS endeavours to empower people with disabilities to increase community participation. Both reforms are being implemented to adhere to community desires to live independently and/or remain living in the family home rather than the traditional emphasis on congregate care settings of group homes and residential facility settings.

The aged care sector reforms recognise that most people would prefer to remain living in their own homes with appropriate support rather than move to a residential aged care facility.

As a result, additional emphasis has been placed on providing home care that will assist people in living at home for as long as possible through a consumer directed care model. These reforms are similar to the changes we are witnessing in the disability sector through the NDIS in the sense that they aspire to assist people to live independently and have greater choice and control in directing services. The two reforms are diverging in the pathway, however, both will eventually arrive at a point where funding is allocated to individuals who meet eligibility and assessment criteria. Their funding will then support them to achieve their plan goals.

Younger Onset Dementia Key Workers (YODKWs) have identified that the means tested nature of the aged care system is not ideal for this group as it can often result in exorbitant costs to the family. YODKWs report that the refundable accommodation deposit (RAD) needing to be paid by an individual with younger onset dementia in residential aged care would come at such a high cost that without any other option, they and their families would struggle. Consultations with YODKWs revealed that in some instances, couples are faced with no other option but to legally separate in order to maintain the financial stability of the family while still trying to provide the person with younger onset dementia with the best possible care and quality of life.

The 2011 Productivity Commission inquiry report proposed that when people who are covered under the NDIS reach the pension age they are able to elect whether they wish to stay under the NDIS or move to the aged care system. The policy on this is unclear to many in the sector, and even if it were to be enacted, it is uncertain whether people would be better off moving from the NDIS to the aged care system. Particularly if they have had many years of support that they are happy with.

Within NSW, successive Governments have dramatically increased the investment in disability services over the last decade, have committed to an early entry into the full scheme of the NDIS by 2018, and also shown increased interest in responding to the needs of people with neurological disability under the age of 65. Disability services have traditionally focused on intellectual and physical disability in NSW, with little policy focus on other disability types. AANSW was encouraged by the interest in responding to the needs of people with younger onset dementia, however, the commitment to a dedicated program was not followed through on by the NSW Government.

As NSW begins its transfer of the State to the NDIS arrangements, AANSW remains concerned about the recognition and focus on younger onset dementia within this reform period. There are lessons to be learnt from pilot sites and programs that suggest improvements are needed to the NDIS for people with neurological disability.

In addition, there are growing concerns about the need for the State Government to retain some resources in the area of making NSW a dementia-friendly State which supports the ongoing participation and engagement of people with younger onset dementia in particular. This includes: social, civic, economic, cultural and spiritual participation at what would be pre-service access, but contribute enormously to delaying progression of dementia and valuing the inherent human rights of people with dementia.

Case Study

Sam and Alex have been living together as a couple for 25 years. Alex is Sam's primary carer and works full time to provide the couple with their only income as Sam has not worked since being diagnosed with dementia 8 years ago. Over the last 8 years, Alex has experienced depression and carer burnout. After exhausting all other options, Sam now requires full time care, but Alex can no longer meet Sam's care needs while working full time and financially supporting the couple. Sam is not eligible for the Disability Support Pension or access to a concessional permanent residential care place due to Alex's income. Alex cannot afford to pay for the bond and care costs on top of their current living expenses. As a result, Alex and Sam, were provided with the option to utilise Centrelink's 'Separation due to illness provisions'. Once they were separated, Sam was means tested without Alex's income and was then eligible for the Disability Support Pension as well as access to a concessional permanent residential care place. This allowed for the cost of Sam's residential aged care to be covered while allowing Alex to continue to work and avoid early retirement.

YOUNGER ONSET DEMENTIA

Approximately 25,100 people in Australia are living with younger onset dementia (that is, a diagnosis of dementia under the age of 65), with some as young as 30³. As a result of the life stage at onset, the needs of this population vary to the needs of those diagnosed with dementia after the age of 65. Partly due to the recent sector and policy reforms, the needs of people with dementia, younger onset in particular, are poorly met with many people falling through the cracks as a result of not fitting neatly into the aged care system or the disability sector.

Dementia is the single greatest cause of disability in older Australians (those aged 65 and over)⁴ and the third leading cause of disability overall, however it is commonly perceived to be an age related illness by those working in the aged care and disability sectors⁵. Dementia is not a normal part of ageing. Currently, dementia is still not well understood or considered as a neurological disability within the disability sector, particularly in cases where it is a primary diagnosis. However, dementia is classified as such by the International Classification of Disability and therefore people under the age of 65 are eligible for disability services across Australia based on disability type requirements⁶.

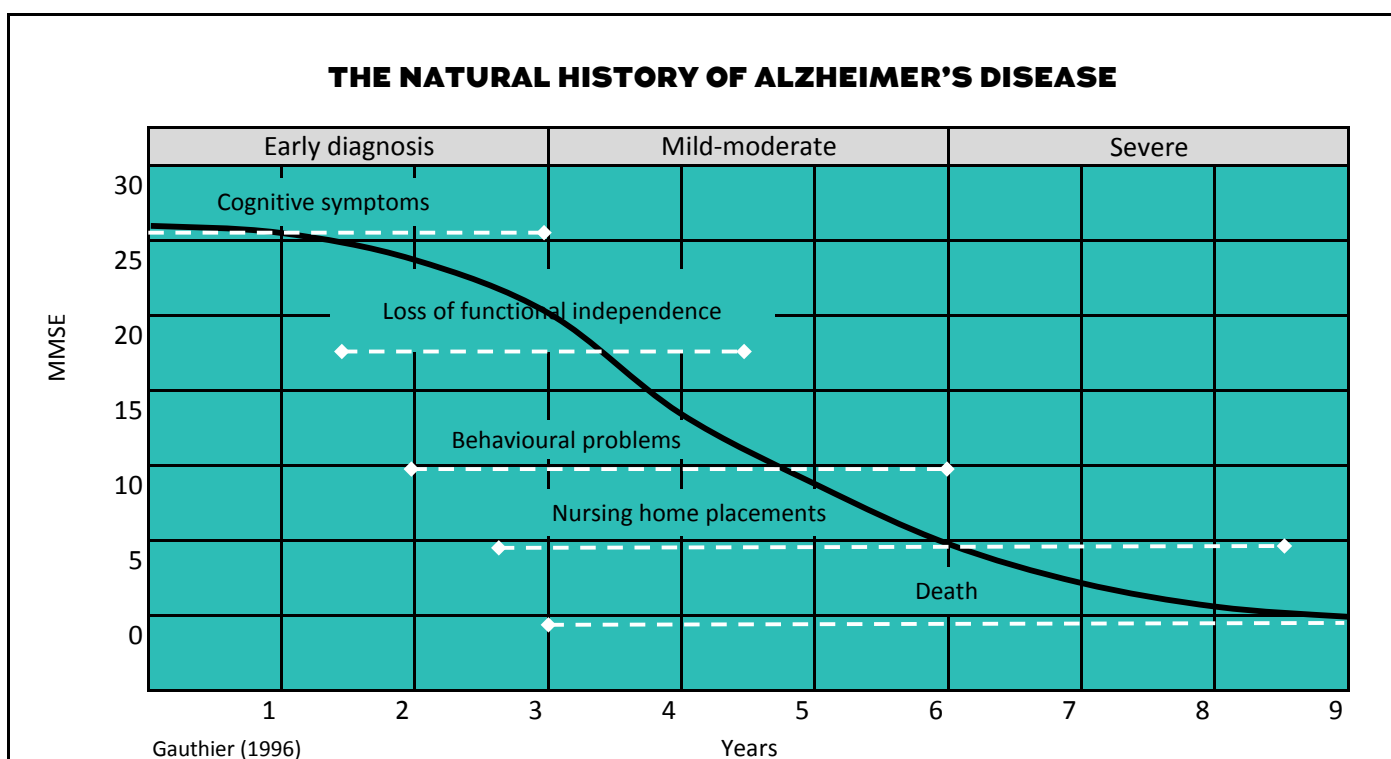
People with younger onset dementia as a primary diagnosis have expressed a need for early intervention support services such as community participation and engagement, family and relationship support, respite support, as well as financial, legal, and employment support⁷. While these services are essential, it is not uncommon for people with younger onset dementia to experience extensive issues in accessing the supports available to them through both the aged care and disability sectors.

Providing adequate community based supports to people with younger onset dementia still living in the family home ensures that they will be given the opportunity to participate in the community and exercise choice and control. There are varying estimates as to the likelihood of admission into

residential aged care for a person with dementia. Approximately 60-90% of people with dementia will enter a residential aged care facility when they reach a point where they require 24/7 support⁸. Figure 1 below demonstrates the natural history of Alzheimer's disease as an example including all cases and not just younger onset dementia.

The graphic representation on the right, shows the functional decline as a result of Alzheimer's disease, clearly indicating the increasing need for access to appropriate long term care options as the dementia progresses. It is highly likely that people with younger onset dementia may need permanent care at some point in their life.

Figure 1 The Natural History of Alzheimer's Disease



YOUNGER ONSET DEMENTIA: DISABILITY

The risk of younger onset dementia is much higher in younger people with lifelong disabilities such as Down Syndrome. The prevalence of dementia for people with Down syndrome increases from under 10% in people aged in their 40s to more than 30% for those in their 50s¹⁰. Given the life expectancy of people with intellectual disability has significantly increased over the past 50 years and will continue to do so, there is a growing need for improvements to be made in the space of dementia knowledge and understanding within the disability sector¹¹.

In the current system, there is potential for ageing people with intellectual disabilities to experience some disadvantages with the current system due to the lack of clarity surrounding access to disability and aged care services as they age and accessing treatment for underlying health issues¹². A timely diagnosis of dementia can greatly influence the prognosis. People with intellectual disabilities often do not receive a timely diagnosis of dementia, often as a result of support staff and family attributing behavioural changes to the underlying disability¹³. In response to this, The Department of Developmental Disability Neuropsychiatry (3DN) at the University of New South Wales has developed an e-learning site which aims to improve the knowledge, skills, and confidence of professionals working in the area to ensure better mental health and overall wellbeing for people with an intellectual disability¹⁴.

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States was created to respond to the growing emergence of people with intellectual disabilities living longer and having an increased risk of developing dementia¹⁵. The goals of the taskforce were to identify a screening instrument that would help substantiate suspicions of dementia-related decline in people living with intellectual disabilities and in turn formulate best practice guidelines for health care and social supports¹⁶. The Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia is an example of an effective response to this public policy challenge¹⁷. The taskforce

draws upon and endorses the original Edinburgh Principles¹⁸ which emphasize that all activities should:

- Promote quality of life
- Use person-centred approaches
- Affirm individual strengths capabilities, skills, and wishes
- Involve the individual, their family and other close supportive persons
- Access and make available appropriate diagnostic assessment and service resources
- Plan and provide services that effectively support the individual to remain in their chosen home and community
- Provide access to services and supports that are available to other people in the general population affected by dementia
- Undertake proactive strategic planning across policy, provider, and advocacy groups

These principles are consistent with the 'Eight Common Principles for Supporting People with Dementia' as noted by the World Health Organisation and should apply to all people with dementia, including those with younger onset dementia and dementia as co-morbidity¹⁹. There is hope that with the roll out of the NDIS and its inclusion of people with intellectual disability and younger onset dementia, as well as those with younger onset dementia as a primary diagnosis, easily accessible and appropriate support options will become increasingly available and easily accessible.

Reassurance is still needed by people with younger onset dementia as well as their families and carers as to whether they can expect NDIS supports until the age of 65. The NDIA has made it clear that if you are aged 65 years and over, you are not eligible to access the NDIS. However, if you are aged 65 and over and you currently receive disability supports, you will not be disadvantaged as you will continue to receive supports that achieve similar outcomes to those you are currently receiving²⁰. The nature of those supports has not been made clear.

Although the NDIA has stated its intentions, users of the current system have identified that this has not been well communicated to them.

As a person's dementia progresses, there may be a need for reorientation in services. An accommodation model for people with intellectual disability should be flexible in order to meet the changing needs of people should they develop dementia and should not require them to move great distances to access suitable supports and services. Government policy should support an ageing in place model which incorporates flexible long term service provision that recognises the importance of planning ahead²¹.



Photo: from the video *Living with intellectual disability and dementia*; Alzheimer's Australia NSW and Why Documentaries, Nov 2015

YOUNGER ONSET DEMENTIA: RELATIONSHIPS

The effects of younger onset dementia extend further than the health of the person living with the disability. Unplanned changes can include income reduction, reduced employment, lowered self-esteem and sense of purpose, with previous life plans no longer viable²². In addition to this, a diagnosis of younger onset dementia can often mean family carers are faced with the dual responsibility of caring for the person with dementia as well as continuing to raise children and manage finances amongst all other things²³.

Carers have reported a constant need for family and relationship supports in order to help manage the stress of caring for a person with younger onset dementia²⁴. Consultations with a number of carers in the Hunter Region Trial Site have reported that there has been confusion about the purpose of the NDIS, how to access it, and how the changes to disability supports will affect access to the supports that both the carer and the person they care for currently receive²⁵. While the main objective of the NDIS is to support people with disability, it is important to understand that carers play a large and important role in not only providing informal supports, but also in helping individuals access the NDIS and other appropriate supports. AANSW supports Carers Australia NSW in its call for the NDIS to improve the availability, consistency, timeliness, and accessibility of information provided to people with disability and their carers in NSW regarding the NDIS²⁶. Alzheimer's Australia NSW also supports Carers Australia NSW in its recommendations to provide NDIS planners with training in carer recognition and support.

There are also concerns from family members and carers about children still living at home with a parent with a diagnosis of younger onset dementia²⁷. It is not uncommon for family carers to feel that they are parenting both their children and their spouse, with children being confronted with the behavioural symptoms sometimes associated with variants of younger onset dementia²⁸. Alzheimer's Australia NSW backs Carers Australia NSW in their call to provide young families with access to support services such as respite and psycho-social-

educational interventions to assist them in coping with the changes²⁹.

Further research reveals that a diagnosis of younger onset dementia has a significant impact on spouses. This is often characterised by concerns of dependency, fear, and increased depression³⁰. Occurrences such as marriage breakdown and increased financial and emotional stress are common in cases of younger onset dementia³¹.

Friendships can also often become strained as people struggle to accept that their younger, otherwise healthy, friend has been diagnosed with dementia. This places the person living with younger onset dementia at risk of becoming increasingly isolated from social supports, extended family and friends, as well as the wider community³². This further highlights the importance for changes in policy that will support carers and young families in order for them to better support the person living with younger onset dementia³³.

In order to address this issue, the government announced the development of an Integrated Plan for Carer Support Services as part of the 2015-16 federal budget with the plan outlining practical means by which the work of unpaid carers can be recognised, supported, and sustained. Accordingly, the Australian government has committed \$33.7 million to deliver a national carer gateway intended to provide a central point for carers of people with disabilities to refer to for information, support, and referral to other services³⁴. AANSW believes that Integrated Plans for carers of people with younger onset dementia need to address the individual circumstances and needs of the carer. Services that are highly valued by carers include: respite, support groups, psychosocial education and counselling. Evidence also shows that these services are cost effective³⁵.



YOUNGER ONSET DEMENTIA: ACCESSING SERVICES AND SUPPORTS

With the roll out of the NDIS, the federal Government will be financially responsible for the delivery of disability and aged care support services. As of present, services that assist people with younger onset dementia to live high quality lives within the community are primarily funded by the Commonwealth Home Support Program (CHSP) and the National Dementia Support Program.

People living with younger onset dementia are eligible to access the State Government disability funded services such as Life Choices, Active Ageing, Community Care Supports Program (CCSP) and the Community Support Program (CSP)³⁶. While these services aim to empower and address the social support needs of younger people with disability, accessing these services as a person with a primary diagnosis of younger onset dementia is not as streamlined as it could be. Upon consultations with Younger Onset Dementia Key Workers, AANSW found that clients experienced extensive wait times (between 8 to 12 weeks), often not receiving supports before reaching a point of crisis.

Accessing the Community Support Program (CSP) as a person with younger onset dementia has been described by Key Workers as 'a bit of a juggling act' in timing the application. The CSP enables people with high support needs due to physical and/or neurological disability to live as independently as possible³⁷. Although the program is suited to people with dementia, the length of the application process makes it questionable whether a person with younger onset dementia will receive the package in time to improve their quality of life at home before their health rapidly deteriorates.

Case Study: Getting a CSP

A client of the YODKWP with mid-stage dementia was encouraged by a key worker to apply for a CSP. The key worker completed the application and submitted it. It took 8-12 weeks for the client to hear the outcome of his application. Unfortunately, the client's dementia progressed rather quickly in that period and he passed away shortly after receiving the approval. He did not have an opportunity to access these services that might have otherwise helped slow down the progression of his dementia and tremendously improve his quality of life.

There are a number of services available to people with dementia that are funded under CHSP. A major role of the Key Worker has been to build capacity across the community services sector in order to improve the suitability of these services for people with younger onset dementia. Prior to the most recent sector reforms, there had been improvements in the provision of services for people living with younger onset dementia delivered by the aged care sector. However, the policy reforms have introduced a tighter funding delineation for aged care services, often excluding people under 65 from accessing these services. Sadly, the policy reforms have seen innovative service providers stop providing younger onset specific services as they have made strategic decisions to specialise in services for over 65s - 'best practice is not always best business'.

As a result, Key Workers have experienced difficulties in finding service providers that still provide services for those aged under 65. People with younger onset dementia and their carers find it overwhelming and discouraging when contacting providers who no longer offer services for younger clients. A number of Key Worker reports also suggest that clients are often lead down the wrong pathway or are not offered an alternative service provider as a result of market competition. Clients

and their carers emphasised that in order to persist in their efforts to obtain supports, they require correct information, such as updated provider lists, and appropriate supports, such as a Key Worker.

The National Dementia Support Program (NDSP) is delivered by Alzheimer's Australia to provide and promote education programs, services, and resources that aim to improve awareness and understanding about dementia while increasing the skills and confidence of people living with dementia, their carers, families, health professionals, volunteers, and community contacts. As a part of this, Alzheimer's Australia provides a range of early intervention supports, education, counselling and support services, and the National Dementia Helpline and Referral Service.

All services offered under the NDSP are accessible by all people living with dementia and are free from both age restrictions and cost barriers; embracing the notion that dementia is stage dependent rather than age dependent. Alzheimer's Australia NSW anticipates that NDSP services will become increasingly important and valuable to people with younger onset dementia in the future. This will be driven by access and eligibility changes being ushered in by the NDIS across Australia at different stages. The experience of NSW will be instructive in whether this prediction is fulfilled as the State is transitioning earlier than others.

ACAT Assessments

Prior to 4 February 2016, people with younger onset dementia were able to contact an ACAT direct if they required an assessment. Now, all individuals requiring an ACAT assessment/referral must apply through the My Aged Care (MAC) gateway. While MAC is useful in making all types of Aged Care services available from one access point, it poses an issue for people with younger onset dementia as it is only accessible by people aged 65 and over. Considering most people with younger onset dementia may require aged care services prior to 65, the gateway is not appropriate for them. While

some of the services accessed through MAC still provide services to those aged under 65, no referral pathway is provided to them.

The ACAT policy, process, and procedures for people with Younger Onset Dementia are often inconsistently interpreted and applied, and as a result, people are prevented from accessing some services that require the assessment to determine eligibility.

Case Study: Accessing long-term accommodation

Mary was diagnosed with younger onset dementia at the age of 54. At 59, Mary's dementia had progressed to the point where her family could no longer provide care for her at home. She required long term residential care, but her only option is residential aged care as there are no long term accommodation options available for people with younger onset dementia. Long term care is not available to her under the support arrangements she currently has with ADHC.

In order to gain access to residential aged care, Mary requires an ACAT assessment which is now only available through the My Aged Care website. Because Mary is under 65, she has been denied an ACAT assessment until she can provide evidence that there are no other services that can meet her needs from the disability sector.

"It's very frustrating because I don't really understand how it all works. I just know that my family can't do this anymore, it's not fair on them."
YODKWP Client

Mary had waited three months for correspondence between the two sectors until she was eventually placed in a residential aged care home.

Lack of understanding of younger onset dementia by My Aged Care staff has been identified as another contributing factor to the inaccessibility of its services by people with younger onset dementia.

There is a need for MAC staff to possess a better understanding of younger onset dementia because they are decision makers over whether or not an ACAT assessment can be done. With the current Guidelines, people with younger onset dementia are eligible through an exhaustion of other options, but rigid adherence to the 65 demarcation on the MAC phone lines sees them never pass this hurdle. As the condition progresses, there is a need for dementia specific services in addition to disability services with the capacity to meet personal, emotional, physical, clinical and end of life care needs.

Case Study: Accessing an ACAT assessment under 65 and through the NDIS

Younger onset dementia key workers reported a difficulty in accessing ACAT assessments through the MAC website for clients under 65 requiring aged care services. A number of factors, including poor understanding of younger onset dementia, prevented key workers from attaining an assessment.

“They just don’t get it. They hear dementia and they’re willing to help you, but when you tell them the age of your mum, they suddenly can’t do anything anymore.” Family Carer

Younger onset dementia key workers based in NSW NDIS trial sites reported that there is a lack of younger onset dementia knowledge by NDIS planners, which has contributed to poor assessment outcomes. Failure to understand the rapidity at which younger onset progresses and the effect that has on functionality has resulted in the allocation of minimal supports from the NDIS, with some clients being directed to early intervention supports.

“Yes, my client is physically capable of showering by herself and yes she can feed herself, but it’s a matter of whether she’ll remember to shower often enough or whether she’ll remember to eat.” - YODKW

The failure to understand the need for a reassessment earlier than the allocated 12 month reassessment period has also resulted in allocated services and supports not meeting the client’s needs.

“My client is rapidly deteriorating. A week ago he could still dress himself, today he doesn’t even know what a shirt is. He needs additional support but can’t access that under his current package. I’ve contacted the NDIA to arrange another planning meeting but they say he isn’t eligible because he was only given one [a package] 3 months ago. They don’t understand how quickly this progresses.” YODW

THE NDIS

There is some uncertainty around the ability of the NDIA to provide for all people with severe disabilities. Figures from 2009 show that 1 in 5 people (approximately 4 million Australians & 18.5% of the total population) were identified as having a disability. Of the 4 million, 3.5 million people (87%) had a disability that inhibited their mobility, ability to communicate and perform self-care activities, or participate in education or employment. Of these 3.5 million people, 1.3 million had a severe or profound disability. While considering these statistics, the Productivity Commission has estimated that approximately 410,000 (12%) of these people would receive NDIS funding with 330,000 (81%) of these people with intellectual, physical, sensory, or psychiatric disabilities causing significantly reduced functioning and the remaining 80,000 (19%) people with early intervention support requirements³⁸. What happens to the 900,000 with severe or profound disabilities that the Productivity Commission believed would not access the scheme? In addition, what supports will be available for the 3.1 million that the Productivity Commission also chose to assume would not be part of their calculations?

A recurring issue faced by people living with Younger onset dementia and their families is the lack of clarity as to how necessary services can be accessed - particularly for those who are facing the full rollout of the NDIS in the near future. It is expected that individuals currently in receipt of ADHC services will be amongst the first to transition into the NDIS, with all others following. It remains unclear what supports will be available for people currently accessing ADHC services, for people living in areas of NDIS roll out who are later deemed ineligible for an individualised package.

In cases where individuals are assessed and deemed ineligible for an NDIS package, cost may act as a barrier to accessing necessary supports. It is sometimes the case that the cost of community activities sometimes precludes people from participating³⁹. Cost may also pose as a barrier to

accessing some mainstream services through ILC without subsidisation.

Case Study: Getting an NDIS package in the trial site

A client of the YODKWP recently experienced the transition to the NDIS. Although the client was already a recipient of ADHC services, he was required to complete an NDIA Access Request form and complete an Evidence of Disability with supporting documentation from a general practitioner and specialist. Once approved, the client attended a planning meeting in which he identified which services he was currently receiving and what he would require in the near future with the progression of his disability. The key worker was helpful in highlighting points that the client had forgotten and improving the understanding of younger onset dementia of the planner. As a result, the NDIA planner was able to draw a plan that met the client's current as well as future needs.

"We were lucky to get a planner who was willing to listen to what my client needed and what he was likely to need in the next few months. She was able to look past his current functional ability and considered where he would be in 12 months-time when allocating him a plan." YODKW in NDIS trial site

"Two of my clients were directed to early intervention; it wasn't even close to enough support." YODKW in NDIS trial site

There is a need for understanding and flexibility in reassessing people with Younger onset dementia as the progression from early intervention level supports to higher care support needs can occur quite quickly. Experiences of those in NSW NDIS trial sites suggest that the NDIS is not responsive to the changing needs of people with younger onset dementia.

It is apparent, from the experiences to date that the NDIS is evolving as it rolls out, with a range of challenges and issues needing to be resolved if people with younger onset dementia are to receive the support they need through the NDIS. Although there have been improvements since the initial pilot, there are concerns that the overwhelming demand on the system once the scheme rolls out nationally may result in a reversion to what it was in the early stages. The timeliness of delivering these supports is essential to ensure that people with younger onset dementia are receiving the best possible supports in order to live a good life and maintain wellbeing.

Case Study: Getting an ACAT assessment while in receipt of an NDIS package

Younger onset dementia key workers in NSW NDIS trial sites report that they have experienced difficulties obtaining an ACAT assessment for clients who are in receipt of an NDIS package and in need of permanent care.

“My client’s needs had progressed too quickly. Her husband and kids couldn’t continue to support her at home for much longer. It took her having an episode to be admitted to hospital and given an ACAT assessment there. Nobody asked if she was on an NDIS package, so I’m not sure if that would have changed the way they handled her case.” YODKW, NDIS trial site.

There is still uncertainty as to how an ACAT assessment can be obtained under these circumstances prior to reaching a point of crisis.

Alzheimer’s Australia is seeing good outcomes for some clients in their NDIS plans, but also some major issues in the planning process and the current inability of the NDIS to fully accommodate the complex needs of younger onset dementia clients and carers. For example, an enablement approach is often encouraged in order to increase self-worth of the client and highlight their remaining capacity,

in cases where the dementia is fairly advanced highlighting the remaining capacity may have the opposite effect. The current NDIS planning process is heavily focused on what the individual with younger onset dementia cannot do, which runs counter to enablement principles currently used by the YODKWs. Providing education about dementia to support planners of the NDIA would improve the experience and the outcomes for people with younger onset dementia. There are different approaches to this education being applied in NSW (no training) and ACT (dementia training provided). Consistency across the country would ensure a level of equity and impartiality for the 25,000 people who could benefit.

The YODKWP delivers a national network of highly skilled system navigators that provide a helping hand to people with younger onset dementia, their carers, and their family. The YODKW role in assisting clients to successfully navigate the complex structures of disability, health, and aged care has been highlighted throughout the major Aged Care reforms. Alzheimer’s Australia is working with the NDIA in order to support clients in trial sites and implement strategies to support an eventual transition of the YODKWP into the NDIS.

People with younger onset dementia should see greater power and choice and the potential emergence of organisations offering younger onset dementia specific services as a result of the increased demand for them.

INFORMATION, LINKAGES, AND CAPACITY BUILDING

The lack of younger onset dementia specific support services and the inappropriateness of mainstream disability and aged care services often results in people not receiving the supports they need to sustain a high quality of life and live well with a diagnosis of dementia at a young age. Recent reforms in both the aged care and disability sectors have focused on making the shift to a more competitive, market based service system with a move away from block funded service delivery and a move towards individual user based funding. It is anticipated that as a result of increasing demand and the widespread roll out of the NDIS, a number of younger onset dementia specific supports would become available for people with the disability under the NDIS as well as the Information, Linkages, and Capacity Building (ILC) under the NDIS.

While there are limited services available that specifically cater to the needs of people with younger onset dementia, the Younger Onset Dementia Key Worker Program (YODKWP) is a Commonwealth Government funded program that provides essential supports to people with dementia and their families including functions around information, linkages, and capacity building. The program provides assistance and linkages to people requiring support in maintaining or securing appropriate care, support, and housing, via the provision of key workers with a thorough understanding of the progression of younger onset dementia. As this program transitions to the NDIS, it is essential that consideration be given to how the provision of this necessary specialist linkage service will be maintained.

Currently, the YODKWP is the only program in NSW provides individualised information and support aimed at improving the quality of life for people with younger onset dementia. The key worker acts as a primary point of contact for people with younger onset dementia, their families and carers. They provide information, support, counselling, advice and help consumers effectively engage

with services appropriate to their individual needs as well as building capacity in the service sector. This program's funding is transitioning from the Department of Social Services into the NDIS. With this transition looming, there has been speculation that the future of support services for people with younger onset dementia lies under the ILC umbrella of the NDIS. With the ILC due to roll out in 2019-20, the uncertainty regarding how the YODKWP will be funded remains.

Information, Linkages, and Capacity Building (ILC) is part of the NDIS. It is a set of activities that will benefit people with disability regardless of their eligibility for an individually funded package under the NDIS. The indicative budget for the ILC is expected to increase slowly over the next few years to approximately \$132 million, when the full roll out of the NDIS is complete in 2019-20, with funds being distributed through grants⁴⁰. The aims for the ILC are to provide information, referral and capacity building supports for people with disability, their families, and carers that are not directly tied to a person through an individually funded package while also partnering with local communities, mainstream and universal services to improve access and inclusion for people with disability.

The ILC Policy Framework has identified five activity streams through which funding will be allocated in order to increase the social and economic participation of people with disability. While the ILC appears to be an opportunity for people with younger onset dementia to access support services more easily, the activity streams reflect services that are effective in increasing the social and economic participation of people with disability but fails to account for people with younger onset dementia who are not able to maintain social and economic participation for very long due to the rapidly declining nature of the disability.

People with younger onset dementia need appropriate information after diagnosis and proactive follow up⁴¹. Support may be required immediately to

counsel and reassure the person with younger onset dementia and their family members that support services are available to assist them. The recently announced federal primary care initiative Healthier Medicare package is designed to provide clients with multiple chronic conditions with a healthcare package tailored to their needs with that care then being coordinated to allow easy navigation of the complex health system. The package is to be trialled through creating 'Health Care Homes' responsible for the ongoing coordination, management and support of a patient's care⁴². Alzheimer's Australia NSW hopes that people with Younger Onset Dementia will be prioritized for the Health Care Homes packages to support them have a care plan co-managed with their GP that helps delay the progression of dementia.

ACCOMMODATION

While efforts to improve dementia knowledge and understanding in the disability sector are on the rise, there are still concerns about how the accommodation needs of people with a primary diagnosis of younger onset dementia will be met in the future.

It is clear that the NDIS has limited funding to provide housing and care for people with younger onset dementia. While those with younger onset dementia as a secondary diagnosis have the option of disability funded housing, there is no purpose built accommodation for people with younger onset dementia as a primary diagnosis. Currently, residential aged care facilities do not cater to the needs and wants of people to whom personal care may be needed, but social support, engagement and activities are of higher importance. As a result of unmet needs, people with younger onset dementia who are placed in residential aged care facilities often exhibit aggression and other behaviours that staff and other residents along with their families find confronting, intimidating and disruptive. This is deleterious to the quality of life, safety, and wellbeing of the person with younger onset dementia and other residents.

Without addressing the supply side of the equation, residential aged care will continue to remain as the only 'choice' for people with younger onset dementia aged between 30 and 65 whose care needs exceed what can be supported at home.

Current Australian service models are ill equipped to accommodate the needs of people with a disability who are ageing. Australian disability and aged care service providers are currently providing services to two very distinct groups with almost no crossover. As a result, people (like those with YOD) are falling between disability services and generic aged care services as they may be considered above the age threshold and unsuitable by the disability sector and below the age threshold and unsuitable by aged care services that primarily focus on the needs of the frail aged.

Case Study: Dementia as a secondary diagnosis

A 49 year old female YODKWP client with Down's Syndrome and Alzheimer's Disease is currently living in a 'low care' group home owned by the NSW Department of Housing but provided by an NGO for people with 'low care disabilities'. The client lives with three other residents who she has lived with 25, 20, and 15 years respectively. Now that her dementia is progressing, the NGO is threatening to move her on the basis that she struggles to manage the stairs safely. An occupational therapist (OT) and cardiologist report supports the client's wish to stay in her current home and age in place, while the NGO still insists on moving her into a 'high care' facility where they believe she will be better off. The OT report suggests that the client's mobility issues are easily overcome with simple home modifications.

"She lives in a house where all of her housemates have the same issue with climbing the stairs, but they don't have dementia. I feel she's being discriminated against...it's not fair, she's lived there for 25 years of her life...this is her home, you can't just pick her up and move her when there are other options." YODKW

Alzheimer's Australia NSW fears that despite recent focus and attention on people with younger onset dementia, *NSW Ageing, Disability and Home Care* (ADHC) has failed to make any inroads in resolving the accommodation and support needs of people with younger onset dementia despite investment from policies such as *Stronger Together I and II*, and the *Young People in Residential Aged Care* (YPIRAC) program.

In early 2016, Alzheimer's Australia NSW conducted consultations with members of the NSW Younger Onset Dementia Service Provider Network, an interagency group with 100 members including aged care and disability providers, health, mental health, allied health and academics which is facilitated by Alzheimer's Australia NSW. Members of the network were asked questions about the appropriateness, desirability, and feasibility of four different accommodation models. Survey results

CONCLUSION

indicate that 88 per cent of respondents believe that residential aged care is inappropriate for people with younger onset dementia as it does not provide adequate social supports, is costly to young families not eligible for a concessional place, and does not provide an empowering environment. All respondents specified that a specialist supported accommodation model similar to disability group homes is the most appropriate and desirable option for people with younger onset dementia as a primary diagnosis. Network members were also questioned about the staff ratios necessary to adequately meet the needs of people with younger onset dementia within the preferred specialist supported accommodation model.

Based on these results Alzheimer's Australia NSW calculated that staffing costs alone would amount to approximately \$1.1 million per annum. Alzheimer's Australia NSW acknowledges that this is a desired model and may not be feasible to achieve in practice given the price limits set by Government funding modelsⁱ. It is considerably more expensive than comparable disability group homes that have been funded by State Governments. However, it does give an indication to the Joint Standing Committee of the expense involved in delivering a model of care and accommodation that is deemed appropriate by experts working with people with younger onset dementia.

The recent NDIA position paper on Specialist Disability Accommodation (SDA) sets out the benchmark pricing and payments approach, operational processes, and administrative arrangements for the SDA, designed in accordance with the SDA Framework, for the funding of the land and built elements of SDA under the NDIS⁴³ recent NDIS position paper on draft pricing and payments. AANSW is happy to see the development of the SDA as a possible supply-side model of investment in specialist accommodation for people with younger onset dementia. It is hoped this investment rectifies the long-standing issues of lack of age and needs appropriate accommodation which has resulted in many people with younger onset dementia living in residential aged care.

Despite the heightened interest and investment by both State and Commonwealth Governments in programs to support people with younger onset dementia, the policy reform process underway in Australia puts in jeopardy much of the progress that has been made. AANSW has concerns that the transition to the NDIS, which is happening earlier in NSW than the rest of Australia, will result in unintended consequences due to the haste in which the transition is being pushed through. The rush to the NDIS also is not ideal with initial experiences of people with younger onset dementia highlighting that while the services and supports offered are effective in meeting the needs of their clients, it has a number of design and implementation issues for this cohort.

Specific concerns highlighted in this paper include: the pre-NDIS eligible period in a person's life with dementia, communication, awareness and understanding of the Scheme, knowledge of dementia by NDIA planners and other officials, lack of clarity around assessment and eligibility determination, responsiveness of the NDIS to progressive neurological disabilities, the almost inevitable need for age and disability appropriate accommodation that is currently not being met, and the issues for people who turn 65 and move from one system to another. This paper has presented positive experiences that can be learnt from and translated across the Scheme, but has also highlighted areas that require attention.

The NDIS is one of the biggest social policy reforms ever undertaken in Australia. This paper has sought to highlight ways in which it can be improved for people with younger onset dementia, a group that has fallen through the cracks of ageing and disability policy. Improved design and implementation of the NDIS can narrow these cracks and improve the quality of life of people with younger onset dementia.

ⁱ Varies by State and whether the service is Government or NGO operated, however, the average staffing costs in disability group homes would be in the range of \$600-700k.

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