



**dementia
australia™**

The new voice of Alzheimer's Australia

**Inquiry into the implementation,
performance and governance of the
National Disability Insurance Scheme in
the ACT**

Submission from Dementia Australia

March 2018

About Dementia Australia

Dementia Australia, the new voice of Dementia Australia, is a unified, national peak body for people of all ages, living with all forms of dementia, their families and carers. We represent the more than 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with consumers, all levels of government, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

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



EXECUTIVE SUMMARY

Dementia Australia welcomes the opportunity to provide input to the ACT Legislative Assembly's Standing Committee on Health, Ageing and Community Services Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT (*the Inquiry*).

Dementia Australia has long believed that the National Disability Insurance Scheme (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 living with dementia have received plans that have had positively life-changing impacts on their lives. However, many others have faced barriers in accessing a plan or have received insufficient plans that adversely affect their quality of life and place some at risk of avoidable hospitalisation.

Dementia Australia's ACT Division currently delivers programs, supports and services under the NDIS, mainly through the Commonwealth Government funded Younger Onset Dementia Key Worker Program (YODKWP), which provides essential supports to people living with dementia, their families and carers by way of information, linkages and capacity building. The YODKWP provides specialist services that are designed to meet the needs of people directly impacted by younger onset dementia. The program provides expert information and advice from the initial point of contact and works alongside the client to develop a comprehensive strategy which optimises the client's engagement with support services and care options throughout their experience of dementia.

In October 2016 when the NDIS announced an intake halt on new participants into the scheme in the ACT, we [raised concerns](#) around the needs of family carers of people with Younger Onset Dementia as a priority for 2018 and beyond. Since then the complexity of the multiple systems that people living with younger onset dementia have to navigate has only increased, with families and carers falling between the cracks of the disability and aged care systems.

The overwhelming feedback from individuals impacted by dementia in the modern world of consumer directed care is that support to navigate the system is imperative. This need is especially acute for people living with dementia and their carers, who often report difficulty in identifying what services are relevant, how they are delivered and how consumers can access them.

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 highlights that there are several areas of concern that need to be addressed before the transition can be successfully completed. To ensure the best outcomes for people with progressive neurodegenerative diseases like younger onset dementia under the NDIS, Dementia Australia recommends:

1. Mandatory ongoing inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease in the ACT. Additionally, support coordination should only be provided by appropriate providers with disease specific knowledge and experience in providing disease specific care and support.
2. Improved pre-planning support for people with a progressive neurodegenerative disease.
3. Continuity of support for those not eligible to access the NDIS

Dementia Australia urges the Committee to consider the current issues relating to transition of the YODKWP to the NDIS in the ACT, and to prioritise the unique needs of this vulnerable cohort in the Territory, who often fall between the cracks of the aged and disability systems.

BACKGROUND: YOUNGER ONSET OF DEMENTIA

Dementia is one of the largest health and social challenges facing Australia and the world. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.¹ Dementia is not a natural part of ageing. It is a disease of the brain and affects a person's ability to function and ultimately to care for themselves. It is a terminal condition that affects people's abilities and memories and has a profound impact on the individual and their loved ones.² It is cloaked in stigma and misunderstanding,³ isolates people with dementia and their carers from social networks,⁴ and carries significant social and economic consequences.⁵ People living with dementia constitute one of the most vulnerable groups in our society. A wide range of evidence comprehensively demonstrates that the care provided to those living with dementia is worse than the care delivered to any other vulnerable group.

It is estimated that there are more than 425,000 Australians living with dementia and 1.2 million people involved in their care; by 2056 there will be over one million people living with dementia. To put it another way, by 2056 more than 650 people will be diagnosed with dementia every day. These numbers currently include more than 25,000 people with younger onset dementia, that is, dementia that develops before the age of 65, in people aged from their thirties-to-sixties and more rarely in a person's twenties. One in 13 people living with dementia today lives with younger onset dementia⁶.

There are many causes of younger onset dementia, with the most common being Alzheimer's disease, stroke and frontotemporal dementia. Dementia is a progressive neurological condition, and as the symptoms become more severe it often becomes difficult to continue to care for the person at home. Unfortunately people with dementia and their families face the difficult issue of a lack of appropriate services to cater for the needs of younger onset dementia, both within the community and in residential care. Often aged care facilities are unwilling or unable to take on clients who may have significant behavioural symptoms and are still very mobile.

Additionally, since Residential Aged Care is geared to the needs of older people it is not suitable to meet the specific needs of people living with younger onset dementia. Amongst various other needs for support suitable for this cohort, there is a significant need for assistance with emotional adjustment to the condition and impacts on the complexities for family, social, relationship, occupational and financial situations that are commonly present for those in young and midlife.

Younger onset dementia inevitably results in significant disability and there is a vital need for expert information, care and personal assistance.

Access to appropriate supports in the community, including respite, community care and key workers, is thus essential to delaying entry into supported or residential care for people living with

1 Australian Bureau of Statistics (2016). *Dementia: Australia's leading cause of death?* Accessed online.

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

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

4 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.

5 Access Economics (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Dementia Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx.

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

younger onset dementia. It is only recently that specialised community services have started to be developed for people with younger onset dementia; previously it was expected that they should be able to fit into mainstream services either through disability or the aged care system.⁷ People living with dementia remain in need of specialist support despite reform efforts to mainstream dementia support within existing services and especially amongst a current lack of significant investment in workforce training and capacity building. Yet there is now a risk that the essential specialist services which have been developed to support younger people with dementia will soon disappear under the mainstream service provision approach of NDIS.

Dementia in the ACT

In 2017 there were an estimated 5,369 people with dementia living in the ACT, a number which is estimated to increase to 7,353 in 2025 and 16,313 by 2056 in the absence of a significant medical breakthrough. This is estimated to cost the ACT \$211 million in 2017, an amount which is expected to soar to \$282 million in eight years, by 2025, and to \$586 million by 2056.⁸

It is estimated that there are 383 people living with younger onset dementia in ACT in 2017, a number that will rise to over 500 by 2036.⁹ In 2016 alone, there were 163 deaths attributed to dementia in the ACT.¹⁰

This represents a significant number of people living with dementia in the ACT. This number of people impacted by dementia can be more than doubled to include their carers and immediate families. This number is growing quickly and the current support mechanisms are at their limit

Reforms aren't going far enough

Health, aged care and disability services reforms over recent years have been increasingly based on the belief that supporting people impacted by dementia should be part of core business for service providers. However, there is much to do before this can become a reality. Consumer and provider experience tells us that there are still significant steps that need to be taken for quality dementia care and support to become an intrinsic part of health, aged care and disability services. This is especially so for marginalised or disadvantaged communities where their experience is often characterised by unacceptably long delays in diagnosis, poor access to treatment and lack of choice and quality in residential and community care to name but a few.

We need a renewed and sustained focus on dementia right now for the hundreds of thousands of Australians impacted by the disease every day *and* to prepare for what we as a community face in the years ahead.

⁷ Jo-Ann Brown, Kylie Sait, Ariella Meltzer, Karen R Fisher, Denise Thompson, Robyn Faine (2012). *Service and Support Requirements of People with Younger Onset Dementia and their Families*, for NSW Department of Family and Community Services, Ageing, Disability and Home Care, Sydney.

⁸ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

⁹ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

¹⁰ Australian Bureau of Statistics (2017) *Causes of Death, Australia, 2016* Accessed online.

Response to the terms of reference

(c) Whether there are unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT.

The Younger Onset Dementia Key Worker Program (YODKWP)

The Younger Onset Dementia Key Worker Program has been a crucial element in the sustained provision of care and support for people affected by younger onset dementia in the ACT. The program aims to improve the quality of life for people with younger onset dementia, as well as their families and carers, by providing them with a highly skilled key point of contact with whom they can develop comprehensive strategies that optimise their engagement with support and care options.

In 2013, Dementia Australia received funding from the then Department of Health and Ageing (now Department of Health) to develop the YODKWP, with funding secured through to the end of June 2018. This program provides a key point of contact for the person living with younger onset dementia and their family throughout the dementia journey by linking them into services and supports.

For decades, researchers, practitioners and consumers have been calling for a program that provides this type of individualised, proactive, person-centred support. This approach is particularly important for this group of clients who, in the past, had often been shuffled between the disability and aged care systems. For the first time, people living with younger onset dementia now have advocates to assist them in navigating this complex service environment. The YODKWP provides expert information and advice from the initial point of contact and works alongside the client to develop a comprehensive strategy which optimises the client's engagement with support services and care options throughout their journey with dementia.

Despite increasing numbers of people living with younger onset dementia in the ACT, as a proportion of people with a disability it is a smaller cohort and as a result numbers of service providers within ACT catering specifically to the needs of people with dementia remain low and difficult for the consumer and NDIS and LAC assessment services to identify. This creates additional vulnerability for this group of ACT community members and needs to be considered in review of the NDIS and other ACT supports. Size and scale of the cohort and support services are important considerations for smaller jurisdictions such as the ACT and may require more creative responses.

In addition to providing support directly to people living with younger onset dementia, their family and carers, Dementia Australia's Key Workers work with the acute, aged care, disability and community care sectors to improve their understanding of the issues facing those living with younger onset dementia and strengthen their capacity to provide services to this group. To date, the YODKWP has assisted thousands of people with younger onset dementia and their families throughout Australia to navigate the service systems and is proving its potential to improve the quality of life of people living with younger onset dementia and their families, as well as building capacity in the service sector.

YODKWP CASE STUDY:

The Key Worker supported a client who had been recently diagnosed with Lewy Body Dementia and had been in hospital for 6 weeks upon referral to the YODKWP. The client had been found in the community disorientated and dehydrated, after their partner had been unable to provide further care and supports. The Key Worker connected the client and carer with counselling and education and supported them to apply to the NDIS. While waiting for their application, the client and carer were introduced to supports and services to reduce social isolation and gain peer support. The Key Worker identified vacancies with supported accommodation providers and supported pre-planning and planning conversations with an SDA provider.

Once the NDIS plan had been approved the Key Worker assisted with implementation of the plan, increased supports around social engagement, provided referrals to age and disease appropriate Allied Health support workers and worked with the accommodation provider to ensure a smooth transition. The consumer is now engaged in her community, has control over her living situation and is making choices as to the direction of her life.

As the case study above highlights, a significant and distinguishing feature of the YODKWP is providing support to families and carers of the person with younger onset dementia. This is essential, as a diagnosis of dementia can have a major impact on employment, finances and family relationships. Research also tells us that the carer burden is significantly higher among carers of individuals with younger onset dementia.¹¹

The ACT experience of the NDIS has been that the needs of carer and family have been often separated from the assessment and planning for the NDIS supports. Dementia Australia advocates that Coordination of Supports for the person with dementia is essential to maintain informal support networks.

“Keep in mind with two little children trying to come to terms that 'Dad' isn't the same. The stress of all the behavioural changes and just trying to run the household and finances, we were all under immense stress. There were many times where I felt that our whole family was going to go under with no help around.”

Carer of person with younger onset dementia

As the Senate Community Affairs References Committee notes in its report, *Care and Management of Younger and Older Australians living with Dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD)*, neither the disability nor aged-care sectors appear to be appropriately equipped to respond to the needs of people with younger onset dementia. The Senate report also noted that the disability sector does not have the expertise to care for people with younger onset dementia.

Programs like the YODKWP are essential in bridging the various gaps between the needs of people living with dementia, their families and carers, and the existing framework of limited supports and services.

“When I was first diagnosed with semantic dementia about 6 years ago it was devastating for me for about one week, then I thought that it may not be as daunting an experience as I first thought. I decided not to get angry but to get focused. I had this condition for the rest of my life so I might as well live with it to the best of my ability, albeit that there were going to be changes

¹¹ van Vliet D, de Vugt ME, Bakker C, Koopmans RT, Verhey FR (2010). 'Impact of early onset dementia on caregivers: a review', *International Journal of Geriatric Psychiatry*, 25: 1091-100.

and challenges ahead... I can't imagine where I would be today without the assistance of expertise offered by the likes of Dementia Australia SA and other allied health professionals."

YODKWP client from South Australia

Despite the excellent progress of the YODKWP both in improving quality of life for clients and in assisting in developing appropriate services in the sector, there is every indication that this program will be subsumed under the NDIS by June 2018. Dementia Australia remains concerned that this will lead to a range of gaps in services and supports for people with younger onset dementia and their carers and will likely lead to people entering residential aged care services prematurely at a significant cost to Government, either within a disability or aged care context.

Broader themes from NDIS Transition

Dementia Australia has long believed that the NDIS has the ability to transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception.

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 younger onset dementia have been overlooked or insufficiently addressed (e.g. because of a lack of understanding of the disease and the potential for communication or cognition challenges, we have seen several examples of plans that do not address key support needs), the outcomes have been overwhelmingly poor.

Experience to date suggests that people with younger onset dementia have difficulty getting through the assessment process and that those in the early stages of the disease are not considered as having a sufficient functional impairment to access services. 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 participating¹². Cost may also pose as a barrier to accessing some mainstream services through ILC without subsidisation.

There are also questions as to how NDIS supports will relate to aged care services and assist people who are already stranded between disability, aged care and community services. 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.

There is also a need for understanding and flexibility in reassessing NDIS plans for 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 NDIS sites suggests that the NDIS is not responsive to the changing needs of people with younger onset dementia. People with progressive neurological diseases like younger onset dementia 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,

¹² Brown, J., Sait, K., Meltzer, A., Fisher, K. R., Thompson, D., Faine, R. (2012). Service and Support Requirements of People with Younger Onset Dementia and their Families, for NSW Department of Family and Community Services, Ageing, Disability, and Home Care, Sydney.

care needs inevitably increase over time. 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 their future needs that go beyond the first year of their plan.

Consideration of their disease and anticipated progression should also be taken into consideration during planning meetings. Therefore, when NDIS planning involve the participant in isolation from their carer, and community supports – the plan outcomes are less than optimal and the participant (and their supporter) is deprived of choice and control. Our consumers have regularly reported that a lack of understanding of the disease has led to disrespectful treatment in planning meetings, where their goals and needs are trivialized or dismissed and their Key Workers are ignored by planners, leaving people deeply upset by the meetings. One client was told that they weren't eligible for home modifications as "they wouldn't need them for long". Another client was ridiculed by the planner for falling asleep during the meeting. Many of these situations could be averted if supports such as Key Workers are encouraged to attend meetings, and their knowledge of the disease and the client is valued.

In response to these concerns and the difficulties reported by people living with a progressive neurological disease entering the NDIS, Dementia Australia, in collaboration with the Neurological Alliance of Australia (NAA)¹³ propose the following recommendations: General Recommendations

1. Ongoing Coordination of Supports for people with progressive neurodegenerative diseases

The number of NDIS participants that no longer have allocations in their NDIS plans for coordination of supports is a significant cause of concern for Dementia Australia. Key issues with this approach include the following:

- No allowance for a Coordinator of Supports takes away a valuable support mechanism at a time when these people need the most help (e.g. navigating a brand new disability system and often confusing technology such as the NDIS portal).
- Coordinators of Support with a good understanding of the unique needs of people with a progressive neurodegenerative disease such as younger onset dementia have proved to be effective advocates who bridge the knowledge gap between the NDIS, the disease and the individual.
- Qualified Coordinators of Support are essential for Scheme sustainability and positive participant outcomes through plan implementation supports, identifying disease and age

¹³ The Neurological Alliance Australia is an alliance of not-for-profit peak national organisations representing adults and children living with progressive neurological and neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment. The Alliance represents over 850,000 Australians living with progressive neurological or neuromuscular conditions that have no known cause and no cure. This group includes adults and children, carers, families, friends and workmates whose life has been affected by a progressive neurological condition.

appropriate providers, monitoring of supports services and enabling greater plan utilisation to meet client goals and needs.

- Without intervention most people with progressive neurodegenerative diseases will be unable to navigate the review process and would be limited by their inadequate plan for the ensuing twelve months.

Consumer Case study

A client in the Toowoomba region wasn't approved for Support Coordination and was advised the LAC would provide that Support Connection instead. In a short period of time the client deteriorated significantly and required home modifications and assistive technology to continue living safely in the home. The carer contacted the LAC to request assistance with how to arrange the appropriate assessments and approvals from the NDIA in order to purchase the relevant technologies and home modifications. The LAC took two weeks to reply to the carer via email and provided a long list of providers but no information on the process. The Key Worker provided assistance to the carer to organise the relevant assessments. The carer called the LAC to request information on where to send the reports; the LAC asked for all reports to be sent to her and she would pass them on to the relevant team within the NDIA for approval. Over a month passed and the carer had not received any feedback on the status of the approval. The Key Worker contact the NDIA on the carer's behalf and was advised the reports had not been received. Numerous attempts were made to contact the LAC to request an update with no return of phone calls or email. The Key Worker advocated directly with the NDIA and sent the reports straight to the relevant team. Unfortunately, during this time the client had experienced a number of falls and due to not having the appropriate equipment the carer was not able to lift him. As a result, the client has required numerous admissions into hospital. These falls could have been avoided with access to appropriate assistive technology and home modifications. If this client had been approved for Support Coordination the home modifications and assistive technologies would have been implemented in a timely manner resulting in better outcomes for this client.

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 one of these diseases. 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. Those that struggle with inadequate supports will be at greater risk of presenting to crisis and emergency services, and of being prematurely or inappropriately institutionalised.

It is also 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 LAC's assess an individual's needs for support co-ordination, and then provide the service themselves. This is becoming a frequent

occurrence that can be observed across all States and Territories where the NDIS have moved to a model where LAC's are also undertaking the support connection roles. There are multiple instances of people with younger onset dementia are having support connection included in their plans, but the LAC's are failing to provide the age and disease appropriate services and supports.

As we have noted earlier, LAC's have limited to no knowledge of complex neurodegenerative conditions like younger onset dementia, which is inadequate from the perspective of need 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 1: Ongoing Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease. Additionally, support coordination should only be provided by appropriate providers with disease specific knowledge and experience in providing disease specific care and support.

2. Pre-planning education/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. Key workers are well placed to provide this support to people living with dementia and leverage existing targeted resources, such as Dementia Australia's [NDIS YOD Toolkit](#).

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

Consumer Case Study

Peter, the carer of a woman with younger onset dementia, felt unprepared when he and his wife attended their first NDIS planning session. Peter and his wife found it difficult and uncomfortable being asked what their needs were as he did not know how to identify or prepare for what their needs were and would be in the future. The NDIS planner had no understanding of dementia and the needs of people living with dementia and as a result the planning session focused on physical needs and solutions. As a result their first NDIS plan provided funded supports totalling \$600.

Seeking assistance to address his wife's many unmet needs in this plan, Peter spoke with one of Dementia Australia's Younger Onset Dementia Key Workers who worked with Peter and his wife to better understand their immediate and future needs. The Key Worker assisted Peter in arranging an NDIS plan review and the resulting plan provided funded supports of \$32,000 (including 9 hours of home care and a week of full respite). This was the life-changing NDIS plan Peter and his wife had hoped for when they entered the NDIS.

Consideration of assistive technology (AT) is another important part of the pre-planning process. AT covers a range of aids and equipment to help people live more independently such as mobility equipment (walking frames and wheelchairs), specialised beds and clothing, specialised alarms and door bells, and a huge range of communication and IT equipment and devices. It is essential that AT options are considered in all NDIS plans for people with progressive neurodegenerative diseases and that follow up ensures timely access to the AT identified.

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, funding is required 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 2: Funded pre-planning support for people with a progressive neurodegenerative disease

3. Continuity of support for those not eligible to access the NDIS

Recommendation 3: That people who are not eligible to access the NDIS are provided with a continued and comparable level of support.

The eligibility criteria for entry into the NDIS is prescriptive for this cohort. The age cut-off of 65 years of age at entry and the need for a formal diagnosis impacts a number of clients who entered the program before the age of 65 but had turned 65 prior to the NDIS becoming available in their area. It also has a deleterious impact on those who are undergoing the lengthy diagnosis process.

For those who have missed the age cut off for the NDIS (sometimes by a matter of weeks) this comes as a terrible blow and, in effect, impacts their ability to continue to receive support from their Key Worker based on an arbitrary cut-off.

Support through the diagnosis process was an important entry point for those referred to Dementia Australia through Primary Care or for those who were concerned about changes to their memory and cognition or that of their loved one. The value of the support and advice provided by a trusted Key Worker during an emotionally difficult period cannot be overstated and is unfortunately lost in the NDIS.

Consumer Case Study

In the ACT, work is still being progressed to support one consumer to access the Scheme who was initially denied eligibility in January 2017, due to their functional assessment despite having a confirmed diagnosis of dementia (List B) and part of a Defined Program (List C). After being denied verbal requests for plan reviews and resubmission of the Access Request, it transpired that all medical documentation had been misplaced from the initial application. This information was resubmitted in person at the local NDIA office, only to be advised in October 2017 that again there was no medical documentation on file. The Key Worker has spent over 20 hours to have the functional assessment reviewed with multiple forms of conflicting advice and information provided by the NDIS. Finally in December 2017, this client was rejected as they had just turned 65 years old, despite having been eligible and having submitted multiple Access Requests in the previous 12 months. This case has now been submitted to the Administrative Appeals Tribunal, and awaiting a further hearing or decision. In the interim, the Key Worker and family are trying to engage services through Carers ACT so that in home supports can be provided as the carer is still in employment.

Additionally, since its inception, the YODKW Program has taken an all-of-family, holistic approach to supporting people with younger onset dementia. The NDIS, however, focuses all funding on the

person with YOD and also aligns goals and outcomes directly with the person with YOD. However it is important to note that often a person living with dementia is supported to stay in community only through the assistance of their families or carers. Without this support, people with dementia are often at risk of premature entry into residential aged care. While the ILC does intend to provide some of this carer support, it is essential that the NDIS ensures adequate Coordination of Supports for people living with YOD to be able to maintain the level of informal supports for these people and support them to remain living at home and in their communities for as long as possible.

Consumer Case Study

Jennifer lived with her husband who was unable to cope with her complex needs. By the time he contacted the Key Worker he had been trying to implement supports through the NDIS plan for several months. Having experience with only one provider he hadn't known about other options and types of supports to put in place. The experience left Jennifer's husband feeling overwhelmed and in a state of burn out. Not long after, Jennifer was placed in the closed dementia ward of an aged residential care facility; she was 58 years old.

A significant proportion of YODKW Program clients are not able to access the NDIS due to eligibility restrictions (age requirements, carers and families) or will not receive continuity of service due to challenges servicing thin markets and lack of psycho-social inclusions in NDIS plans. Alternative mechanisms are imperative to ensure that all people living with younger onset dementia, their families and carers are able to access disease- and age- appropriate supports, regardless of where they live.

Conclusion

Implementation of these three recommendations will not only improve NDIS plan outcomes for people with progressive neurodegenerative diseases but will also directly improve outputs set out in the Productivity Commission's *Services for people with disability performance indicator framework*,¹⁴ namely:

- Access – Assistance for younger people with disability in, or at risk of, entering residential aged care;
- Appropriateness; and
- Quality – Client and carer satisfaction.

These will result in improved outcomes – in principle and in practice, including:

- Increased labour force participation of primary carers of people with disability; and
- Social participation of people with disability.

Dementia Australia remains an advocate of the NDIS and understands the roll out of this Scheme is one of the greatest changes to healthcare since the introduction of Medicare. However, if people with a progressive neurological disease are to receive equitable and effective support within the NDIS it is imperative that the NDIA and government address these unmet needs within the context of this Inquiry.

¹⁴ <http://www.pc.gov.au/research/ongoing/report-on-government-services/2017/community-services/services-for-people-with-disability/rogs-2017-volume-f-chapter15.pdf>.