

**FIGHT ALZHEIMER'S**  
**SAVE AUSTRALIA**  
**FIGHTDEMENTIA.ORG.AU**

**SUBMISSION TO THE**  
**PRODUCTIVITY COMMISSION**

**REVIEW INTO NATIONAL**  
**DISABILITY INSURANCE**  
**SCHEME (NDIS) COSTS**

**March 2017**

## EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide a submission to the Productivity Commission's Review of National Disability Insurance Scheme (NDIS) Costs.

Alzheimer's Australia has long believed that the NDIS will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception. To date some NDIS participants living with dementia have received plans that have had positive, 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.

Alzheimer's Australia 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.

It is currently proposed that the YODKWP will transition to the NDIS completely by 30 June 2018; however, our current experience of ongoing transition activities highlight that there are several areas of concern that need to be addressed before the transition can be successfully completed. To ensure the best outcomes for people with progressive neurodegenerative diseases like younger onset dementia under the NDIS, Alzheimer's Australia recommends:

1. Improved pre-planning support for people with a progressive neurodegenerative disease;
2. NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease; and,
3. Mandatory inclusion of 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.

In this submission, Alzheimer's Australia includes comment on two areas which impact on the cost of the NDIS:

1. Broad themes/recommendations relating to the impact of the NDIS on people living with younger onset dementia; and
2. Responses to the questions posed in the Issues Paper.

## Background

Alzheimer's Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia. Dementia is the second leading cause of death in Australia overall and it will have an increasing impact on the health system due to population ageing. Currently there are more than 410,000 Australians living with dementia and this figure is expected to increase to almost over a million by 2056<sup>1</sup>.

There are 25,938 people living with younger onset dementia, expected to rise to 29,375 people by 2025 and 42,252 people by 2056.<sup>2</sup> Aboriginal and Torres Strait Islander people are over represented in this group as they experience dementia at a rate 3 to 5 times higher than the general Australian population and often with symptoms starting at younger ages.<sup>3</sup>

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.

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 residential care for people living with 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.<sup>4</sup> 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.

### **The Younger Onset Dementia Key Worker Program (YODKWP)**

In 2013, Alzheimer's 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 2017. 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, consumers have been calling for a program that provides this type of individualised, proactive, person-centred support. This approach is particularly important for

---

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

<sup>2</sup> Ibid.

<sup>3</sup> Alzheimer's Australia (2014). *Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research*.

<sup>4</sup> 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.

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.

In addition to providing support directly to people living with younger onset dementia, their family and carers, Alzheimer's 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 navigate the health system and is proving its potential to improve the quality of life of people living with dementia and their families, as well as building capacity in the service sector.

#### **YODKWP Case Study from Victoria:**

A key worker in Victoria supported a person and his family to accept a recent diagnosis of frontotemporal dementia. The man was supported by the YODKW to disclose his diagnosis to his employer and receive entitlements when he decided he was no longer able to work. The key worker worked with the football club, of which the client was a long standing member, to support his ongoing involvement in the club.

The key worker also provided support to the client's teenage children, including working with the school to ensure supports were put in place. This has been done while linking the family into a number of other services and assisting with complex behavioural and psychological symptoms that needed extra support. This client's wife has commented that she does not know that she would have coped had it not been for the support from the YODKWP.

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.<sup>5</sup>

***“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

---

<sup>5</sup> 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.

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 and challenges ahead.... I can’t imagine where I would be today without the assistance of expertise offered by the likes of Alzheimer’s 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. Alzheimer’s Australia remains concerned that this will lead to a range of gaps in services and supports for people with younger onset dementia 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**

Alzheimer’s 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. To date some NDIS participants with dementia have received plans that have had positive, 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 unnecessarily escalate care needs. .

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 that leads to an attempt to conduct planning sessions over the phone despite communication or cognition challenges, or the creation of plans that do not address key support needs), the outcomes have been overwhelmingly poor.

Experience to date in the trial sites 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. 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.

People with a 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, however, 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. People with cognitive or communication impairment require patience and understanding, limited distractions, clear speech, eye contact and non-verbal indicators which are difficult to achieve over the phone. Therefore, when NDIS planning sessions are conducted solely over the phone – and when they involve the participant in isolation from their carer, or vice versa, as is frequently reported by our consumers – the plan outcomes are less than optimal and the participant (and their supporter) is deprived of choice and control.

In response to these concerns and the difficulties reported by people living with a progressive neurological disease entering the NDIS, Alzheimer's Australia, in collaboration with the Neurological Alliance of Australia (NAA)<sup>6</sup> propose the following recommendations:

## **General Recommendations**

### **1. 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.

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

### **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

---

<sup>6</sup> 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.

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 Alzheimer's 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 1: Improved pre-planning support for people with a progressive neurodegenerative disease**

#### **2. Face to face planning meetings**

A face-to-face NDIS planning session with an NDIS planner who has a sound knowledge of cognitive impairment and neurodegenerative diseases, such as those in NDIS Complex Care Teams, are considered by the NAA as best practice and have produced NDIS plans that most appropriately meet the needs of people with a progressive neurodegenerative disease.

Unfortunately, this approach is not uniformly implemented across the country or even across regions.

For example, NDIS planning sessions over the phone have proved to be inappropriate for people with a neurodegenerative disease and can result in poor outcomes, often requiring an urgent NDIS plan review.

### Consumer Case Study

Leslie called Alzheimer's Australia in a state of distress as she had an NDIS planning session over the phone (with no forewarning) and could not recall who she had talked to or the details of the conversation. It took Leslie, with the help of a YODKW, over 6 hours to gather the basic information required for Leslie to apply for a review of her NDIS planning session.

Chris was asked to complete an NDIS planning session for his wife over the phone with no prior warning and not having done any supported pre-planning. On receipt of the plan, Chris contacted Alzheimer's Australia to discuss plan implementation; however, after discussing his wife's needs for the coming months and Chris's plans to return to part-time work it became clear the \$11,000 provided for 12 months were inadequate to meet his wife's complex needs. Chris is now waiting on a response from the NDIA regarding a review of his wife's plan.

Feedback from people with progressive neurodegenerative diseases has revealed that Local Area Coordinators (LACs) have also shown insufficient knowledge of their disease, the impact of that condition on their lives, the most effective service interventions and the degenerative and fatal nature of their disease.

### Consumer Case Study

Annie called the Parkinson's 1800 support line as she worried about an over the phone NDIS planning session that had taken place earlier that day. Annie's volume and quality of speech has been impaired due to Parkinson's and she also requires longer to respond to questions. She felt rushed and because her response is delayed she felt that the assessor didn't get a clear indication of her needs. Annie and a Parkinson's Nurse Specialist were able to take the time put information together in order to apply for a review for Annie's plan.

The first time Annie applied for disability support she was told that even with Parkinson's, a degenerative neurological condition with no cure, she was considered "not disabled enough".

A person with Multiple Sclerosis (MS) was asked by the LAC at a planning meeting, "How long will MS last?"

Another person with MS with only head movement was asked by the LAC at their planning meeting if they would require personal care or if they would be able to hang out their own washing?

To offer true choice and control in individual plans, NDIS planning sessions must take into consideration the unique needs of all participants by gaining a better understanding of the diseases impacting clients and, wherever possible, meeting with these people face to face during the NDIS planning phase.

**Recommendation 2: NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease**



### 3. 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 Alzheimer's 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 diseases such as younger onset dementia have proved to be effective advocates who bridge the knowledge gap between the NDIS, the disease and the individual.
- 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 Coordinator of Supports, provided by Alzheimer's Australia, assisted a 58 year old woman with younger onset dementia living in a rural area by linking her into a physiotherapist and an occupational therapist who both specialised in neurodegenerative conditions, a speech pathologist who assisted with her progressive non-fluent aphasia and other service providers with staff that had experience in neurodegenerative diseases. The Coordinator of Supports assisted their client's carer to interview potential providers to ensure they had appropriate knowledge and experience in supporting a person with younger onset dementia.

In addition to finding services and programs that met the very specific needs of their client and understood her disease the Coordinator of Supports also developed a communication system between allied health and in-home support provider to ensure their client received supports that were adaptable to changes in her condition.

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 clients disease and journey, such as the YODKW, many people with a progressive neurodegenerative disease may fall through the cracks and be unable to access appropriate services.

It is 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 infact 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 S/T's where the NDIS have moved to a model where LAC's are also undertaking the support coordination roles. This means that in some instances people with younger onset dementia are having support coordination included in their plans, but the LAC's are providing the service.

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 3: Mandatory inclusion of 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.**

## General Conclusions

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*,<sup>7</sup> 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.

Alzheimer's 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 addresses these unmet needs within the context of this review of costs.

---

<sup>7</sup> <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>.

## Response to Questions raised in the PC Issues Paper:

Alzheimer's Australia has consulted with consumers and other stakeholders, including direct service staff, about the applicable key areas outlined in the Issues Paper. Our key findings and comments are outlined below.

### Future estimates — some pressures emerging

- *Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?*

As mentioned in previous sections of this submission, finding appropriate services for people living with younger onset dementia continues to be a challenging task. Research by Alzheimer's Australia found that "*few (consumers) have reported finding anything appropriate to meet their needs and it's often left to the goodwill of providers to provide services. This may be at the end of a frustrating and long process (for the family carer and person with dementia), and so the younger person's dementia may have progressed markedly by that stage.*"<sup>8</sup>

Historically, people with younger onset dementia, their family and carers have had to try and navigate the disability and aged care sectors in search for appropriate services, with many consumers falling through the cracks. For decades, 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.

Thus, with large scale reforms sweeping across both aged care and the disability sectors, many service providers who would normally adapt to meet the unique needs of people with younger onset dementia, have disappeared. This could be contributing to the low utilisations rates for people with this form of dementia on the NDIS.

Alzheimer's Australia's experience of working through the transition also indicates that there is a disconnect between services that the consumer needs, and the ones that are ultimately funded through the NDIS plan. Often Local Area Coordinators have poor understanding of progressive and terminal conditions such as YOD, which can result in allocation of funds towards services the consumer may never end up utilising.

- *Why is there a mismatch between benchmark package costs and actual package costs?*

This is indicative of less than optimal stakeholder engagement during the planning and developmental stages of the NDIS. There has been no strategic consultation around appropriate services for people with younger onset dementia, or the actual cost of

---

<sup>8</sup> Alzheimer's Australia (2007). *Exploring the Needs of Younger People with Dementia in Australia, Report to Australian Government Department of Health and Ageing*. Available Online: <https://www.fightdementia.org.au/files/20101027-Nat-YOD-Exploring-needs-Australia.pdf>.

service delivery to this cohort with existing consumer representative organisations such as Alzheimer's Australia and other specialist organisations. Moreover, the complex care needs of people living with younger onset dementia, may mean that an efficient interface and coordination with other health services is vital, but lacking.

## **Scheme Boundaries**

- *To what extent is the speed of the NDIS rollout affecting eligibility assessment processes?*

As highlighted through case studies in previous sections, expediency seems to have been prioritised over appropriate in-depth planning. For example, assessment processes are routinely provided by local area coordinators with no demonstrated knowledge of complex neurodegenerative conditions like younger onset dementia; and planning meetings are routinely conducted over the phone, which is a completely inappropriate medium for people with a cognitive impairment.

- *Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services?*

Services designed to meet the needs of people living with younger onset dementia are generally limited, regardless of the policy or legislative context under which they are delivered. The challenge of negotiating the service system is enormous for clients affected by this form of dementia and an apparent lack of ability or willingness to offer services, coupled with a fundamental lack of understanding about younger onset dementia and how it fits into the NDIS or other service sectors, can lead to confusion, fragmented and inefficient service delivery, a need for emergency care services or avoidable hospital admissions and a delay in accessing meaningful support.

## **Information, Linkages and Capacity Building Support**

- *What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?*

In Alzheimer's Australia's experience, LACs do not have adequate disease knowledge which is essential to successfully and appropriately provide assessment services for consumers. To address this lack of specialist information, the NDIS should consider outsourcing assessment services to disease specific organisations or consumer advocacy groups, who are much better positioned to effectively assess consumer needs.

There are also concerns about how the NDIS will respond to disabilities that are progressive and where function and needs change very rapidly.

*The rate of progression of dementia in younger onset dementia can be very rapid, and the current waiting periods through NDIS are a huge issue for key workers and clients of the YODKWP. In one unfortunate situation, a YODKWP client's condition deteriorated rapidly while he was waiting for appropriate support through NDIS. The client's application was in place as he deteriorated, however, he was hospitalised and needed permanent placement in that time and there was confusion around whether NDIS would*

*support this as they don't have capacity to find permanent placement or whether it should be the aged care system. The feedback from the wife of this client is that NDIS had no understanding of YOD. The client died while waiting for placement.*

These issues in understanding the dementia-specific diagnosis journey can be resolved by ILC funding for disease specialist support programs, such as the YODKWP, which will enable the delivery of individualised support to people with YOD even before they are eligible for the NDIS.

### **Planning Processes, Assessment Tools and Support Packages**

- *Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?*
- *Do NDIA assessment tools meet the agreed criteria?*
- *Are the criteria for participant supports clear and effective?*

In our experience, there are large variances in what is considered “reasonable and necessary” in relation to assessment planning. For example, one person with younger onset dementia was assessed and given horse riding lessons, while another person was not allowed bathroom aids.<sup>9</sup> There is clearly a need for planners and assessors to receive more education on specific conditions, such as dementia to assist them in providing appropriate supports. There also needs to be an oversight and improvement process that monitors how an assessor or planner determines what is considered ‘reasonable and necessary’. There should be ongoing and routine evaluation of this process to ensure that consumers are receiving the most appropriate supports based on their needs and requirements. The NDIS planning assessments should not be limited to functional assessments, especially for those with progressive neurodegenerative diseases as they do not adequately address the changing and degenerative nature of these diseases.

### **Criteria for participant supports**

As Alzheimer’s Australia has highlighted through various submissions to the NDIA and the Department of Social Services, dementia does not only impact the person receiving the diagnosis as the effects of dementia are far reaching and often include family members and carers. At present, the NDIS primarily focuses on linking services for the individual and limits the scope for involvement of family members and carers.

This gives rise to a number of issues for people with dementia and their family members and carers, including the difficulty some people living with dementia have in articulating their care needs to an NDIS planner and who require a family member to advocate and discuss their care needs with the NDIS planner. Many carers also experience distress both as a result of the diagnosis and providing informal care. Family members and carers also require support and counselling to lessen carer burden and ensure they can continue in the caring role as long as possible.

---

<sup>9</sup> Information provided by internal NDIS working group.

Right now, through the YODKWP, key workers act as a primary point of contact for people with younger onset dementia, their carers, families and friends. They support individuals and families to take an active role in their own health and wellbeing through the provision of information, counselling, advice and advocacy. Key workers also assist individuals and their carers work together to develop goals and action plans, navigate the health system and engage with services appropriate to their own unique needs, i.e. younger-onset specific social clubs, respite, retreats, etc. Thus inclusion of relevant supports and services for carers of people living with Dementia is an important aspect that should be considered as part of the criterion for participant supports.

### **Workforce Readiness**

- *Is increasing the NDIS workforce by 60 000-70 000 full time equivalent positions by 2019-20 feasible under present policy settings? If not, what policy settings would be necessary to achieve this goal, and what ramifications would that have for scheme costs?*

As outlined previously, it is not feasible for NDIS LACs to have specialist information on all conditions that span the NDIS eligibility spectrum. The LAC roles in certain instances should therefore be outsourced to disease-specific groups that understand the needs of people with specific diseases as opposed to expecting NDIS Planners or LACs to understand a myriad of different diseases/disabilities.

Delegating the LAC role to disease specific groups will also be a more effective approach to supporting an individual with planning, establishing linkages with mainstream and other supports, facilitating peer support networks and understanding the most effective support options appropriate to the for a person living with a degenerative condition such as younger onset dementia.

### **Provider Readiness**

- *How do 'in-kind' services affect the transition to the full scheme and ultimately scheme costs?*

As mentioned above, the YODKWP is earmarked to transition to the NDIS by 30 June 2018. However, while our In-kind funding will cease after this date, this is still much earlier than the full roll out of the NDIS scheme, which is currently planned for 2019-2020. This will leave many vulnerable people with younger onset dementia with no formal support for a full year.

- *What are the best mechanisms for supplying thin markets, particularly rural/ remote areas and scheme participants with costly, complex, specialised or high intensity needs? Will providers also be able to deliver supports that meet the culturally and linguistically diverse needs of scheme participants, and Aboriginal and Torres Strait Islander Australians?*

It is important to ensure that the care provided under the NDIS is of the highest standard, in particular for consumers living with dementia. Aboriginal and Torres Strait Islander people are over represented in this group as they experience dementia at a rate 3 to 5

times higher than the general Australian population and often with symptoms starting at younger ages.<sup>10</sup>

It is thus critical to protect access to service for people from special needs backgrounds or with specific care needs such as dementia. A genuinely open market may well increase the number of mainstream service providers, but individuals and communities with special needs may not be best placed to advocate for service or place demands on the market.

Thus there must be some financial incentive to support providers to artificially supplement reduction of services in less commercially viable areas. There should be consideration and provision of more hours of Coordination of Support for those in underserved areas to allow Support Coordinators to build capacity.

- *How will the changed market design affect the degree of collaboration or co-operation between providers? How will the full scheme rollout affect their fundraising and volunteering activities? How might this affect the costs of the scheme?*

With little direction or support from NDIA there is reduced collaboration and cooperation between providers as each regards the other as a primary competitor in the marketplace. This will result in duplication and unnecessarily thin markets and increase costs for the scheme.

## **Participant Readiness**

- *How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?*

An essential component of the YODKWP is that it provides support from the time of first having concerns to the end stages of dementia. This means that people are connected to services and supports before they enter the formal care system and are provided with ongoing support throughout their dementia journey. In some cases this happens when people are in the very early stages of the disease, before they have the level of functional impairment that is required for eligibility to the NDIS.

This early-intervention approach is essential in supporting people to remain independent for as long as possible while enjoying a good quality of life and ensuring that people living with dementia do not enter residential care earlier than necessary<sup>11</sup> thus reducing avoidable Government expenditure.

People with younger onset dementia in the trial sites have indicated that they find the application process difficult and confusing with some consumers giving up because the process was too difficult. Key workers are helping people with younger onset dementia in the trial sites apply for the NDIS, prepare for planning meetings and ensure they have

---

<sup>10</sup> Alzheimer's Australia (2014). *Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research*.

<sup>11</sup> The Royal Australasian College of Physicians Submission (2012). *House Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention*.

appropriate support to implement their NDIS plan to receive services. This support would normally not be funded through the NDIS, and once YODKWP transitions completely into the NDIS, people with younger onset dementia would be forced to face the application process without support.

The administrative burden of enrolling into NDIS has also been a major barrier for our clients. Currently, the Evidence of Disability Form must be filled out by GP or specialist for each client. The completion of this form is dependent on the doctor having a thorough understanding of the functional capacity of the person with dementia. The Access Request Form must accompany the Evidence of Disability Form. Understanding the forms, and how to complete them is an area identified as a barrier to those with cognitive impairment. Key workers have needed to assist in this process, unless the person has a competent family member or supporter.

The key worker role has also been essential in assisting NDIA planners to develop a plan for a client with advancing dementia. NDIS planners, while eager to assist, have very limited knowledge of younger onset of dementia and Alzheimer's disease, and minimal information on what services a client with progressive functional decline may need. They also lack the capacity to estimate the number of hours of support and appropriate resourcing that would be required. Our key worker's experience has been that the NDIS plan would not have been suitable for the client's needs if key worker advocacy had not been available.

## **Governance and Administration of the NDIS**

- *Do existing administrative and governance arrangements affect (or have the potential to affect) the provision of services or scheme costs? What changes, if any, would improve the arrangements?*

Existing administrative and governance arrangements are too opaque and the split in governance and funding between Federal and State results in difficulties for those seeking to address systemic issues in NDIS implementation that affect all states and territories. Additionally, there are significant differences in NDIS plan outcomes across different states and territories.

- *Are there appropriate and effective mechanisms for dealing with disputes with the NDIA?*

No there are not: this is due to difficulties in identifying appropriate mechanisms for dealing with disputes in each state and territory, lack of information or responses from local NDIS offices to resolve disputes. There is also no clear mechanism for addressing systemic NDIS issues on a national level.

## **Financial Sustainability**

Alzheimer's Australia recognises the challenge faced by Governments in balancing financial sustainability of the NDIS with the access and choice demanded by consumers. But it is important to recognise the advantages that specialist services can provide, both in



supporting the mainstream delivery of supports under the NDIS, as well as off-setting costs through early intervention.

For example, currently, there are a significant number of young people in residential aged care in three of the NDIS launch sites: Barwon, Hunter and the ACT. A study by PwC and the Sumner Foundation estimated that by June 2016 there would be 145 people under 65 in RAC in Hunter, 96 in Barwon and 74-79 in the ACT.<sup>12</sup> The report also estimates the cost of meeting the needs of younger people in residential aged care in 2015-16 to be nearly \$14 million in the ACT, \$20 million in the Barwon site, and almost \$29 million in the Hunter launch site. With 30% of all younger residential aged care residents estimated to be diagnosed with dementia, the younger onset-specific needs the NDIS needs to be able to deliver are considerable. As the report notes, the NDIS will be unable to meet these needs without a large injection of capital funding and a building plan and program.<sup>13</sup>

It is critical to ensure that services that provide early intervention and prevent early, often inappropriate admissions to residential aged care, help develop the service sector and build capacity, as well as create pathways back to the community for people inappropriately committed to residential care, are essential to the ongoing management of this cohort. This is where specialist programs like YODKWP are vital, as they are principally designed to support people with younger onset dementia across the whole of the dementia journey, from pre-diagnosis to possible residential care entry. The YODKWP also aims to build capacity with existing services and explore new partnerships, to better meet the care needs of younger people with dementia in community, so that they do not end up turning to inappropriate residential care as the only resort.

## ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information.

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

Our organisation advocates on the basis of evidence-based policy, promotes awareness of dementia, delivers national projects and programs under contract from the Commonwealth, and provides research grants to emerging researchers. We are committed to a strong consumer focus and have a number of consumer advisory mechanisms, which actively seek and represent the voice of people with dementia themselves, as well as carers. We participate on many Ministerial and Departmental Committees, and contribute to consultation

---

<sup>12</sup> Winkler, D. et al. (2013). *National Disability Insurance Scheme Launch Sites: Projection of the number of people in residential aged care.*

<sup>13</sup> Ibid.

forums and advisory groups. We are also a sponsoring member of the National Aged Care Alliance and are involved in other key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

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