

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

**NDIS: INFORMATION, LINKAGES AND
CAPACITY BUILDING POLICY
FRAMEWORK**

Online Consultation

March 2015

ALZHEIMER'S AUSTRALIA

Executive Summary

Alzheimer's Australia welcomes the opportunity to provide a submission to the NDIS on the Information, Linkages and Capacity Building Policy Framework.

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 third leading cause of death in Australia overall and second for women, and will have an increasing impact on the health system due to population ageing. Currently there are more than 342,800 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050¹.

There are 25,100 Australians with dementia who are under the age of 65. This number is expected to increase to 36,800 by 2050². There are many causes of younger onset dementia, with the most common being Alzheimer's disease, stroke and frontotemporal dementia.

It is essential that the NDIS ensures continuity of information, linkages and capacity building for this group of vulnerable clients. The Commonwealth Government currently funds the Younger Onset of Key Dementia Program (YODKWP) (contract ends 30 June 2016) which provides essential supports to people with dementia and their families including functions around information, linkages and capacity building.

Currently, there is every indication that this program will be subsumed under the NDIS. However this is an ill-informed approach that is not reflective of the desires of consumers, carers or experts in this area and will lead to significant gaps in services for people with younger onset dementia in the community.

The YODKWP program provides specialist services that are designed specifically to the needs of people with YOD. 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 journey with dementia.

The Program's proposed transition to the NDIS, will result in a loss of access to specialist services which the Younger Onset Dementia Key Worker Program provides. Many important features will be lost under the proposed transition plan, such as support for family and carers, information for people with dementia and families and the building of capacity within the service sector to provide services that meet the needs of people with younger onset dementia.

It is essential, that if this program is transferred to NDIS that the key functions around information, capacity building, and linkages continue and are block funded through the NDIS-ILC. The development of mainstream, non-condition specific services will not meet the needs of people with younger onset dementia. People living with younger onset dementia and their families and carers already fall between the cracks of both the disability and the aged care sector. They have unique needs and it is essential that they have access to specialised dementia services which cannot be delivered by the mainstream disability sector.

In conclusion, the NDIS is ill-equipped to respond to the specialised needs of people with dementia and it is Alzheimer's Australia's view that it is essential to continue to support the YODKWP to meet the unique needs of people with Younger Onset Dementia. The intention to transition the YODKWP funding to NDIS will result in poor outcomes for people with YOD. As detailed in our submission, Alzheimer's Australia recommends the ongoing block

¹ Australian Institute of Health and Welfare (2012). Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

² *ibid.*

funding of core elements of the YODKWP to ensure continuity of care and better outcomes for people with YOD transitioning to NDIS.

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP under the ILC Framework to:

- 1. Deliver dementia specific early intervention services under the objectives of Stream one: Information, linkages and referrals activities**
- 2. Deliver individualised support for people with YOD under the objectives of Stream four: Individual capacity building**
- 3. Deliver dementia specific capacity development under the objectives of Stream three: Community awareness and capacity building, as well as Stream two: Capacity building for mainstream services**
- 4. Support families and carers of people with YOD under the objectives of Stream four: Individual capacity building**
- 5. Deliver dementia specific information under the objectives of Stream one: Information, linkages and referrals activities**
- 6. Support and assist people in obtaining a diagnosis under the objectives of Stream four: Individual capacity building**

About Younger Onset Dementia

It is estimated that there are approximately 25,100 Australians with younger onset dementia³. This represents approximately 8% of the total number of people with dementia⁴. 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 ages⁵. The total numbers of people with younger onset dementia is expected to increase to 36,800 by 2050⁶.

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. But the current lack of age appropriate residential care services is a huge issue for people with YOD.

According to AIHW statistics, approximately 30% of these residents under the age of 65 in residential aged care (1,901) have a diagnosis of dementia⁷. Even though the total numbers of people with younger onset dementia within residential care are relatively small, this reflects a significant number of consumers who are living within a care environment that in most cases is not age appropriate and often in a situation where care staff struggle to meet the needs of the person with dementia. This can lead to an exacerbation of symptoms and poor quality of life.

These numbers also suggest that only 8% of people with younger onset dementia are currently living in residential aged care, with the majority residing within the community. This likely reflects both a desire by families to keep younger people at home for as long as possible as well as the lack of adequate arrangements in residential aged care to support this group. Thus community based specialised care and support is critical to meet the needs of people with YOD and their family and carers.

³ ibid

⁴ It should be noted that these figures are based on analysis of international prevalence data which has been applied to Australian demographics.

⁵ Alzheimer's Australia (2014). Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research. Canberra: AA

⁶ AIHW op. cit.

⁷ Australian Institute of Health and Welfare (2014). Residential aged care and aged care packages in the community 2012–13. Canberra: AIHW

Younger onset of Dementia Key Worker Program (YODKWP):

In 2013, Alzheimer's Australia received funding from the then Department of Health and Ageing (now Department of Social Services) to develop the YODKWP, with funding secured through to 2016. This program provides a key point of contact for the person with dementia and their family throughout the dementia journey 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 this group of clients who in the past had often been shuffled between the disability and aged care systems. For the first time, people with younger onset dementia now have advocates to assist them in navigating this complex service environment. The YODKWP 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 journey with dementia.

In addition to providing support directly to people with younger onset dementia and their family and carers, the 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 Fronto-Temporal 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 dementia⁸.

"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 YOD)

⁸ Op. Cit RANZCP 2013.

The YODKWP thus provides specialised support to the individual and family carer in circumstances where there are no appropriate services, poor understanding of dementia and confusion about the roles of the aged care and disabilities systems.

Programs like 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 SA)

Access to appropriate supports in the community, including respite, community care and key workers, is essential to delaying entry into residential care. 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 system⁹. Yet with the move to NDIS with its current focus on delivery of Tier 3 services, there is now a risk that essential services which have recently been developed to support younger people will soon be dismantled.

Despite the excellent progress of the YODKWP both in improving quality of life for clients but also in assisting in developing appropriate services in the sector, there is every indication that this program will be subsumed under the NDIS. With the NDIS's current emphasis on supporting clients with 'functional disabilities' through Tier-3 supports, this is an ill-informed approach that is not reflective of the desires of consumers, carers or experts in this area. This will lead to a range of gaps in services and supports for people with younger onset dementia.

Issues with transitioning YODKWP to NDIS

Background

Alzheimer's Australia has been informed by DSS that the YODKW program will be transitioned into NDIS as the trial sites come online. To date, funding from the YODKW program has been provided in-kind in NDIS trial sites. Essentially this in-kind funding is an acknowledgment that the Commonwealth is block funding a program that provides services that may fall under the remit of NDIS. The in-kind funding has had no impact on the funding for the key worker program, but was instead an accounting of time spent by key workers providing NDIS services.

DSS has recently informed Alzheimer's Australia that there is now a desire to move to a “cash-out” model in the trial sites for the YOD KW Program. In essence it is being proposed that the funding for the key worker program be transferred to NDIS in these trial sites.

Alzheimer's Australia is not supportive of the move to transfer funding from the YODKW Program to NDIS in the trial sites. Key workers provide a comprehensive range of services

⁹ Op. Cit Brown 2012.

and it is impossible to carve out certain responsibilities to be provided by NDIS in future without losing the integrity of the program. Loss of specialised dementia services offered under the YODKWP will have a huge impact on people living with younger onset dementia and their families and carers. Alzheimer's Australia's experience in trial sites so far also highlights the significant misalignments between the two programs that exist at the moment:

Ongoing impact of transition of YODKWP to NDIS Tier 3

There are serious concerns around how the NDIS will meet the needs of people with younger onset dementia, especially with its current emphasis on the delivery of Tier 3 services and supports. Experience to date in the trial sites suggests that people with younger onset dementia have difficulty getting through the assessment process and those in the early stages of the disease are considered as not 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.

The decision to gradually dismantle the key worker model to be incorporated into NDIS is not supported by consumers or experts. There are serious concerns about how the NDIS will respond to the specialised needs of people with dementia. It is clear that the unique one-on-one service model underpinning the YODKWP, which is highly valued by consumers, will not be replicated by NDIS.

As the National Disability Services noted in their response to the Senate Inquiry into the care and management of younger and older individuals with BPSD, while there is potential for people with younger onset dementia to access better quality services under NDIS, it is not 'a given', especially for people with younger onset dementia experiencing the behavioural and psychiatric symptoms of dementia.

"These people—as they become participants under the NDIS—will have greater choice over the services they could receive, but organisations may not want to provide services to this group (this is often the experience of families). The NDIS must give consideration to how it will encourage or support the existence of specialist services for people with very challenging behaviours. The aged care sector must do likewise"¹⁰.

Without this holistic support, people with dementia and their family carers will find it difficult to navigate the service system and to get access to the support and information they require, compounding the issues faced by the person with dementia. Block funding of the YODKWP ensures that key workers can provide the services and supports early in the disease, and build capacity within the service sector and the community, ensuring that younger onset dementia clients are supported through all care settings, including residential aged care facilities.

The evidence in the trial sites to date suggests real concerns around how NDIS supports people with dementia. Alzheimer's Australia's experience in delivering support services in NDIS trial sites leads us to conclude that there is significant misalignment between service provision and support for people with younger onset dementia under the key worker model versus the NDIS. Transferring funding from this program to NDIS at this stage will leave people with younger onset dementia once again struggling to get access to assessments and the support that they require.

¹⁰ National Disability Services Submission (2012). Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD). Canberra.

By moving the YODKWP into the NDIS under the tier-3 model, key features of the program will be lost including:

- early intervention/support for clients prior to eligibility for NDIS
- capacity building in the service sector
- advocacy
- support for family and carers

These are key program elements that align well with the proposed five streams of activities that the ILC aims to implement. However, it is important to note that The YODKWP provides specialised support to people with YOD and a broader, across disability strategy will not meet the needs of YODLW Program clients. We already know that current transition plans mean that a people with YOD in trial sites are beginning to lose access to these vital services which the NDIS does not currently fund or support.

It is thus imperative that these services continue to remain block funded to ensure the continuity of care for all YODKWP clients transitioning to the NDIS. The broader structure of the key worker model is critical to the Program's service delivery, and dismantling and restructuring it under a cash-out model may lead to poorer outcomes for consumers, as our experience in trial sites already demonstrates.

YODKWP and the ILC Framework

The proposed ILC Framework for NDIS indicates that supports will be delivered through five streams of activity:

- Information, Linkages and Referrals
- Capacity building for mainstream services
- Community awareness and capacity building
- Individual capacity building
- Local area coordination

As detailed in the previous section, the YODKWP currently provides support to clients and their carer's and families that could fit broadly under all these activity streams. However, it is important to note that the services provided under the YODKWP are specialised to meet the needs of people living with dementia. People living with younger onset dementia already fall through the cracks between disability and the aged care sector, so the focus on a specialised program that is flexible to the needs of dementia, and that can follow the person with dementia through all care settings is critical.

Alzheimer's Australia has encountered some significant issues in transitioning to NDIS in trial sites such as Barwon, Hunter and the ACT. These issues highlight the inadequacy of the NDIS Tier-3 service delivery model to deal with the specific needs of people living with younger onset dementia. However these issues can be resolved through the objectives of the ILC framework, as long as the focus on dementia-specialist services is retained.

Some of these issues, and pathways through which they can be resolved are as detailed below.

1. YODKWP Services are provided before people are eligible for NDIS

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 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 necessary¹¹ thus reducing avoidable Government expenditure.

Thus block funding the YODKWP to assist people with YOD in accessing early intervention services through the NDIS will fulfil all the outcomes that are outlined under Stream one: Information, linkages and referrals of the ILC framework. As the ILC framework notes, Information is usually needed before people are able to access services and supports. Block funding will thus enable the YODKWP to work in collaboration with the NDIS to build and develop appropriate pathways to support for people living with YOD.

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP to deliver dementia specific early intervention services under Stream One: *Information, linkages and referrals activities* as outlined in the ILC framework.

2. Challenges/Support with application/planning process

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 appropriate support to implement their NDIS plan to receive services. This support would not be funded through the NDIS, and if the YODKWP is dismantled, 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.

In our experience, there are also large variances in what is considered "reasonable and necessary". e.g. one person with younger onset dementia has been given horse riding lessons, while another person was not allowed bathroom aids. (Information from NDIS working group meetings).

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

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 the NDIS continuation of block-funding for the YODKWP Program, which will enable our KW's to continue to deliver individualised support to people with YOD even before they are eligible for the NDIS. This service also aligns well with the objectives of *Stream four: Individual capacity building* under the ILC framework.

Block funding the YODKWP to deliver these supports will 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 YOD.

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP to deliver individualised support for people with YOD under the objectives of *Stream four: Individual capacity building* of the ILC Framework

3. Core services of the YODKWP which NDIS currently does not support:

There are a range of services which the key workers currently provide which will be lost when the program is brought under the NDIS. Critically, the range of services YODKWP provides is specialised and unique to the needs of people with YOD. The mainstream across disability approach of providing information, linkages and capacity development will not be suitable for people with YOD, many of whom are already impacted by the NDIS's inability to meet their needs. These include:

a. Capacity development

A critical objective of the YODKWP is to provide sector support and capacity development to meet the specific and unique needs of each client. This could include:

- Addressing gaps in services (e.g. developing programs for social engagement)
- Building capacity in the local service sector to ensure appropriate services are available
- Networking with local GP's, geriatricians and other specialists to ensure that individuals with younger onset dementia are referred to the key worker soon after diagnosis
- Networking with key workers in other states and territories to share information, examples of best-practice and provide support.

These are services that the NDIS does not formally support for YODKW clients in its current form.

A specific example of capacity development is the work key workers are doing under YODKWP to help consumers access appropriate respite services:

Respite provides an important break for the carer as well as an opportunity for social engagement for the person with dementia. Often for carers who maintain employment, respite can be an essential service¹². Unfortunately there is a lack of age appropriate respite options for people with younger onset dementia and often respite services will turn people away once they have developed behavioural symptoms¹³. This puts enormous strain on the carer and can lead to social isolation for the person with dementia.

There are examples where younger onset dementia specific respite services have been successfully developed and have had a positive impact on clients, but unfortunately these are the exception and are often due to the development work of key workers. If the YODKWP is defunded, these types of innovative solutions will be less likely to be developed.

For example, in Western Australia (WA), there is a pilot program that offers younger onset dementia specific residential respite services which was developed collaboratively by Alzheimer's Australia WA YODKWP, the Independent Living Centre of WA and Juniper (an aged care provider).

In the Australian Capital Territory (ACT), the YODKWP has developed a social engagement program where people with younger onset dementia volunteer at Greening Australia. This innovative approach provides respite for the carer while also providing opportunities for meaningful engagement for the person with dementia.

This critical element of KW's providing dementia-specific capacity development can also be delivered under the NDIS through a block-funded model. KW capacity development aligns well with the objectives and activities outlined under Stream three: Community awareness and capacity building, as well as Stream two: Capacity building for mainstream services.

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP to deliver dementia specific capacity development under the objectives of Stream three: Community awareness and capacity building, as well as Stream two: Capacity building for mainstream services of the ILC Framework

b. Support for family and carers

Through the YODKWP, key worker's 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.

Our experience has shown that in most instances, it is not just the individual who needs assistance but the family, friends and partners. With the NDIS currently not aimed at

¹² Op. Cit. Brown 2012.

¹³ Howe A (2013). Alzheimer's Australia Respite Review: Policy Paper. Canberra: AA

providing direct support to family and carers, this is another critical component of the YODKWP that risks being lost in transition under the Tier-2 model of service delivery.

It is critical that the NDIS continue to block fund provision of essential family and carer supports for people with YOD to ensure continuity of care for transitioning clients. As the ILC framework notes, Individual capacity building has the potential to benefit a range of people with disability, and their families and carers, who are eligible for an individualised funding package or who are just outside of the access criteria for the scheme and would otherwise need to test their eligibility (and therefore support the insurance principles of the NDIS).

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP to support families and carers of people with YOD under the objectives of *Stream four: Individual capacity building* of the ILC Framework

c. Information

Key workers have also supported clients transitioning into long term care and assisting to improve their quality of life by educating staff and improving social programs to meet the needs of younger people living with dementia, which are currently not in scope for the NDIS. Provision of timely information, advice, crisis prevention, referral and community development supports are vital supports that the block-funded YODKWP provides to meet client needs. There is a significant risk that these activities could disappear under the NDIS because these services cannot be purchased out of individual packages.

The ILC framework outlines the intention for the Information, Linkages and Referrals activity stream to support the development of information networks which will help people navigate the range of supports available as part of the NDIS. The YODKWP can continue to provide these services for people with YOD under an ongoing block funded model, and ensure the provision of dementia specific timely information provision.

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP to deliver dementia specific information under the *Information, linkages and referrals activities* as outlined in the ILC framework.

d. Assistance seeking diagnosis

People with younger onset dementia have difficulty getting access to a timely diagnosis. Dementia is relatively rare for people under the age of 65 and therefore doctors need to rule out a range of other conditions before considering a diagnosis of dementia. The average time between first symptoms of dementia and an accurate diagnosis is 3.1 years for people over the age of 65¹⁴. The delay for younger people is often significantly longer, with one study indicating that the duration between symptom onset and the diagnosis of younger onset dementia exceeded that of later onset dementia by an average of 1.6 years¹⁵. Often the initial symptoms of younger onset dementia can be mistaken for symptoms of mental illness and may result in misdiagnosis and inappropriate treatments. This adds to the stress for people with younger onset dementia and their families.

¹⁴ Speechly, C. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189,487-9.

¹⁵ van Vliet D. et al (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychol Med.* 2013 Feb;43(2):423-32. doi: 10.1017/S0033291712001122. Epub 2012 May 28

Key workers have played an important role in assisting some people with younger onset dementia to get access to an appropriate diagnosis including through linking clients to appropriate specialists and providing support throughout the process. Thus the support key workers provide in assisting clients getting a diagnosis, and which would not be funded under the NDIS Tier 3 service delivery catalogue, will have a huge impact on people living with YOD.

Similar to the provision of support for family and cares, assistance in obtaining a diagnosis enhances Individual capacity building as outlined in the ILC framework and has the potential to benefit a range of people with disability, and their families and carers, who are eligible for an individualised funding package or who are just outside of the access criteria for the scheme and would otherwise need to test their eligibility.

Alzheimer's Australia recommends that the NDIS continue to block fund the YODKWP to support and assist people in obtaining a diagnosis under the objectives of *Stream four: Individual capacity building* of the ILC Framework

Conclusion

People with younger onset dementia struggle to get access to appropriate care and support both within the community and in residential care. Historically, there has been a lack of clarity of the roles of the disability and aged care systems in providing support and people living with younger onset dementia already fall through the cracks between disability and the aged care sector.

The Younger Onset Dementia Key Worker Program, which was established in 2013, has provided consumers for the first time with much needed specialist support and advocacy in getting access to appropriate services. This Program has also worked with the service sector in developing specialist programs and services such as innovative approaches to respite.

In summary, the integrated approach of the YODKWP in working with people from the point of diagnosis throughout the dementia journey and being linked in to the service sector is essential to supporting the person with younger onset dementia and their family and carers. While the NDIS can provide supports in some aspect, if particular functions are carved out, this would take away from the benefits of having a single point of contact which can provide specialist support throughout the dementia journey and link people to appropriate services and supports.

YODKWP clients need dementia specific services that cannot be delivered by broader disability focussed tier-2 and tier-3 supports. It is very important to note that the services provided under the YODKWP are specialised to meet the needs of people living with younger onset dementia. While the proposed ILC framework may be able to deliver the activities outlined above for people with dementia in the future, it is important to note that this cannot be delivered through a generalist approach aimed at mainstream service providers. Alzheimer's Australia recommends the ongoing block funding of core elements of the YODKWP to ensure continuity of care and better outcomes for people with YOD transitioning to NDIS.