



# **Capability and Culture of the NDIA**

**A Dementia Australia submission to Joint Standing Committee on the National Disability Insurance Scheme**

**December 15, 2022**

This page is left blank intentionally

## Contents

Dementia Australia.....	4
Dementia in Australia.....	4
Introduction.....	4
Younger onset dementia.....	5
Summary of Recommendations.....	5
Dementia knowledge among NDIA staff.....	6
Person-centred approach to NDIS planning.....	6
Support Coordination.....	8
Complexity with Navigating the NDIS.....	9
Timeliness.....	9
Collaboration between aged care and disability systems.....	10
Staff Consistency.....	11
Engagement of family and carers.....	11
Conclusion.....	12

## **Dementia Australia**

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the estimated half a million Australians living with dementia and 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Founded by carers more than 35 years ago, our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

## **Dementia in Australia**

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. There are estimated to be almost half a million Australians currently living with dementia and around 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be almost 1.1 million people living with dementia by 2058.<sup>1</sup>

## **Introduction**

Dementia Australia welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS). Dementia Australia's submission to the inquiry into the Capability and Culture of the National Disability Insurance Agency (NDIA) is informed by feedback from people with younger onset dementia, their families and carers, as well as Dementia Australia staff. This submission primarily focuses on the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants accessing information, support and services from the Agency.

## **Younger onset dementia**

Although it is more common in older people, dementia is not a natural part of ageing and it affects people in their 40s, 50s and even 30s. The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia. Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia and their families.

The Australian Institute of Health and Welfare (AIHW) estimates that around 27,800 Australians had younger onset dementia in 2021 and this number is projected to increase to 39,000 by 2050.<sup>ii</sup>

Some people living with younger onset dementia rely on support through the NDIS to enable them and their families to live well with their diagnosis of dementia. Broadly, people with younger onset dementia have mixed views of the NDIS; where some describe the benefits reaped from the NDIS, others have described their experiences to be ‘frustrating, confusing and distressing’. The key issues for people with younger onset dementia in their experiences with the NDIA include the following outlined below.

### **Summary of Recommendations**

1. Provide mandatory dementia education for all NDIA staff with a focus on person-centred care
2. Implement an automatic pathway to Support Coordination and planning directly with the NDIA for those living with a degenerative condition
3. Develop NDIS dementia navigator
4. Provide greater transparency and improved communication throughout the NDIS processes and decision making
5. Develop an integrated referral pathway between the disability and aged care systems to ensure people with younger onset dementia receive timely access to appropriate services
6. Amend the NDIS rules for nominees to reflect the needs of people with a cognitive impairment, who may require family and carers to act on the individual’s behalf

## **Dementia knowledge among NDIA staff**

Dementia Australia staff and people impacted by younger onset dementia identify inconsistent dementia awareness amongst NDIA staff, which has impacted the quality of NDIS plans to meet the specific needs of people with younger onset dementia. There is a lack of understanding and recognition within the NDIS structure and approach that dementia is a progressive condition, and this lack of knowledge is apparent in the exclusion of carers and family engagement during assessments, capacity building supports and creating and managing plans.

“We have all come across planners who really do not understand the nature of the various forms of dementia and who have judged our clients on how they presented on the actual day of their meeting, which of course has resulted in a plan that has been inadequate for many our clients’ needs.” Dementia Australia staff member

It is essential that NDIA staff, including planners and local area coordinators, receive training and education on complex disabilities such as younger onset dementia. Mandatory dementia education should be embedded into the training for all NDIA staff. Mandatory dementia training should also be reflected in the NDIS Act.

“They will need an in-depth knowledge of dementia. They will need to be sensitive to other people's needs and forms of communication. They will need training and prior experience. They will need to have access to medical records and any previous assessments, neurological or otherwise. They will need good communication and observation skills. They will need to look for non-verbal cues and behaviours. They will need to include any carers, guardians, family, or friends either with the client or separately. The assessment may need to be conducted over several sessions as clients' condition can vary day by day and fatigue and medications may affect condition.” Former carer

## Person-centred approach to NDIS planning

Reports from people with younger onset dementia and Dementia Australia staff identify inconsistencies in the quality of the NDIS planning process. Ultimately, without a mandatory requirement for training in dementia, planners do not consistently possess the necessary skills and knowledge to conduct productive planning meetings. Unlike other disabilities,

dementia can impact individuals in different ways – the progression, type and severity of symptoms will vary depending on the type and stage of their dementia. A ‘one-size fits all’ approach to care planning simply does not work for people with dementia; support plans must be tailored to the individual and reflect each individual’s goals and values.

The experiences relayed to us indicate that support planning processes are not always collaborative, and many planners arrive with pre-determined ideas of what is best for the client, despite not having a conversation with the individual about their preferences for support. Conversely, where planners understand younger onset dementia, individuals have reported positive engagements with the NDIS. Planners who had dementia-specific skills better understood the challenges the individual with younger onset dementia was facing and this meant they were able to direct individuals to effective supports and construct an effective NDIS plan. As such, when planners understand younger onset dementia, there is a marked improvement in the experience of participants, and to the effectiveness of NDIS plans in supporting people with dementia. Engaging people with dementia in a meaningful and sensitive manner during planning meetings is central to developing person-centred plans, which reflect an individual’s values and preferences. However, the experience of multiple people with younger onset dementia indicate that planning meetings can be intrusive, cause stress for the individual and are not conducive to a collaborative conversation about their care. Specifically, people with younger onset dementia have described their planning meetings to be too long, fatiguing and use overly-invasive questioning– which makes people feel uncomfortable and resistant to engage.

‘Give people with cognitive issues more time to do an actual plan meeting. NDIS staff members should come out and answer questions and provide information rather than just showing up to fill out an application.’ Person living with younger onset dementia

Tailoring NDIS meetings to ensure they enable people with a cognitive impairment to participate – for example, by reducing the length of meetings and ensuring questions are not overly complex – would represent a more person-centred approach to NDIS meetings for people with dementia.

Additionally, cognitive disorders are not adequately considered throughout the planning process and may lead to results that falsely inflate an individual’s level of functioning. For example, the World Health Organisation Disability Assessment Schedule (WHODAS) - which

is the main instrument of assessment utilised at planning meetings - is primarily based on physical limitations. This neglects the reality that whilst those with cognitive impairment may be physically well, their cognitive capacity is not given equal weight during their assessment. These systemic issues impact the funding provided and are not reflective of the lived experience of those living with neurodegenerative conditions. The inclusion of more questions pertaining to cognitive capacity would better match the plan to the individual's needs.

### Support Coordination

One of the main objectives of the NDIS is to build capacity with the aim to reduce the likelihood of future supports. This is challenging for people living with a degenerative condition such as younger onset dementia who will require more support over time, not less. Support coordination is offered as a capacity building support with an eligibility criterion that the individual is likely to develop the skills and confidence needed to be able to navigate the NDIS independently. The lack of understanding of dementia as a progressive condition is reflected in the approach to support coordination as the needs of people with dementia become more complex over time, risks to their health and welfare increase and, at the same, time their capacity to make decisions and have input into the processes impacting them declines.

Informally, we had been advised by the NDIA that people with neurodegenerative conditions should be allocated to NDIS planners as opposed to Local Area Coordinators (LACs) due to their complexity. If a person has a planner develop the plan (instead of an LAC), a support coordinator is typically automatically assigned. Unfortunately, many LACs seem all too unaware of this protocol and will conduct the assessment themselves, meaning that obtaining a support coordinator becomes a lot more challenging. Support coordination becomes more critical for a person with increasing needs and decreasing capacity to participate and understand NDIS processes. Dementia Australia staff report difficulties for clients if support coordination is not included in a first plan, in seeking for it to be approved in subsequent plans.

‘Overall, I have found NDIA staff quite open and amenable to changes. However, the LAC had no degree of empathy, and just ‘do their own thing.’ Person living with younger onset dementia



Support coordination is highly beneficial for people with younger onset dementia. People with younger onset dementia who are also supported through the access request process and pre-planning tend to receive plans that match their needs more closely than clients who do not have this support. Dementia Australia staff report that some clients without support coordination do not end up fully optimising the potential of their plan due to lack of understanding on how to best utilise their funding, e.g., only using their plan for cleaning. Additionally, the lack of support coordination has an impact on carers, as they end up being the ones who must set-up and coordinate supports whilst managing medical appointments, their own schedules, work, or young children which adds excessive stress and impacts their ability to provide care.

Having an automatic pathway to Support Coordination and planning directly with the NDIA for those living with a degenerative condition would help ensure people living with dementia are supported throughout the NDIS process.

## **Complexity with Navigating the NDIS**

### Timeliness

One of the anticipated advantages of the NDIS is the ability to review and amend plans as people's needs change. However, time delays in reassessment can make these processes ineffective and impact on participant's timely access to appropriate support. Additionally, the move to 2–3-year plans without review is a decision that does not consider the needs of people living with dementia. In 2-3 years, a person with dementia's needs will have changed and increased, and the change of circumstance review process is complex and poorly understood by participants and their nominees. This is noticeably problematic where support coordination is not funded. In planning with participants who have a degenerative condition a one-year plan should be automatic rather than having to request it.

‘Accessing the NDIS is difficult and confusing with a total lack of complete answers.’

‘You receive a phone call and are told your planning meeting is in two weeks in many cases. The literally confusing amount of paperwork you have to provide most of which have no real bearing on their disability.’ Person living with younger onset dementia

Greater transparency and improved communication throughout the NDIS processes and decision making is needed so participants clearly understand why decisions about their

application, plans and reviews are being made. NDIA decisions should be delivered in a sensitive and transparent way, that takes into consideration the unique communication and cognitive needs of people with younger onset dementia. In addition, all participants should have easy access to a follow up contact, with whom they can discuss the rationale for a decision outcome.

Given the unique challenge of navigating the disability and aged care systems, Dementia Australia recommends that a single NDIS dementia navigator be funded.

### Collaboration between aged care and disability systems

People with younger onset dementia currently may require supports through two separate systems – aged care (My Aged Care) and disability (NDIS). The siloed working of both systems creates a complicated process for people with younger onset dementia, who are often precariously placed between both systems.

Existing supports under the NDIS do not have the capacity to fully meet the needs of a person with dementia. A partnership between the NDIA and My Aged Care would ensure that the right package of supports is being provided to everyone, reduce excessive wait times for support and remove the duplication of assessment administration. A common example raised by people with a lived experience of younger onset dementia is the challenge of obtaining an Aged Care Assessment Team (ACAT) assessment under the Aged Care system. Many people with younger onset dementia are being turned away from My Aged Care and told they can only access aged care services once they have exhausted all other options. Yet, the reality is, younger people are only accessing aged care supports because there are currently limited support options across either the disability or aged care sectors that meet their needs. For example, there are challenges around accessing residential care or respite care options which can provide ongoing supports that meets the unique needs of people with dementia (let alone younger onset dementia). To access aged care support, individuals end up relying on the NDIA to communicate with My Aged Care effectively and clearly about what is required from the aged care system. This imperfect process often creates a significant time delay to accessing supports. A partnership approach between the NDIA and My Aged Care would underpin more effective communication between both systems and thus make it easier for people with younger onset dementia to access aged care services when they need them. Ultimately, identifying the interdependencies between both

systems and carving out a single pathway is necessary if we want to prevent people with younger onset dementia from falling through the cracks of the disability and aged care systems.

The disability and age care systems should commit to working collaboratively to create a single pathway for obtaining supports. The single pathway should remove the requirement for people with younger onset dementia to engage with dual systems to receive the support they require. This partnership approach, where both systems create a streamlined pathway for accessing supports, would reduce the confusion and complex administrative burden that delays access to support for people with younger onset dementia.

### Staff Consistency

Consistency within the NDIA staffing has been reported as a concern for plan management. People living with dementia have reported follow up issues from planners and local area coordinators (LACs). LACs are written into plans or plan implementation and follow up, but most of the time clients report never hearing back from them and not being able to contact them to follow up for themselves. The contact centre staff are generally helpful with simple queries, however if the question is more complex it can be challenging to find an answer, and there is no clear way to connect with someone who is qualified to assist. It would be helpful to have a 'go to' point of contact in the NDIA to either answer questions or follow up to make sure they are answered.

### Engagement of family and carers

Whilst the NDIS Act includes provisions to allow family members or carers to be engaged in NDIS processes, in practice family and carers often feel restricted from engaging in meetings. Specifically, some advocates described planners as reluctant to allow family members to respond to questions – therefore pressing the individual with dementia to answer, even when they may not have cognitive capacity to do so. People with dementia and their carers report overly intrusive and difficult planning meetings that exclude the involvement and support of an advocate or family member. The red tape around client involvement means that people with dementia are required to attend and be involved in their planning meetings, even if it is not their preference to do so. There is also a reported gap in knowledge among NDIA staff that people with dementia often lack insight into their own

capabilities and needs, and that a carer's report is an essential source of information. For people with dementia who do not have family or an advocate, the NDIS is very difficult to navigate, access and use effectively. These people often miss out on access where they would have been eligible due to lack of ability to understand and navigate the system. The consequence of this is that if people with dementia are not funded for support coordination, their needs/goals are often not met through their plan.

'I was advised that the person with dementia would have to answer a series of questions. I advised the person that my wife would find that a significant challenge and would be unlikely to be able to answer the questions accurately. I asked for the questions and was told I could not have them... After a vigorous discussion I was given all the questions but advised I could not prompt my wife because that was in breach of the Act.' Carer of a person with Younger Onset Dementia

The NDIS rules for nominees should be amended to reflect the needs of people with a cognitive impairment, who may require family and carers to act on the individual's behalf. NDIA staff should actively encourage the engagement of family members and carers – where the individual has given consent to do so. Where an individual has indicated a preference for an advocate to act on their behalf, NDIA staff should honour this.

## **Conclusion**

Dementia Australia would welcome the opportunity to work closely with the NDIA to ensure that the concerns of people living with dementia, their families and carers are responded to and that the NDIA processes are supportive of people impacted by younger onset dementia.

We thank the Committee for considering this submission and would welcome any further opportunities for consultation.

---

i *Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra*

ii *AIHW (2022). Younger onset dementia: new insights using linked data*