



**Senate Community Affairs
Legislation Committee's Inquiry
into the National Disability
Insurance Scheme Amendment
(Getting the NDIS Back on Track
No. 1) Bill 2024**

Dementia Australia Submission

May 2024

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

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 living 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.

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Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054, a projected percentage change of 93%.ⁱ More than 1.6 million people in Australia are involved in the care of someone living with dementia.ⁱⁱ

Dementia is the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women.ⁱⁱⁱ

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. It is now also recognised that dementia affects individuals across the lifespan including children, teenagers, and young adults. There are over 100 rare genetic conditions that can cause childhood dementia.^{iv}

In 2024 it is estimated there are almost 29,000 people living with younger onset dementia. This figure is projected to increase to almost 41,000 by 2054.^v

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.

Introduction

Dementia Australia welcomes the opportunity to make a submission to the Senate Community Affairs Legislation Committee's inquiry into the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024. Our submission is informed by feedback from people living with younger onset dementia, their families and carers, as well as Dementia Australia staff.

Dementia Australia has made submissions to several National Disability Insurance Scheme (NDIS) inquiries in recent years, and we refer you to those for further information about the experience of the NDIS for people impacted by younger onset dementia – see <https://www.dementia.org.au/submissions>

In this submission, we focus on the considerations for people living with younger onset dementia and their carers as it pertains to the NDIS Amendment Bill. Dementia Australia also supports the issues and recommendations outlined in the submissions by the Young People in Nursing Homes National Alliance (YPINHNA) and the Neurological Alliance Australia (NAA).

Until the specific Rules for the Bill are released, it is difficult to determine how these proposed changes will affect individuals living with younger onset dementia. We advocate for a co-design approach and consultation with those who have lived experience to ensure that the development and implementation of these rules respond to the unique needs of people living with dementia and their carers. Dementia Australia recommends our comprehensive guide to meaningful engagement with people living with dementia, families and carers called **Half the Story**.

Considerations of the Bill for people living with younger onset dementia

Definitions and eligibility criteria

The Bill amends the definitions and criteria related to NDIS supports and participants. Changes in how supports are defined and classified could impact what services are available to people living with dementia, especially those with complex care and support needs.

The emphasis on meeting "disability requirements" and "early intervention requirements" needs careful consideration to ensure that people with younger onset dementia are not inadvertently excluded due to the nature of their condition, which might not always fit traditional disability or early intervention frameworks.

The need for timely support and responsiveness is critical in supporting progressive conditions such as younger onset dementia. The variable nature of these conditions means that the needs of individuals can change rapidly. The legislative framework must therefore be designed to accommodate this variability.

“When my husband was first diagnosed with early onset Alzheimer's our GP and Specialist advised us that this would be an automatic acceptance to NDIS as he was only 54. Within a month he had to stop working and driving. So I submitted all the paperwork and reports to NDIS. Unfortunately, the NDIS denied our application twice - it wasn't until I went to the office in person and spoke with them that they decided to accept our application - which of course took months to approve. We were already financially under pressure.” Carer

“The first application was declined which meant a need to reapply. This just adds to stress you already have to deal with. In later stages of [redacted]’s condition he ran out of funds which contributed to his condition deteriorating.” Carer

Currently, people experience extended waiting periods for access decisions to be made, resulting in missed opportunities to receive vital support which underscores the urgency for more timely decision-making processes.

Needs assessment

The proposed changes to the Bill depend on the implementation of a needs assessment process which, at present, remains vague. Younger onset dementia is progressive and degenerative, meaning the assessment process must be evidence-based and timely to accommodate rapidly evolving needs.

“NDIS terms and focus are based on skill/ capacity building. For those suffering from dementia this is often not appropriate as this is a degenerative disease, so skills are lost not built.” Carer

“My experience has been that I’ve had to educate LAC’s on dementia or at least my particular younger onset dementia. It’s not a bad thing, that I’m advocating, but I strongly believe that NDIS should be trained about types of dementia and their symptoms.” Person living with younger onset dementia

There are concerns about the possible use of standardised assessments to determine the level of support required for people living with younger onset dementia. The assessment process needs to be sensitive and appropriate to identify and capture the particular and progressive needs of those with younger onset dementia.

Additionally, there are concerns about whether assessors will have the necessary skills and knowledge to appropriately evaluate and understand the unique challenges faced by individuals with younger onset dementia. A current lack of understanding of younger onset dementia has led to inadequate plans for some that do not meet their progressing needs. It is therefore essential that there is sufficient dementia training and education for those conducting assessments.

“My NDIS LAC was unable to capture the details of my diagnosis of early onset dementia, posterior cortical atrophy. The LAC failed to understand the impacts of my diagnosis. By not reading and understanding our submission it became inaccurate and inadequate before it was put in place.” Person living with younger onset dementia

Funding and supports

The revised definition of what qualifies as a NDIS support in section 10 of the Bill poses potential risks, especially for those with progressive conditions if section 10(a)(iv) restricts or omits essential health supports funded as disability related health support. Additionally, it remains uncertain if participants can challenge decisions about what qualifies as a ‘NDIS Support’ or contest the categorisation of a support.

Additionally, the Bill introduces new concepts of “flexible” and “stated supports”. Flexible supports can be spent on supports of the participant’s choice as long as they are deemed to be within the scope of disability supports relevant to the participant’s impairment and meet the support criteria in Section 10, which as stated above is dependent on the new definition of NDIS supports. Stated supports specifies funding for particular supports. This could help in securing necessary aids or services that are critical for dementia care, such as specialised therapies or carer training.

Under the new framework plans, a person will receive a flexible budget and a fixed budget. Flexible funding allows funding to be allocated to a range of NDIS supports as needed, which can be beneficial for adapting to the progressive nature of dementia.

Rules and definitions around these funding mechanisms should be clear and inclusive of the specific needs of people with dementia, enabling access to a broad range of required supports without unnecessary restrictions.

It is unclear in the Bill how the early intervention or permanent disability pathways will engage with foundational supports and how the supports available between service systems will be

accessed. To effectively support people living with younger onset dementia, it is essential that supports provided by states and territories are tailored to meet their needs. Coordination between state and territory systems and the NDIS must be strengthened to prevent systemic gaps in care.

Navigation and support coordination

People living with younger onset dementia and carers frequently report their frustration with the complexity of navigating the NDIS system. This negative experience often leads to adverse consequences for the participant, as they struggle to effectively advocate for the supports they require and secure them in their plan.

“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

Support coordination facilitates access to necessary services, system navigation, and adjusting care plans as needs change. Support coordination for people with complex, changing needs, such as those with younger onset dementia, increases their chances of receiving comprehensive support tailored to their progressive condition.

Plan management and reassessment

The Bill outlines procedures for the reassessment of plans and introduces conditions under which plans can be adjusted or funding can be rolled over.

Flexible reassessment schedules and rollover provisions that reflect the variable progression of dementia could ensure that people living with dementia and their families can plan long-term without the risk of losing essential funding.

It has been reported to Dementia Australia that it is currently taking up to six months for a change of circumstance to be actioned within the NDIA. This delay can have significant effects on people living with dementia and can leave them without necessary support, leading to declines in their physical health, emotional well-being, and overall quality of life. Delays can also increase the burden on carers, who must fill the gap left by the lack of appropriate supports. Additionally, without timely updates to funding or services, families may incur out-of-pocket expenses to meet urgent needs, leading to financial stress.

“My first plan was a mess and after intervention by the administrative appeals it was more relevant to me. It remained so until covid and for three years I have not been able to meet with a NDIS planner.” Person living with younger onset dementia

“In the first instance when my change of circumstances had to go to arbitration, it took two years and many submissions, several appearances before an arbitrator before I was finally heard and the change to my home was agreed to. It was really very difficult because at the time I was and I am losing my ability to read/ and write (type) as I still am.” Person living with younger onset dementia

Conclusion

The NDIS Amendment Bill introduces several changes that could significantly impact people living with younger onset dementia, their families and carers. Although the Bill presents opportunities for more tailored and flexible care approaches, it also poses potential challenges and until the Rules are released, we cannot determine how and the extent to which these changes will affect people living with younger onset dementia, their families and carers.

Dementia Australia advocates for a co-design approach and consultation with those who have lived experience to ensure that the development and implementation of the Rules genuinely reflect the needs of the dementia community. We welcome further opportunities for consultation to ensure the NDIS is responsive to the needs of people impacted by younger onset dementia, their families and carers.

ⁱ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.

ⁱⁱ Based on Dementia Australia's analysis of the following publications - Department of Health and Aged Care, 2020 Aged Care Workforce Census Report, 2020, p. 6; Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023

ⁱⁱⁱ Australian Institute of Health and Welfare (2023) Dementia in Australia, Summary, Impact <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

^{iv} Childhood Dementia Initiative (2023) <https://www.childhooddementia.org/>

^v Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.