



# **NDIS Participant Experience in Rural, Regional and Remote Australia**

A Dementia Australia Submission

February 22, 2024

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# Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the more than 421,000 Australians living with dementia and more than 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.

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## Introduction

Dementia Australia welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS). Our submission is informed by survey feedback from people living with younger onset dementia, their families and carers living in regional, rural and remote Australia, and their experiences with the NDIS. Feedback has also been provided by Dementia Australia staff.

Dementia Australia has made submissions to several NDIS inquiries in recent years, and we refer you to those for further information – see <https://www.dementia.org.au/submissions>

In this submission, we focus on the key, ongoing systemic issues people living with younger onset dementia, their families and carers experience with the NDIS in regional, rural and remote Australia.

## 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 more than 421,000 Australians currently living with dementia and more than 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be over 812,500 living with dementia by 2054.<sup>1</sup>

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<sup>1</sup> Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

## 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.

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.<sup>2</sup>

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.<sup>3</sup>

Some people living with younger onset dementia and families of children living with dementia rely on support through the NDIS to enable them and their families to live well with their diagnosis of dementia. Broadly, people impacted by 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’.

## Background

Approximately 28 per cent of Australia's population resides in rural and remote areas, where they face significant barriers to accessing healthcare and support services.<sup>4</sup> This includes challenges in obtaining medical care, allied health services, and both personal and specialised care, as well as difficulties in finding suitable accommodation services like respite and residential care. The scarcity of resources and care options in these communities increases these obstacles, particularly affecting individuals with younger onset dementia, who already have limited specialised support options available, putting them and their carers at increased risk of reduced quality of life, functional decline, unnecessary hospitalisation, social isolation, carer burnout, and premature transition to residential aged care.

Furthermore, Aboriginal and Torres Strait Islander people, those from Culturally and Linguistically Diverse (CALD) backgrounds, and individuals from low socio-economic groups encounter additional barriers in accessing services due to a complex interplay of factors including historical, cultural and linguistic differences, geographical isolation, and economic constraints. The lack of culturally sensitive services, language support, and targeted outreach

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<sup>2</sup> Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.

<sup>3</sup> Childhood Dementia Initiative (2024). <https://www.childhooddementia.org/>.

<sup>4</sup> AIHW (2022). Rural and remote health.

programs exacerbates the difficulty in accessing NDIS services. Ensuring equitable access to appropriate supports tailored to meet their specific needs is crucial to mitigate these risks.

## **The experience of applicants and participants at all stages of the NDIS**

The NDIS process in regional, rural and remote areas is generally more challenging compared to urban settings due to a scarcity of NDIS staff and limited support options. Feedback has reflected that individuals living with dementia residing in regional, rural and remote locations face many challenges during the NDIS application, plan design, implementation, and review stages. Survey responses highlight significant challenges during the NDIS application process, including a lack of pre planning support, and difficulties in understanding and completing forms. Further, 75 per cent of our survey respondents stated they have experienced significant delays in communication with NDIS staff.

Additionally, the NDIS application process is particularly challenging for individuals with dementia in rural and remote areas due to limited access to medical specialists, the necessity of long-distance travel to access services and the high costs associated with both travel and obtaining necessary medical documentation. These challenges are compounded by the scarcity of healthcare resources in these areas, making it difficult to gather the comprehensive assessments required for the NDIS application.

Feedback from survey respondents highlight delays in the implementation of NDIS plans, including prolonged wait times for changes in circumstances and funding approvals. There have also been reports of extensive delays in authorising allied health services like speech therapy and occupational therapy (OT) assessment.

“Our NDIS was approved in September. The OT assessment didn’t happen until mid-December and we are still waiting a report. We have only just (late January) had a speech therapy assessment”. Carer

Feedback on NDIS plan reviews also highlight unmet needs and inadequate adjustments including a lack of funding for increased support requirements due to dementia progression and challenges in obtaining necessary modifications. Respondents to our survey also express frustration over plans being rolled over without reassessment, the struggle to secure adequate Supported Independent Living (SIL), as well as experiences of significant life changes (e.g., separation) that necessitate updated support arrangements not adequately addressed by the NDIS plan reviews. These issues are exacerbated by high NDIS and support staff turnover, which leads to poorer service quality and mistakes in the planning process. Plan reviews are often delayed and complicated, causing poor outcomes for people living with younger onset dementia, their families and carers.

The NDIS process presents significant challenges for individuals with dementia in regional, rural, and remote areas, exacerbated by a scarcity of healthcare resources, limited access to specialists, and the high costs of travel and documentation. These difficulties are further compounded by high staff turnover and limited support options, leading to delays and poor outcomes in plan reviews and implementation, particularly affecting those with younger onset

dementia and their carers. Survey feedback underscores the struggles faced at various stages of the NDIS journey, including application difficulties, implementation delays and inadequate plan adjustments, highlighting a systemic need for improved support and accessibility for this population.

## Need for dementia education

Residing in regional, rural and remote areas limits both the number of options for service providers and support workers more generally, but also means that there are few or no options for providers and support workers that understand younger onset dementia. This lack of dementia specific knowledge also extends to General Practitioners (GPs) and allied health providers. Over 60 per cent of our survey respondents rated the knowledge and understanding of dementia among local area coordinators, planners and general NDIS staff as slightly knowledgeable or not at all knowledgeable. This finding highlights the urgent need for targeted education and training programs. Such programs would not only improve the quality of care and support available to individuals with dementia but also enhance the capacity of the NDIS to meet the unique needs of this population effectively. Addressing this knowledge gap is essential for ensuring that individuals with younger onset dementia receive the specialised care and support they require to live well, particularly in underserved regional, rural, and remote communities.

“Finding competent providers and/or carers that have experience in Early Onset Dementia patients is almost impossible. Most providers and/or carers specialise in Aged care or disability care, but rarely both and never early onset dementia. When you are hoping to get insights and assistance into the ongoing care and treatment of your loved one and you know that your carers (as well as your GPs for that matter) knowledge of the disease is nowhere near your own, it puts an enormous burden back onto the family members involved.” Carer

## Inconsistent communication

Lack of consistency within the NDIA workforce has been reported as a concern, with people reporting follow up issues from planners and LACs. LACs are written into plans or plan implementation and follow up, but people with dementia and carers report never hearing back from them and not being able to contact them to follow up for themselves. Participants have also reported having to explain their situation during each contact attempt as they are directed to a new point of contact each time. High staff turnover and high caseloads for staff working in regional rural and remote areas are likely reasons for these issues.

“We have experienced planners not returning phone calls or emails and too many people involved in the approval process. We often get told different things from different NDIS staff”. Carer

“Constant delays. Original rejection of SIL funding was only received after I went into local office. NDIS promise to call and email but do not”. Carer

“Our NDIS was approved in September. The OT assessment didn’t happen until mid-December and we are still waiting a report. We have only just (late January) had a speech therapy assessment”. Carer

“During the process if the department wanted to speak with you got 5 minutes notice, so I missed a few calls as I am a shift worker as well as a carer. When I would ring the number back the person that finally answered had no clue what the call was about. This increased our waiting time by months. I’m sure there is a better way to do this.” Carer

As previously mentioned above, the findings from our survey, indicate that 75 percent of respondents experienced significant delays in communication or services, which highlights systemic issue within the NDIS that are further exacerbated in regional, rural, and remote communities, where services and supports are already limited. The data highlights an urgent need for the NDIS to streamline its processes, improve efficiency in communication, and ensure that services are delivered in a timely manner to meet the needs of all participants, regardless of their location.

## Limited choice and control

In rural, regional and remote locations, there are often limited disability provider options which can restrict client choice and control, and subsequently impacts the quality of the care received. There have been instances of monopolies by single service providers in some regions and that these providers can impose rates significantly above the norm, further restricting client options due to inflated costs. This challenge extends to accessing specialised services and allied health services which often necessitates seeking assistance from providers located far away and leads to high transportation costs.

“Because of the lack of carers in these areas, providers can charge whatever they like. Where the published rate was meant to be a maximum that the NDIS would pay and participants could negotiate better rates between providers, this figure is now the absolute minimum that will be charged, with some providers charging 20% above this rate for self-managed clients with no negotiation. They are still only paying their staff minimum wages, so the quality of care has not improved just the cost.” Carer

“We moved from suburbia for affordability and were surprised that most well-known and trustworthy carer organisations don’t operate in our area.” Carer

## Lack of services and supports

Feedback from staff, carers and people living with dementia highlights a lack of services in supports in regional rural and remote areas. Over 50 percent of respondents have found it difficult or very difficult to find and access NDIS funded services in their area. Additionally, nearly 60 per cent have experienced situations where a service they needed was unavailable, unaffordable or not covered by the NDIS. Survey responses highlight that it is difficult to locate services or supports that are suitable for those with younger onset dementia.

“Before I changed to a self-managed fund there were no registered providers in my postcode. If I got anyone there would be a 280 km travel fee on top of the hourly rate plus an extra 3 hours for travel.” Carer

These findings underscore a critical gap in the NDIS framework, particularly in the provision of services and supports in regional, rural, and remote areas, reflecting a broader disparity in service availability and accessibility. The situation is further exacerbated for those with younger onset dementia, for whom suitable services are even harder to locate. This lack of accessible services not only impedes the quality of life for individuals with dementia and their families but also places additional emotional and financial strain on them. Without targeted interventions and policy adjustments, individuals living in less urbanised areas will continue to face significant barriers to receiving adequate care and support. This disparity undermines the NDIS's foundational goal of providing equitable support to all Australians with disabilities, calling for tailored solutions to address these unmet needs and ensure that no individual is disadvantaged by their geographical location.

## **Experiences of Culturally and Linguistically Diverse (CALD) groups**

Information provided by Dementia Australia staff present a concerning picture of the barriers faced by people from CALD backgrounds when accessing the NDIS, particularly for non-English speaking applicants. Key issues identified include inadequate interpreter services, lack of preparedness and access to essential documents by Local Area Coordinators (LACs), inefficient communication, and process management. These challenges lead to unnecessary stress, delays in receiving support, and confusion during the planning process. The slow development of plans, despite ongoing follow-ups, further exacerbate the situation, requiring significant time investment from support persons to navigate the system's complexities.

These issues are particularly pronounced in regional, rural, and remote areas due to fewer service providers and specialists in these areas and fewer options for culturally appropriate support. Additionally, increased distance from service centres makes it harder to access in-person meetings, requiring reliance on potentially unreliable communication methods. The availability of interpreters, especially for less commonly spoken languages, is likely to be even more limited outside of metropolitan areas. Potential limitations in internet access and digital literacy can hinder online application processes and virtual meetings. There may be a greater gap in awareness and understanding of the NDIS process among both potential applicants and local service providers in regional areas.

These factors underscore the need for targeted strategies to improve NDIS accessibility and support for CALD individuals, ensuring that the system is inclusive and equitable.

## **Conclusion**

The feedback from Dementia Australia staff, people living with younger onset dementia and their carers highlights challenges in service provision, staff consistency, and client choice in



regional, rural, and remote Australia, highlighting the need for more robust support structures for NDIS participants in these regions. This submission aligns with our previous submissions on the NDIS, where we have outlined detailed recommendations aimed at improving accessibility, service delivery, and support mechanisms for individuals with younger onset dementia.<sup>5 6 7</sup> We reiterate our support for these recommendations and express our endorsement of the proposals put forward by the Neurological Alliance Australia (NAA) to this Inquiry. We appreciate the opportunity to contribute to this Inquiry and welcome the opportunity for further discussion.

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<sup>5</sup> Dementia Australia (2023). NDIS Review. [https://www.dementia.org.au/sites/default/files/2023-09/NDIS-Review-Submission\\_acc.pdf](https://www.dementia.org.au/sites/default/files/2023-09/NDIS-Review-Submission_acc.pdf)

<sup>6</sup> Dementia Australia (2023). NDIS Quality and Safeguarding Framework Submission. <https://www.dementia.org.au/sites/default/files/2023-08/NDIS-Quality-and-Safeguarding-Framework-Consultation.pdf>

<sup>7</sup> Dementia Australia 2022. Capability and Culture of the NDIA. <https://www.dementia.org.au/sites/default/files/2023-01/Dementia-Australia-Submission-to-The-Capability-and-Culture-of-the-NDIA-Inquiry.pdf>