NDIS Rules: New Framework Planning

March 2026

Introduction

Dementia Australia welcomes the opportunity to provide input to the Department of Health, Disability and Ageing’s consultation on New Framework Planning (NFP).

Dementia Australia is the peak body representing people of all ages living with dementia including people living with young onset dementia and the estimated 1,500 children living with childhood dementia in Australia, as well as their carers and families.[1]

Dementia is a progressive and life limiting illness that is now the leading cause of death in Australia.[2] In 2026, it is estimated there are 446,500 people living with all forms of dementia in Australia. Without a significant intervention, this figure is projected to increase to over 1 million by 2065.[2] There are an estimated 1.7 million Australians involved in the care of people with dementia.[1]

Young onset dementia refers to any dementia diagnosed in adults aged 18-65. In 2026, an estimated 29,000 Australians live with young onset dementia, projected to increase to an estimated 41,000 by 2054.[3]

People with young onset dementia often receive a diagnosis during prime working, parenting and financially demanding years. The condition’s progressive trajectory which is characterised by gradual loss of cognitive and physical function, means that support needs will increase over time. All people living with young onset dementia are potentially eligible for NDIS supports yet based on the latest data provided by the NDIA only a small proportion are accessing the scheme.

Dementia Australia consultations with people with living experience highlights that the NDIS is not consistently meeting the needs of people living with young onset dementia. Experiences highlight a lack of transparency in decision-making, significant variability in planning outcomes, and a system that is not well designed to respond to the progressive and fluctuating nature of dementia. Outcomes are often dependent on the dementia knowledge and capability of planners, assessors and providers, with limited understanding of cognitive impairment often leading to underestimation of need. People living with young onset dementia and their carers also report challenges navigating the scheme, including difficulties understanding

---

[1] Based on Dementia Australia’s analysis of the following publications - National Dementia Action Plan; Australian Institute of Health and Welfare (2024) 2023 Aged Care Provider Workforce Survey: Summary report, AIHW, Australian Government

processes, providing and understanding what constitutes appropriate evidence, and effectively advocating for supports. Together, these factors highlight that meeting the needs of people living with young onset dementia requires a system that is transparent, dementia-capable, and responsive to those with cognitive impairment.

We support the intent of NFP to improve consistency, reduce administrative burden and create more transparent budgets. However, the proposed reforms represent a fundamental structural shift in how support needs are assessed and funded. As currently designed, there is a significant risk that the new framework planning may not adequately capture the needs of people with progressive cognitive conditions, including those with young onset dementia.

The use of the Integrated Assessment Tool (IAT) in Aged Care has demonstrated the importance of ensuring assessment tools are validated across different cohorts, including cognitive impairment, assessors are appropriately trained, and implementation is closely monitored to identify unintended impacts. These learnings should be carefully reflected in the development and rollout of the New Framework Planning approach.

Concerns about the accessibility of NDIS consultations have been consistently raised by consumer advocacy groups. Dementia Australia strongly encourages the Department to ensure that future consultations include accessible formats, plain language materials and targeted engagement opportunities so that people with lived experience can participate meaningfully in policy development.

Step 1: Preparing for the Support Needs Assessment Process

Under the NFP arrangements participants will receive a Notice of Impairments and a Notice to have a new framework plan, alongside information to prepare for a support needs assessment. While this aims to improve transparency and readiness, there are significant concerns regarding the clarity, accessibility and practical usability of this information for people living with dementia.

For people with young onset dementia, cognitive impairment can make it difficult to process complex written information, understand procedural steps, and prepare effectively without support. Current materials are often fragmented and highly technical. This aligns with broader experiences in the NDIS, where participants and carers frequently describe the system as overwhelming and difficult to navigate.

> *“The very act of getting onto NDIS was the biggest challenge. So bureaucratic and confusing to a layperson. Need an advocate to help you apply.” – Person living with dementia*

Those with the greatest needs are often the least able to advocate for themselves, while their carers are frequently stressed, time-poor and managing significant emotional and practical burdens. This creates a paradox where those most in need of support are at greatest risk of being under-represented in assessment processes.

Importantly, people living with dementia may lack insight into their own needs due to cognitive impairment. As noted in staff feedback, “just because someone says they don’t need support doesn't mean that is true. They may lack insight into their disability.” Equally due to the stigma and fear about the loss of independence people living with dementia can be reluctant to disclose or acknowledge their full support needs, resulting in underestimation of need during assessment processes.

While the proposed framework allows participants to have a nominee, family member or advocate attend the support needs assessment, there is limited clarity regarding the role and weight of their input. For people living with dementia, who may have reduced insight into their own needs, carers and support persons play a critical role in accurately describing functional impact and support requirements. Without clear guidance on how this input is considered, there is a risk that assessments may rely too heavily on participant self-report and not fully capture need.

> *“People with certain dementias, commonly significantly overstate their capacity. And if they live alone, the person living with dementia may not have a support person with the required knowledge to help inform this.” Carer*

Recommendation:

- That all assessment information should be accessible, dementia-friendly and clearly explain participant rights, the role of the assessment, and how decisions will be made.
- Participants should be given sufficient notice and actively supported to prepare for assessments, including through the involvement of carers or advocates.

Step 2: The Support Needs Assessment

Overview of key concerns

Under the proposed framework, participants will undergo a standardised support needs assessment, including the use of tools such as I-CAN and a personal and environmental circumstances questionnaire (PECQ), with the resulting assessment report directly informing funding decisions. While this model aims to improve consistency and equity, ensuring validity and appropriateness for people living with progressive cognitive conditions such as young onset dementia is critical.

It is widely recognised that the current system can result in funding decisions that are inconsistent and not reflective of actual need. Feedback from Dementia Australia staff working with clients with young onset dementia indicates that “budgets are not standardised and often are not reflective of client needs.”

While greater standardisation has potential to improve funding equity, there is a risk that replacing assessor discretion with structured assessment tools may introduce a different form of inequity if those tools are not fit for purpose for people living with dementia and do not adequately capture the complexity, progression and variability of conditions such as dementia. Moreover, standardised tools require the person administering them to have knowledge, skills and education in dementia to correctly utilise the assessment tool.

Limitations of standardised assessment for dementia

Structured assessments such as I-CAN rely on interview-based responses and provide a snapshot of functioning at a single point in time. For people living with young onset dementia, this approach is inherently problematic. Dementia is characterised by progressive decline and fluctuating capacity, and individuals may present differently in structured assessment settings compared to their everyday environments, they will also have times of the day where they experience variation in cognitive ability and have changes on a day-to-day basis. Cognitive impairment may also affect a participant's ability to accurately report or recognise their needs.

There is currently limited evidence available regarding the validity of the I-CAN tool for progressive cognitive conditions. Dementia Australia also notes a lack of clarity on whether the I-CAN tool has been specifically validated for use in determining individual funding levels within the NDIS.

Dementia also spans multiple domains, including cognitive, behavioural, physical and communication impairments which can create increased support needs when considered holistically. This complexity does not always align neatly with structured assessment tools, creating a risk that support needs may be underestimated or not fully captured.

In addition, assessment approaches must recognise that dementia is a progressive condition characterised by declining functional capacity, while also acknowledging that rehabilitation and reablement-focused supports can play an important role in helping people with young onset dementia maintain independence and delay functional decline. For people living with dementia, the primary goal of many supports is not rehabilitation but maintaining function, slowing decline and supporting participation. If assessment frameworks rely on improvement-based assumptions or value-for-money considerations tied to measurable functional gains maintenance-based supports may be undervalued or excluded.

Assessor capability

The accuracy of assessments will depend heavily on assessor capability in dementia. Evidence from Dementia Australia staff working with people living with young onset dementia indicates that plans are more likely to meet participants' needs when planners and Local Area Coordinators have a strong understanding of dementia. Conversely, a lack of condition-specific expertise can result in misinterpretation of needs and inappropriate planning outcomes. The effectiveness of standardised assessment tools is also inherently dependent on the skill, experience and judgement of the person administering them.

> *"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*

This risk is heightened in a model that relies on standardised assessments as the primary source of evidence.

> *"It would be of huge benefit if NDIS required their assessors to be engaged in ongoing training to ensure they have an adequate understanding of the disabilities. What will be funded depends on the assessor's judgement of whether or not it is "necessary" to support the individual to live independently. This is incredibly frustrating". Carer*

Real-world impacts of assessment and planning decisions

We have heard from staff and people with living experience that changes in assessment and planning processes can lead to people losing supports they have relied on for many years, even though their condition has not improved. This is particularly concerning for people living with dementia, where needs increase over time.

There are also concerns that supports such as exercise physiology or physiotherapy are not funded consistently, with decisions sometimes influenced by how "value for money" is interpreted. For people with dementia, these supports are vital for maintaining function, independence and quality of life.

> *"A review by NDIS resulted in removal of all my allied therapy. Exercise Physio, Counselling and Podiatry."- Person living with dementia*

While participants may request a replacement Support Needs Assessment or seek internal or external review, the consultation materials do not provide clarity on expected timeframes, interim funding arrangements, or how supports are maintained during the review process. For people living with progressive conditions such as dementia, delays in reassessment or reinstatement of supports can lead to rapid functional decline.

The Reviews and Appeals fact sheet confirms that a replacement Support Needs Assessment may increase, decrease or not change assessed support needs. This creates a significant disincentive for participants to seek review where they believe their needs were underestimated.

Recommendations

- The NDIA should publish evidence on the validity and reliability of the I-CAN tool for people living with young onset dementia and other progressive cognitive conditions. Where this is not considered sufficient by stakeholders, further testing and validation should be undertaken before the tool is implemented.
- Support Needs Assessors must undertake mandatory specialised training in dementia and progressive neurological conditions.
- Dementia Australia and relevant consumer advisory bodies (such as the NDIS Participant Reference Group and Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPRAG)) should be consulted on the assessment tools and assessor training requirements prior to implementation.
- Assessment processes must recognise the progressive and fluctuating nature of dementia, including variability in functioning and the impact of cognitive impairment on a participant's ability to self-report needs. They should allow flexibility in how information is gathered, including multiple sessions where required and the involvement of carers, nominees and treating clinicians.
- Plans must allow timely adjustment where support needs increase, without unnecessary procedural barriers or delays.
- Assessment frameworks and associated funding methodologies must recognise that supports for progressive conditions such as dementia appropriately focus on maintaining function and quality of life.. Value-for-money considerations should reflect the role of allied health and therapeutic supports in maintaining independence and delaying functional decline.
- Participants and their carers or nominees should have the opportunity to review and respond to draft assessment reports before finalisation.
- Replacement Support Needs Assessments should be accessible and timely where there are concerns about accuracy, participant distress, communication barriers or assessor expertise.
- The NDIA should closely monitor assessment outcomes during implementation to ensure that the new framework does not result in unintended reductions in supports for people living with dementia.

Step 3: Building a Plan

Under the proposed framework, a participant's total budget will be determined through a standardised budget method based on the outputs of the Support Needs Assessment, with funding divided into flexible and stated supports. While this model seeks to improve transparency and consistency, it represents a significant structural shift in how funding decisions are made.

For people with young onset dementia, needs can change rapidly within a plan period, and flexibility has been essential in allowing supports to be adapted accordingly. Staff emphasise that flexibility enables creative and responsive support arrangements and allows funding to be reprioritised as needs evolve. Reductions in flexibility, or an over-reliance on stated supports, may limit the ability to respond effectively to progression and could result in poorer outcomes.

> *"A person's disease often progresses faster than the approval for appropriate funding, requiring another submission of a plan review & further delays in receiving support." – Dementia Australia staff*

There is also limited transparency regarding how assessment outputs will translate into final funding amounts. While the framework promises clarity, the budget method rules remain technical and are not yet fully available. Without clear explanation of how progression, variability and complexity are weighted within the calculations, there is a risk that the model may not adequately reflect the realities of progressive cognitive conditions.

There is also a lack of transparency regarding how personal and environmental factors, including informal support provided by family and friends, will be factored into the assessment process. While the framework indicates that informal supports will be reflected in budget calculations, it is unclear how this will be applied in practice. There is a significant risk that informal supports may be assumed to be available and sustainable, resulting in reduced funded supports and increased burden on carers.

> *"Not to use the fact that family and friends may help on occasions. NDIS is not paying them the governmentt is already saving hundreds of millions by family and friends doing small things. The NDIS should not be able to cut funding or refuse NDIS because of that." Carer*

Recommendation:

- Informal supports should not be assumed in needs based funding calculations, recognising the significant and often unsustainable burden experienced by carers.
- Greater transparency is provided on how assessment outputs are translated into funding decisions, including clear justification where supports are reduced or not funded in line with assessed need.

Step 4: Using a Plan

The final step of the proposed framework focuses on how participants use their plans, including the distinction between flexible and stated supports and any restrictions on funding use. While the intention is to support effective use of funding, there are potential risks in the practical implementation of plans for people living with dementia.

Many participants with young onset dementia experience cognitive impairment that affects their ability to understand, manage and navigate their plans. As previously noted, participants often find the system "overwhelming" and "confusing". Without appropriate support, there is a risk that participants may be unable to effectively use their funding, leading to underutilisation of supports or disengagement from the system.

The framework proposes that participants may have an implementation meeting with a NDIA delegate to understand their budget and connect with providers. While this may assist some participants, it is unclear whether these meetings will be routinely offered or whether additional support will be available for people with cognitive impairment who require ongoing assistance to manage their plans. A single implementation meeting is unlikely to be sufficient for participants experiencing progressive cognitive decline. Moreover, the NDIA delegates must be trained in working with someone experiencing cognitive decline.

There are also concerns about how participants will navigate plan requirements such as funding restrictions, stated supports, provider eligibility requirements and quoting processes. Without adequate guidance and support coordination, participants may struggle to access funded. Recent fraud and integrity measures implemented by the NDIA have also made some participants and carers concerned about inadvertently using funds incorrectly. Dementia Australia has heard that some participants are hesitant to use their funding for fear of making an honest mistake and being subject to compliance action or moved to a NDIA-managed plan. This may discourage participants from using their supports and contribute to underutilisation of funding. Clear and accessible pathways must also exist to adjust supports where needs change over time.

Recommendations

- Participants be provided with clear, accessible information about how to use their plans, including the distinction between flexible and stated supports.
- Ongoing guidance should be available, particularly for people with cognitive impairment, and regular check-ins should be built into the system to ensure plans remain appropriate over time.
- Clear pathways for raising concerns, adjusting supports and seeking reviews should also be developed.
- NDIA staff providing support must be trained in dementia.

Conclusion

Dementia Australia supports the intent to improve equity and consistency within the NDIS.

However, we have significant concerns about the proposed changes being able to accurately capture complex, progressive and fluctuating conditions, and to ensure that funding decisions are informed by both standardised assessments and clinical expertise.

The capability of the assessment workforce, the collection and monitoring of data on assessment outcomes, and mechanisms to identify and respond quickly to unintended impacts are vitally important.

Dementia Australia looks forward to continued engagement to ensure the new framework is fit for purpose and delivers equitable outcomes for people living with dementia and their families.

References

1. Childhood Dementia Initiative. *Childhood dementia facts and statistics*. 2025; Available from: **https://www.childhooddementia.org/health-professionals/understanding-childhood-dementia**.
2. Australian Institute of Health and Welfare, *Dementia in Australia*. 2025, Australian Government.
3. Dementia Australia, *Commissioned AIHW Dementia Prevalence Data 2024-2054*. 2023, Dementia Australia.