

Inquiry into the Administration of the National Disability Insurance Scheme (NDIS)

A Dementia Australia Submission

January 2026

Introduction

Dementia Australia welcomes the opportunity to provide feedback to the Joint Committee of Public Accounts and Audit's inquiry into the administration of the NDIS. We have taken a focus on how the NDIA monitors, measures and reports performance for people with young onset dementia.

Dementia Australia is the peak body representing people of all ages living with dementia including the 29,000 people living with young onset dementia (aged less than 65 years) and the 1 in every 2,900 babies born with a condition that causes childhood dementia, as well as their carers and families. All people living with young onset dementia are potentially eligible for NDIS supports yet based on the latest data provided by the NDIS only a small proportion are accessing the scheme.

Dementia is a progressive and life limiting illness that is now the leading cause of death in Australia.^[1] In 2026, it is estimated there are 446,500 people living with all forms of dementia in Australia. Without a significant medical breakthrough, this figure is projected to increase to over 1 million by 2065.^[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 an estimated 41,000 by 2054.^[2] There are an estimated 1.7 million Australians involved in the care of someone with dementia.¹

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

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

time. Many NDIS processes, rules, and performance measures still assume skill development or stabilisation while not reflecting the realities of progressive neurocognitive decline.

This submission outlines gaps in NDIA performance visibility for this cohort and recommends practical steps aligned to the Committee's terms of reference.

NDIA performance reporting: Current state

Public NDIA performance reporting currently includes:

- Quarterly Reports to Disability Ministers
- Annual Performance Statements
- Data and Insights dashboards covering 15 primary disability types
- Participant outcomes reports and national/regional outcomes dashboards
- Market, pricing and integrity reporting

However, across these reporting mechanisms, dementia is not visible as a distinct participant cohort.

Visibility of NDIA performance for participants living with dementia is poor

Despite the significant and growing impact of young onset dementia there is currently no dedicated dementia-specific performance reporting in NDIA public dashboards or outcomes publications.

Absence of dementia-specific dashboards

The NDIA publishes participant dashboards across fifteen disability groups. Dementia does not appear as a standalone dashboard or sub-cohort and is typically included under "Other Neurological". This results in a systemic blind spot when it comes to NDIS access, experience and outcomes for people living with dementia.

Outcomes reporting not disaggregated for dementia

While outcomes reports and dashboards track independence, daily living, participation and carer experiences, they do not provide any dementia-specific results. This prevents assessment of the Scheme's effectiveness in maintaining function or delaying decline outcomes for this cohort.

Integrity reporting lacks a dementia lens

The Fraud Fusion Taskforce and broader integrity initiatives report aggregate actions against non-compliance. However, reporting does not distinguish impacts of NDIA integrity activities, including fraud detection, compliance and enforcement actions, on participants with cognitive impairment, nor identify whether these activities contribute to unintended under-utilisation or loss of legitimate supports. Based on consultation with people with young onset dementia accessing the scheme, participants report being fearful of making errors in using their funding and the possible consequences. They report not fully understanding approvals, rules and

processes and that easy read documentation and hard copy documentation is often not available. Evidence from the Dementia Australia Advisory Committee (DAAC) NDIS special meeting indicates that participants and advocates experience significant challenges due to limited dementia-specific knowledge among NDIA staff, including planners and Local Area Coordinators. These gaps contribute to misunderstandings about the progressive nature of dementia, inconsistent decision-making, and plans that do not adequately respond to participants' evolving support needs.

Evaluation and data linkage (Investment Effectiveness Program) lacks dementia-specific analysis

The NDIA's Investment Effectiveness Program (IEP) seeks to measure the link between funded supports and participant outcomes. However, no dementia-specific sub-studies or analyses are publicly reported, limiting the Scheme's ability to understand which supports meaningfully sustain function or reduce downstream costs (e.g., avoidable hospitalisations, premature entry to aged care).

Recommendation

To address the JCPAA's terms of reference and strengthen Parliament's and the public's ability to monitor NDIA performance, especially for dementia, Dementia Australia recommends:

Establishing dementia -specific performance reporting

- Create a dedicated dementia dashboard within NDIA's Data & Insights site, aligned to Quarterly Reports and Annual Performance Statements, with public data tables.
- Minimum metrics should include:
 - Access and planning timeliness (Participant Service Guarantee timeframes) and outcomes for new access requests and plan reassessments
 - Plan characteristics (budget components, support types, assistive tech, home & community supports)
 - Market indicators (provider density, wait times, cancellations, thin markets signals)
 - Functional outcomes (Activities of Daily Living (ADLs), cognitive supports effectiveness, carer outcomes), leveraging the Outcomes & Goals framework with dementia disaggregation
 - Review and appeal metrics (AAT/NDIS Commission interactions where relevant)
 - Safeguards/integrity (complaints trends, fraud/compliance activities affecting dementia supports)

Conclusion

The absence of dementia from NDIA performance reporting obscures whether the Scheme is effectively supporting people living with dementia.

Data is available to enable dementia-specific reporting across existing NDIA publications, but it is not currently reported. Reporting this data will improve transparency, accountability, inform pricing and policy, strengthen safeguarding, and ensure Parliament has the data required to assess whether the Scheme is functioning effectively for this growing cohort.

Dementia Australia welcomes the opportunity for further discussion.

References

1. Australian Institute of Health and Welfare, *Dementia in Australia*. 2025, Australian Government.
2. Dementia Australia, *Commissioned AIHW Dementia Prevalence Data 2024-2054*. 2023, Dementia Australia.