



NDIS Quality and Safeguarding Framework

A Dementia Australia Submission

29 May 2023

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the more than 400,000 Australians living with dementia and 1.5 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. There are estimated to be more than 400,000 Australians currently living with dementia. It is one of the largest health and social challenges facing Australia and the world and without a significant medical breakthrough, it is estimated that there will be more than 800,000 people living with dementia by 2058.ⁱ In 2023, it is estimated there are more than 28,650 people with younger onset dementia, expected to rise to more than 42,400 people by 2058. This can include people in their 30s, 40s and 50s.ⁱⁱ

Introduction

Dementia Australia welcomes the opportunity to provide this submission on the NDIS Quality and Safeguarding Framework. Our submission responds to most of the questions identified in the paper and draws on the experience of people living with dementia, their families and carers.

Dementia is an umbrella term used to describe the symptoms of a large group of neurocognitive conditions that cause progressive decline in function. Dementia is more than memory loss - symptoms include impairments to speech, reasoning, visuospatial ability, emotional response, social skills and motor function. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is an incurable, terminal condition. However, many people with dementia, particularly those diagnosed in early stages, can expect to live with the condition for many years. It is imperative that we support people with dementia to live well, with dignity, respect and autonomy. Dementia still lacks recognition as a progressive cognitive disability despite it being the single greatest cause of disability in older Australians (people aged 65 and over)

and the third leading cause of disability overall.ⁱⁱⁱ Dementia also impacts children and results from progressive brain damage and is caused by over 70 rare genetic disorders.^{iv}

Our submission responds to most of the questions identified in the terms of reference, focusing on people living with dementia and draws on the experience of people living with dementia, their families and carers.

What is working well about the Framework? What is not working well to promote safeguards of people with disability and the quality of supports?

Dementia Australia broadly support the objectives and principles of the current NDIS Quality and Safeguarding Framework and acknowledges the importance of the Framework in promoting safeguards and quality supports for people with disabilities. Some aspects of the Framework that are working well include:

- The establishment of the NDIS Quality and Safeguards Commission (NDIS Commission) as an independent regulatory body responsible for oversight and compliance.
- The introduction of the NDIS Code of Conduct, which sets clear expectations for the behaviour and ethical standards of workers and providers.
- The provision of complaint mechanisms and procedures to address concerns and ensure participant safety.

However, there are areas that need improvement:

- **Accessibility:** The Framework should address accessibility issues faced by people with dementia, ensuring that information, supports, and complaint mechanisms are accessible and tailored to their specific needs.
- **Dementia-specific expertise:** The Framework should recognise the unique challenges faced by people with dementia and promote the availability of specialised dementia training and supports for NDIS staff and service providers.
- **Focus on capacity building:** The capability of people living with dementia will decline as dementia progresses and the NDIS needs to be able to respond to this more appropriately, recognising that NDIS participants with dementia will need more support overtime, not less.

“Improve the level of governance over support service providers to ensure support workers are appropriately trained in all aspects of dementia care, personal care etc. support providers should be required to show evidence of their ongoing training commitment. Governance in terms of agreements being fit for purpose and reflective of the parties to them. Can someone with dementia meet the obligations outlined.” - Carer of a person living with dementia

Is there still a need for a Framework? If so:

What role should the Framework play going forward?

There is a continued need for a Framework to ensure the quality and safeguarding of NDIS supports. The Framework should aim to promote person-centred care, protection from harm, and the rights and dignity of people with dementia.

A future Framework should prioritise the following:

- Inclusion of dementia-specific considerations, including accessible information and tailored supports for people living with dementia.
- Strengthened collaboration between the NDIS Commission, healthcare professionals, and dementia organisations to ensure a coordinated approach to quality and safeguarding.
- Enhanced safeguards against financial abuse.
- Enhanced decision-making supports for individuals with impaired capacity.
- Regular reviews and updates to reflect evolving best practices, emerging issues, and the changing needs of people with dementia.

“Providers overcharge and there’s nothing that can be done once the bill has been paid and the NDIS won’t report provider. There’s no accountability.” - Carer of person living with dementia

What monitoring of the implementation and ongoing effectiveness of the Framework is required?

Ongoing monitoring should include regular evaluations of the effectiveness of the Framework in safeguarding people with dementia and ensuring quality supports and collaboration with consumer advocacy groups, including those representing people living with dementia, to gather feedback and ensure continuous improvement.

What supports, services, and actors should the Framework cover?

The Framework should cover a wide range of supports, services and actors to ensure comprehensive quality and safeguarding measures. Specifically, it should encompass participants with diverse needs, including those with younger onset dementia, childhood dementia as well as those with co-existing disabilities or complex care requirements.

What changes are required to the roles and responsibilities of different actors in the Framework?

How could these actors work together better to deliver a coordinated approach to quality and safeguarding?

To achieve a coordinated approach, the roles and responsibilities of different actors within the Framework should be clarified and enhanced. Suggested changes include:

- Strengthened collaboration between the NDIS Commission, healthcare professionals, and dementia organisations to share information, expertise, and best practices.
- Increased engagement and involvement of people with dementia and their families in the design, implementation, and monitoring of the Framework. Dementia Australia has released, *Half the Story: A guide to meaningful consultation with people living with dementia, families, and carers*¹. By utilising *Half the Story*, the NDIS Quality and Safeguarding Framework can benefit from incorporating dementia-accessible co-design principles, fostering genuine participation, and addressing the unique needs of individuals living with dementia.
- Clear guidance and expectations for service providers to ensure a person-centred approach and adherence to quality dementia care.

“Providers don’t understand person-centred care and the NDIS agreement doesn’t reflect a client that has dementia. There are obligations put on the person with dementia which shows laziness from support provider and not considerate of the person. Just trying to tick boxes and make money without providing an adequate level of support.” – carer of someone with dementia

What changes are required to the types of strategies and measures implemented under the Framework?

How should the Framework go about balancing different priorities, such as the balance between protecting people with disability from harm and promoting their choice and control; and the balance between ensuring regulatory approaches support market entry and quality service delivery while protecting participants who are at risk of harm?

Balancing Priorities: The Framework should strive to strike a balance between protecting people with dementia from harm and promoting their dignity of risk, choice and control. This can be achieved through:

- Risk assessment processes that consider individual needs, preferences, and capacities to determine appropriate levels of support and safeguards.
- Clear guidelines and training for workers and providers on person-centred approaches and supported decision-making for people with dementia. The new NDIS Supported Decision Making Policy should be responsive to the needs of individuals with progressive cognitive disabilities, including dementia, ensuring their inclusion in decision-making processes. Dementia Australia's supported decision-making position statement² offers a valuable framework for promoting autonomy and self-determination for people with dementia.

¹ *Half the Story A guide to meaningful consultation with people living with dementia, families and carers* (2022): <https://www.dementiafriendly.org.au/sites/default/files/2022-10/Half-the-story.pdf>

² Dementia Australia (2022) Supported Decision Making: <https://www.dementia.org.au/sites/default/files/2022-10/Supported-decision-making-policy-position-statement.pdf>

- Regular review and evaluation of the effectiveness of strategies and measures to ensure that they are achieving the intended outcomes and striking the right balance.

To balance regulatory approaches, the Framework should:

- Encourage innovative and high-quality dementia-specific supports and services.
- Implement accreditation processes that consider specialised dementia care standards and ensure providers meet quality benchmarks.
- Establish mechanisms for ongoing monitoring and evaluation to identify and address potential gaps or risks in service delivery.

What is required to drive improvements in the quality of supports and services?

Feedback received from people living with dementia and their carers highlights the urgent need for better complaints processes and mechanisms to address the barriers faced by people living with dementia.

“They may fear it may jeopardise their level of care and attention. They may worry they are being a nuisance or a burden. They may worry carers may not have the time to listen and heed their complaints.” – Former carer

These barriers undermine the ability of individuals to voice their concerns and seek resolution.

Slow response, lack of transparency, limited knowledge of available pathways, difficulty in understanding the extent of risks, confusion regarding where to report complaints and the stigma attached to disclosing vulnerabilities were highlighted as barriers to a robust complaints process.

To ensure effective complaints resolution, it is crucial to address these barriers and create a system that is responsive, transparent, easily accessible, and respectful of the rights and voices of individuals with dementia. This includes providing clear information, fostering effective communication, training staff to understand the unique needs of people with dementia, and implementing processes that prioritise the dignity and well-being of individuals.

Improving complaints processes and mechanisms is essential to empower individuals with dementia, ensure their concerns are heard and addressed, and promote a culture of accountability and quality within the NDIS.

To drive improvements in the quality of supports and services, the Framework should include:

- Mandatory education and training for workers in dementia care, person-centred approaches, and evidence-based practices.
- Regular evaluation and feedback mechanisms from participants, including people with dementia and their families, to inform service improvements, such as complaints.
- Collaboration with dementia organisations and researchers to develop and disseminate best practice guidelines specific to dementia care.

What is required to ensure the regulation of providers and workers is proportionate and effective?

- Regular auditing and inspections of providers to assess compliance with quality and safeguarding standards.
- Collaboration between the NDIS Commission, regulatory bodies, and industry stakeholders to share information and coordinate efforts, reducing duplication and ensuring proportionate regulation.

Conclusion

Dementia Australia broadly supports the NDIS Quality and Safeguarding Framework. The Framework should recognise the importance of working with people living with dementia, their families and carers to co-design solutions, as well as continued support to build on the evidence base in legislation, policy and programs that result in improved outcomes. Improving and/or maintaining independence, choice, control and giving people the right to make their own decisions for as long as possible should be a priority. This includes the need for education but also the need for clear and transparent processes to support people who do raise concerns.

i Australian Institute of Health and Welfare (2022) *Dementia in Australia*, AIHW, Australian Government, accessed 20 January 2023.

ii Australian Institute of Health and Welfare (2022) *Dementia in Australia*, AIHW, Australian Government, accessed 20 January 2023.

iii Australian Institute of Health and Welfare (2012) *Dementia in Australia*

iv Childhood Dementia Initiative (n.d.). *What is childhood dementia?* Childhood Dementia.