NDIS Provider and Worker Registration Taskforce

May 2024

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.[i] 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.

The Dementia Australia Policy team can be contacted at **policyteam@dementia.org.au**

Introduction

Dementia Australia welcomes the opportunity to make a submission to the National Disability Insurance Scheme (NDIS) Provider and Worker Registration Taskforce. Dementia Australia has made submissions to several NDIS inquiries in recent years, including **NDIS Participant Experience in Rural, Regional and Remote Australia**, **NDIS Review** and **NDIS Quality and Safeguarding Framework**.

It is important to continue to involve people with living experience of dementia in the reform process and genuinely engage them, especially those with experience of the disability sector. Our submission is therefore informed by feedback from people living with younger onset dementia, their families and carers, and their experiences with the NDIS. Feedback has also been provided by Dementia Australia staff who are directly involved in supporting people with younger onset dementia to access the NDIS.

Dementia Australia recommends that consultation with people living with dementia aligns with **Half the Story: A guide to meaningful consultation with people living with dementia, families and carers**.

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.[ii]

Younger onset dementia

Dementia is more common in older people, but it can also be diagnosed in people in their 30s, 40s and 50s. 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. People with younger onset dementia – who often receive a diagnosis when they are in full-time employment and raising and financially supporting a family – is often 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.[iii]

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.

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. Feedback from our consultations with this younger cohort reveal mixed views about the efficacy the NDIS. Some individuals acknowledge the benefits of NDIS support while others have described their experiences as 'frustrating, confusing and distressing'.

How do you currently engage with the NDIS?

As an advocacy organisation for people living with dementia and their carers, Dementia Australia engages with the NDIS by participating in consultations to influence the development of NDIS policies and practices.

Additionally, we assist with supporting clients to gain access to the NDIS through our counselling, post diagnostic support and family education sessions.

What do you think of the proposed levels of registration and enrolment in the Report?

The proposed levels of registration and enrolment, designed to be risk-proportionate, are a positive step towards simplifying the regulatory environment and making it more responsive to the risks presented by different types of supports. However, specialised services and supports for those with younger onset dementia can be difficult to access, and there are currently significant constraints on access to dementia care services in regional, rural and remote areas. With the implementation of this new regulatory model, some providers may be discouraged from remaining in the system, further exacerbating access issues.

In regions with limited provider availability, mandatory registration could lead to a scarcity of services, negatively impacting those with dementia.

“We moved from suburbia for affordability and were surprised that most well-known and trustworthy carer organisations don't operate in our area. Haven't found the small local organisations we've tried very satisfactory. So, I've used Mable and word of mouth to find carers. This has been an arduous and sometimes disappointing process. We now have some great carers, but if they have a holiday or are sick, there's no back up.” Carer

“Before I changed to a self-managed fund there were no registered providers in [redacted] 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

Action 17.1*: The Department of Social Services and the new National Disability Supports Quality and Safeguards Commission should design and implement a graduated risk-proportionate regulatory model for the whole provider market. This should be developed in consultation with people with disability, providers and other regulators. The model should include mandatory registration or enrolment of all providers, with requirements proportionate to the risks of a provider’s activities and operations.

This should provide full visibility of the market, incorporate requirements that are more finely tuned to risk, and address gaps, excessive burdens and duplication in current requirements. New supports and functions proposed in other recommendations (including Navigators, Lead Practitioners and foundational support providers) should be regulated under this model to ensure appropriate safeguarding of people with disability and avoid creating gaps in regulation. The implementation of this model should be informed by the development of a provider risk framework that identifies and evaluates the risk profile of different types of supports and providers.

Dementia Australia supports the proposed graduated, risk-proportionate model as this model facilitates the delivery of services that correspond to the risk they present, thereby ensuring that all care levels—from lowest risk to highest—are provided with the necessary oversight and competency. Additionally, this model would make a significant contribution to people living with dementia receiving high-quality and appropriate care as well as the support needed to make informed choices about that care.

Further, it is important to note that a person with dementia can experience complex challenges and higher perceived risks. For services classified under the proposed model as ‘lowest/low risk’, such as cleaning or maintenance, workers who are not educated on how to engage with someone living with dementia can inadvertently cause distress or confusion. Therefore, it is crucial to ensure that all service providers, regardless of the risk level of their services, receive training on the specific needs of people living with dementia.

We support the emphasis on consumer engagement and consultation in developing this model. Involving people living with dementia and their carers in shaping these regulations and training programs ensures that the services are aligned with their needs.

What key features of the proposed model are important to you?

Action 17.4*: The Department of Social Services, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should expand the coverage of worker screening requirements.

Worker screening should be mandatory for all individuals working in risk assessed roles for registered providers, and all individuals working for enrolled providers in roles where normal duties include the direct delivery of specified supports or services to people with disability or are likely to require more than incidental contact with people with disability. Expanding worker screening requirements to these roles would support a more risk-proportionate approach to regulation, ensuring workers do not pose an unacceptable risk to people with disability.

Expanded worker screening requirements should be informed by engagement with people with disability, providers, workers and unions and adopted as part of the new regulatory model (see Action 17.1). This should be accompanied by mandatory basic online training for workers to understand their obligations.

We strongly advocate for dementia-specific training and education for workers providing services to people living with dementia, as it is essential for delivering high-quality care. Such training ensures that carers are equipped with the knowledge and skills to meet the needs of people living with dementia, enhancing the effectiveness of their care. Furthermore, involving people with lived experience of dementia in shaping these training requirements is crucial. Their direct input can define what competencies are necessary, ensuring that the training is relevant and truly beneficial.

What is the most important thing to you that you want the Taskforce to consider when developing their advice?

Action 17.5*: The Department of Finance and the Department of Social Services, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should improve, streamline and harmonise worker screening processes for care and support workers. Expanding worker screening requirements to more NDIS workers (see Action 17.4) should be supported by efforts to improve the operation of the worker screening process. This should include urgent work to reduce timeframes, improve consistency across jurisdictions and streamline and harmonise checks across the care and support sector.

Dementia Australia advocates for strong quality assurance measures within the model, ensuring that care providers and workers for people with dementia are regularly assessed so that unreliable workers cannot slip through the cracks, and move around the sector (s) including interstate.

> “When we have support workers who are supporting people with dementia, more governance of quality of people working in the space is needed.” Carer

In your view, how can the proposed model uphold the rights of people with disabilities, including the right to live independently and be included in the community, be free from violence, abuse, neglect and exploitation, have an adequate standard of living and economic and social participation?

The proposed model for regulating NDIS providers has the potential to uphold the rights of people with disabilities by fostering independence and ensuring that a wide range of service options and provider types are available within the regulatory framework. This diversity supports the fundamental right of individuals to make personal choices about their care and living arrangements, promoting their autonomy and inclusion.

To protect individuals from violence, abuse, neglect, and exploitation, the model includes comprehensive safeguards. These include stringent worker screening and training requirements, alongside robust audit and feedback mechanisms as outlined in Action 17.6. Such measures ensure that all service providers adhere to high standards of safety and care, thereby safeguarding the well-being of people with disabilities, as this is an issue that has been raised by people living with dementia and their carers in previous consultations.

> “‘Providers overcharge and there’s nothing that can be done once the bills been paid- won’t report provider a – there’s no accountability.’ Carer

The proposed model emphasises reducing unnecessary regulatory burdens on providers, which can facilitate the provision of quality and accessible services. By streamlining processes and eliminating duplicative requirements, the model helps ensure that high-quality services are not only maintained but are also made more affordable and accessible. This approach supports an adequate standard of living and boosts social and economic participation for people with disabilities.

Crucially, the model advocates for ongoing consultation with the disability community at every stage of developing the regulatory actions. This inclusion ensures that the voices of people with disabilities are central to shaping the policies that directly affect their lives, further reinforcing their rights and ensuring that the regulatory framework is responsive, effective, and equitable.

Conclusion

The proposed new, graduated, risk-proportionate model for the regulation of providers and workers presents several benefits aimed at enhancing the quality and safety of services within the NDIS. However, for individuals living with younger onset dementia and their carers, this proposal raises concerns about the potential to reduce the choice and availability, especially in areas with limited service options, such as regional, rural and remote areas. Dementia Australia advocates for a nuanced approach that balances the necessity for increased regulation to protect vulnerable individuals with the need to preserve personal choice and control over care decisions. A balanced approach would ensure safety without compromising the quality of care or accessibility.

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

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