The National Disability Insurance Scheme Review

A Dementia Australia submission

August 22, 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.

Introduction

Dementia Australia welcomes the opportunity to make a submission to National Disability Insurance Agency (NDIS) Review (the Review). Our submission is informed by feedback from people living with younger onset dementia, their families and carers, as well as 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 and proposed solutions.

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 400,000 Australians currently living with dementia and around 1.5 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be over 800,000 people living with dementia by 2058.[1]

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

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

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 2023 it is estimated there are more than 28,650 people living with younger onset dementia. This figure is projected to increase to more than 42,400 by 2058.[2]

It is now also recognised that dementia affects individuals across the lifespan, including children, teenagers, and young adults. There are over 70 rare genetic disorders that can cause childhood dementia. In Australia, an estimated 2,300 children and young people currently live with dementia, highlighting the need for greater recognition and support for all age groups impacted by the condition.[3]

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’.

Summary of Recommendations

1. People living with dementia have the option to have an automatic pathway to Support Coordination.
2. Explore development of protocol for the NDIA to contact GPs or specialists directly to work through the Access Request Form.
3. Amend the NDIS rules for nominees to reflect the needs of people with a cognitive impairment who may require family and carers to act on the individual’s behalf.
4. Provide compulsory dementia education for all NDIA staff with a focus on person-centred care.
5. Implement automatic 1-year plans for people with neurodegenerative conditions.
6. Fund a single NDIS dementia navigator.
7. Provide greater transparency and improved communication throughout the NDIS processes and decision making.
8. Develop capacity in the disability sector for suitable accommodation options for those with younger onset dementia as a matter of urgency.

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

[3] Childhood Dementia Initiative (2023) https://www.childhooddementia.org/

Accessing the NDIS

People living with dementia frequently report their frustration over the complexity of navigating the NDIS system. This negative experience often leads to adverse consequences for the individual, as they struggle to effectively advocate for the supports they require and secure them in their plan. In a Dementia Australia survey, carers and people living with dementia were asked to identify issues they experience with the NDIS, and 44 per cent of survey participants reported facing difficulties in navigating NDIS processes, while 47 per cent of respondents highlighted a lack of awareness of available supports.

> “The NDIS is insanely difficult for a person to access, particularly if they have dementia or a cognitive impairment. As the daughter of a patient with dementia, I found it hard to advocate for her and access her NDIS plan due the strict rules held by the NDIS. Further to this, I called multiple people and no-one really seems to understand the processes or be able to guide you or point you in the right direction. It's a really poorly run system in my opinion and needs a lot of work in improving its framework and training those that work there in the processes.”– Carer

Many people living with younger onset dementia face challenges accessing the NDIS, particularly via the Access Request Form (ARF). Without sufficient support people living with younger onset dementia and their families reported that they were not able to complete the ARF, which caused delays. Additionally, it has been reported that some GPs struggle to accurately fill out the ARF, leading to potential system rejections. Although many GPs and specialists report being willing to support the application, they often lack understanding about the importance of providing specific details and using NDIS-relevant language. This issue is particularly pronounced in regional or remote areas, where specialists may not possess the necessary knowledge to assist clients effectively in this process.

In the experience of some people impacted by dementia, NDIA staff and Local Area Coordinators (LACs) provide insufficient support to guide people through the entire process, from application to managing their plans. Many individuals with a diagnosis and their carers are unfamiliar with accessing supports and may not see themselves as having a disability. Consequently, there is hesitation and a lack of understanding about approaching services and available options. Further, it has been reported that LACs lack the time and resources to provide adequate assistance and are unable to recommend providers.

Recommendations

When NDIA staff are assessing access requests, the streaming needs to be addressed for people with degenerative conditions. As younger onset dementia falls into this category, people living with dementia should be streamed intensive which allows for support coordination in the plan. It also ensures that the first planning meetings are held with a NDIA planner who has a broader knowledge base than LACs.

Additionally, it is recommended that in the instance further information is required for assessment, the NDIA contact the GP or specialist who has completed the form as it would alleviate the need to speak to the client themselves when consent has been given for the medical professional to do this. Speaking with the GP also encourages correct information to be disclosed at access.

Engagement of family and carers

Whilst the NDIS Act includes provisions to allow family members or carers to be engaged in NDIS processes, in practice family and carers often report feeling restricted from engaging in meetings. Specifically, some people living with dementia and carers described planners as reluctant to allow family members to respond to questions – therefore pressing the individual with dementia to answer, even when they may not have cognitive capacity to do so.

People with dementia and their carers also report overly intrusive and difficult planning meetings that exclude the involvement and support of an advocate or family member. The red tape around client involvement means that people with dementia are required to attend and be involved in their planning meetings, even if is their preference not to do so. There is also a reported gap in knowledge among NDIA staff that people with dementia may lack insight into their own capabilities and needs, and that a carer's report is an essential additional source of information.

For people with dementia who do not have family or an advocate, they report that the NDIS is very difficult to navigate, access and use effectively. These people may miss out on access where they would have been eligible due to lack of ability to understand and navigate the system. The consequence of this is that if people with dementia are not funded for support coordination, their needs/goals are often not met through their plan.

> "I was advised that the person with dementia would have to answer a series of questions. I advised the person that my wife would find that a significant challenge and would be unlikely to be able to answer the questions accurately. I asked for the questions and was told I could not have them… After a vigorous discussion I was given all the questions but advised I could not prompt my wife because that was in breach of the Act." Carer of a person with younger onset dementia

Recommendations:

The NDIS rules for nominees should be amended to reflect the needs of people with a cognitive impairment who may require family and carers to act on the individual's behalf.

Dementia Australia believes that the 2008 UN-CRPD represents an important recognition of the rights of people with a cognitive disability to make decisions about all aspects of their lives. Dementia Australia strongly supports the principles of supported decision-making for people living with dementia as this approach places the person with dementia at the centre of the decision-making process. Dementia Australia also recognises that dementia is a progressive condition, and there will be contexts in which substitute decision-making is an appropriate approach.

Acknowledging this complexity, Dementia Australia endorses the spectrum model of supported decision-making. The provision of different types of support at different stages of dementia, tailored specifically for everyone, offers an appropriate framework to guide supported decision-making for people living with dementia accessing the NDIS and support the engagement of family members and carers – where the individual has given consent to do so.

Lack of dementia knowledge

Dementia Australia staff and individuals impacted by younger onset dementia have identified inconsistent knowledge of dementia among LACs and Planners, leading to inappropriate NDIS plans that do not meet the specific needs of people with younger onset dementia. This lack of understanding includes a lack of knowledge of childhood dementia, and there have been reports of the NDIA staff not believing the children can have dementia and thus being denied access.

> “NDIS terms and focus are based on skill/ capacity building. For those suffering from dementia this is often not appropriate as this is a degenerative disease so skills are lost not built”. – carer

> “They don’t think children have dementia and parents have a hard time getting NDIS support because they [NDIA employees] don’t believe children can get dementia.” - carer

The disparity between plans completed by NDIA planners and LACs is also significant. Dementia Australia staff report that people with younger onset dementia who are assisted in the planning process by LACs do not receive support coordination and are not restreamed to intensive. This results in clients not understanding how to implement and use plans which leads to plan reviews being requested and outcomes not being achieved. Support Coordinators have also found it difficult to locate service providers with dementia knowledge.

The lack of dementia knowledge among LACs was reported as a major issue in our survey of carers and people living with dementia. Survey participants were asked about issues experienced with the NDIS and 73 per cent of respondents selected a lack understanding of dementia among LACs as their main issue.

In our survey, over 50 per cent of respondents reported having a plan that did not meet their needs at some point in time.

> “My NDIS LAC was unable to capture the details of my diagnosis of early onset dementia, posterior cortical atrophy. The LAC failed to understand the impacts of my diagnosis. By not reading and understanding our submission it became inaccurate and inadequate before it was put in place. The LAC unfortunately had no idea how to put together this application and there made this document worthless before the plan was put in place.” – Person living with dementia

Addressing issues of dementia knowledge is crucial to ensuring that NDIS plans effectively meet the specific needs of people with younger onset dementia.

> “My experience has been that I’ve had to educate LACs on dementia or at least my particular younger onset dementia. It’s not a bad thing, that I’m advocating, but I strongly believe that NDIS should be trained about types of dementia & their symptoms.” – Person living with dementia

Recommendations

Training and education

Dementia Australia recommends providing compulsory dementia education for all NDIA staff with a focus on person-centred care. Providing compulsory dementia education for all NDIA staff is critical to improving the overall experience and outcomes for participants with dementia as well as delivering additional skills in communication and understanding cognitive impairment in all forms. Such education fosters a person-centred approach, facilitates tailored plan reviews and outcomes, and empowers individuals and their support networks to actively engage in the planning process. Ultimately, it would contribute to creating more equitable, compassionate, and effective NDIS plans that meet the specific and evolving needs of people living with dementia.

Dementia education is crucial for all elements of the disability workforce. It is essential that staff – regardless of whether they are nurses, personal care assistants, front of house staff or support staff – are equipped with the necessary knowledge and skills to appropriately support people living with dementia. These skills not only need to be embedded in strategies that build the capacity of existing staff but also career and education pathways for new staff.

As vital as it is that workers in this field are responsive to the needs of the consumers they will be serving, it is equally essential to consult with the very people who will be directly impacted by the services. As such, Dementia Australia recommends having a requirement that people living with dementia, families and carers are consulted in the development of vocational training.

Consultation with service users (or potential service users) and their representative bodies will not only ensure that the training is relevant and effective, but it will also help build trust and confidence in the services provided. Moreover, the involvement of peak bodies and representatives in the training process will help to ensure that the services provided are informed by best practice and current consumer needs and expectations. This will also enhance the credibility and quality of the training and the services provided, as well as demonstrate a commitment to working in partnership with key stakeholders.

Involving people with lived experience in jobs and skills training can be achieved through a variety of methods, including focus groups, surveys, and one-on-one consultations. Half the story is a guide to meaningful consultation with people living with dementia, families, and carers and can provide a useful tool when consulting consumers. Half the story can be found here: **http://www.dementiafriendly.org.au/find-resources/half-story-meaningful-consultation**.

Plan reviews

One of the anticipated advantages of the NDIS is the ability to review and amend plans as people's needs change. However, time delays in reassessment can impact on participant's timely access to appropriate support. Additionally, the move to 2–3-year plans without review is a decision that does not consider the needs of people living with dementia. In 2-3 years, a person with dementia's needs will have changed and increased, and the change of circumstance review process is complex and poorly understood by participants and their nominees. This is noticeably problematic where support coordination is not funded.

> "Accessing the NDIS is difficult and confusing with a total lack of complete answers.' You receive a phone call and are told your planning meeting is in two weeks in many cases. The literally confusing amount of paperwork you have to provide most of which have no real bearing on their disability." Person living with younger onset dementia

Recommendations

Greater transparency and improved communication throughout the NDIS processes and decision making is needed so participants clearly understand why decisions about their application, plans and reviews are being made. NDIS decisions should be delivered in a sensitive and transparent way, that takes into consideration the unique communication and cognitive needs of people with younger onset dementia.

In addition, all participants should have easy access to a follow up contact, with whom they can discuss the rationale for a decision outcome. Additionally, in planning with participants who have a degenerative condition, a one-year plan should be automatic rather than having to request it.

Ongoing support

Staff consistency

Lack of consistency within the NDIA workforce has been reported as a concern for plan management. People living with dementia have reported 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. The contact centre staff are reportedly helpful with simple queries, however if the question is more complex it can be challenging to find an informed answer from someone who is qualified to assist. Participants have reported having to explain their situation during each contact attempt.

Recommendations

Provision for a ‘go to’ point of contact in the NDIA has been recommended as a solution to staff consistency. Additionally, having staff who are dementia educated would ensure that more staff can answer complex dementia related queries.

Lack of appropriate accommodation

Finding age-appropriate accommodation that is equipped to meet the progressive needs of people with younger onset dementia is a significant challenge. In the absence of suitable disability accommodation, the only option for many people with younger onset dementia has been to enter residential aged care. However, the Royal Commission into Aged Care Quality and Safety noted the inappropriateness of residential aged care for younger people and government policy is now to support younger people to find other forms of accommodation. An unintended consequence of this is that the lack of appropriate residential care options offered through the NDIS, combined with the strict eligibility for younger people to access residential aged care, creates significant challenges for people living with younger onset dementia, their families and carers.

Accommodation options offered under the disability system are rarely equipped to support individuals with complex neurodegenerative conditions like dementia as they are typically set up for people with disabilities that remain relatively stable over the course of their life.

> “As aged care isn’t appropriate, there aren’t many residential care facilities that can be accessed for those with younger onset. They are often too far away and in a lot of country areas they are non-existent.” - Person living with dementia

People with younger onset dementia currently may require supports through two separate systems – aged care and disability. The siloed working of both systems creates a complicated process for people with younger onset dementia.

Recommendations

Better collaboration between aged care and disability systems

Dementia Australia recognises the importance of people living with younger onset dementia accessing appropriate forms of accommodation, irrespective of the policy system through which they obtain it. The core features of quality supported accommodation, as identified by people living with younger onset dementia, their families and carers include:

- Staff who are trained in dementia care and equipped to respond to the changing care needs of people living with dementia. This is particularly important when individuals enter the end-of-life stage.
- A ‘home-like’ physical environment which is designed to support residents to live independently.
- A person-centred model of care which emphasises the value of everyone, their history, experiences and culture.

- Access to meaningful activities, which meet individual’s needs, strengths and abilities • Enablement principles guide the delivery of care to maximise and maintain the individual’s function and comfort.

A collaborative approach that improves residential care options for people with younger onset dementia in the disability space, incorporates flexible models of housing and improves staff understanding of dementia and the importance of sharing knowledge across both sectors is necessary to support people living with younger onset dementia.

Conclusion

We thank the NDIS Review for considering this submission and would welcome any further opportunities for consultation.