Support Coordination under the National Disability Insurance Scheme

A submission to the National Disability Insurance Agency

11 September 2020

About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission in response to the support coordination discussion paper as part of the review of the current support coordination service model. Our responses to the consultation questions demonstrate the critical importance of support coordination for National Disability Insurance Scheme (NDIS) participants living with younger onset dementia.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive conditions which cause progressive decline in a person’s functioning. Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer’s disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 459,000 Australians living with dementia in 2020[1] and around 1.6 million people[2] involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.[3]

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.[4]

It is generally not well understood that dementia is a progressive cognitive disability. Dementia is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.[5]

Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people but it can affect people in their 40s, 50s and even their 30s.[6]

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[1] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

[2] Based on Dementia Australia’s analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer’s Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer’s Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

[3] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

[4] Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

[5] Australian Institute of Health and Welfare (2012) *Dementia in Australia*

[6] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

The impact of younger onset dementia

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2020, there are an estimated 27,800 people with younger onset dementia. This number is expected to rise to almost 29,500 people by 2028 and more than 41,000 people by 2058.[7]

Although dementia is most commonly diagnosed in people over 65, the prevalence and impact of dementia in younger people is significant. 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.

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.

People with younger onset dementia have historically reported difficulties in accessing the support they require and finding age-appropriate services.[8] [9] While this is still a considerable challenge, effective support coordination under the NDIS enables participants with younger onset dementia to navigate complex systems and access appropriate supports to meet their changing needs. Support coordination in NDIS plans is therefore critically important for people with younger onset dementia.

> “We’re the glue that holds the plan together.” Dementia Australia support coordinator

Response to consultation questions

Inclusion of support coordination in plans

1. **What factors should be considered when determining if, when and for how long support coordination should be funded in an NDIS participant’s plan?**

Younger onset dementia is a progressive neurodegenerative disability. People with younger onset dementia, their families and carers are required to navigate a complex system of extensive services and supports to meet their changing needs. As the condition progresses, carers experience increasing stress and burden, and need support themselves. People with younger onset dementia often do not have the insight to understand the extent of their needs or have lost the ability to effectively communicate them. Consequently, coordination of

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[7] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

[8] Brown, J., Sait, K., Meltzer, A., Fisher, K. R., Thompson, D., Faine, R. (2012) *Service and Support Requirements of People with Younger Onset Dementia and their Families*, for NSW Department of Family and Community Services, Ageing, Disability, and Home Care, Sydney

[9] Stupar, M., Miskovski, K. & Moore, B. (2016) *Younger Onset Dementia: Still Slipping Through the Cracks*, Alzheimer’s Australia NSW Discussion Paper Number 16, May 2016

support should be included in NDIS plans for all people with younger onset dementia for the entire duration of the plan.

> “When my husband and I found out that I was approved for the NDIS we got in touch with our Dementia Australia NDIS support coordinator. He was marvellous! And continues to be. He stepped us through the business of getting our plan together and seeing it through to implementation. He attended meetings with us and he knew not only how to manage with NDIS questions and forms, but also making sure that the plan looked after me and my needs. He continues to be a great support and ‘go between’ with us and NDIS. I, we, could not have done it without him.” Person living with younger onset dementia

2. **Should the current three level structure of support coordination be retained or changed?**

Dementia Australia is of the view that that the current three level structure of support coordination is appropriate and should be retained.

3. **How should support coordination interact with other NDIS supports? For example, local area coordinators, community connectors, liaison officers and recovery coaches?**

In our experience, very few Local Area Coordinators (LACs) fully understand the needs of people living with younger onset dementia and are therefore limited in their capacity to support them. Planners are often hard to reach and come from other states, and therefore do not have the relevant local service knowledge.

Over time our support coordinators are developing and strengthening relationships with planners through the submission of NDIS progress reports. This building of trust and professional understanding is benefiting our clients. However, increased access to planners and greater consistency in National Disability Insurance Agency (NDIA) staff would greatly assist in improving efficiencies and responsiveness to the changing needs of NDIS participants with younger onset dementia.

4. **How should support coordination interact with and complement existing mainstream services?**

Dementia Australia support coordinators report frequently assisting hospital staff and other health professionals to understand the needs of people living with younger onset dementia as well as the NDIS processes to ensure the needs of clients are met. The value of support coordination is not always recognised or understood by doctors, specialise, hospital social workers, NDIS local area coordinators and service providers. Dementia Australia suggests that awareness raising of the value of support coordination is needed among mainstream services to ensure that support coordinators do not have to repeatedly educate staff.

5. **What can or should be done to address the level of utilisation of support coordination in plans; and is this any different to general issues of utilisation?**

Utilisation of support coordination in plans is not necessarily the most effective measure of efficiency or success. Measuring outcomes based on expenditure and not the individual needs of NDIS participants is inappropriate. If support coordinators are appropriately trained, have clearly defined roles and expectations, access to appropriate resources, and have built rapport and trust with their clients and their support networks, the clients feedback and achieved outcomes in comparison to their plan goals is the best measure of success.

> "We should not be driven by the coordination of supports plan utilisation but by our clients, the people we serve." Dementia Australia support coordinator

Role of support coordination

6. **What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?**

Dementia Australia support coordinators are very clear about the boundaries of their role. Support coordinators should empower clients and their families to make decisions about services and supports rather than make decisions on behalf of clients.

Our support coordinators work closely with other service providers and provide information to ensure NDIS participants with younger onset dementia are connected to appropriate services. The professional relationships our support coordinators develop and maintain, as well as their specialist knowledge, ensure people with younger onset dementia are appropriately connected with the multidisciplinary supports they need to achieve their goals, receive quality care, and live as well as possible with dementia.

7. **Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes?**

Although the changing NDIS landscape and areas like supported independent living (SIL) have been challenging to navigate, Dementia Australia support coordinators are skilled at providing support during transitions to residential care/accommodation. Sourcing accommodation is a small component of the support our support coordinators provide, and employment opportunities are generally not applicable to our clients. This exemplifies the challenge we face supporting clients with a degenerative condition within a scheme focused on independence, building capacity and opportunities for employment.

The strong relationships the Dementia Australia support coordinators develop with their clients ensure that they feel support during key life stages. Given the significant losses people with younger onset dementia, their families and carers are experiencing, it would not beneficial for different support coordination services during this time. The trusting relationships our support coordinators develop with their clients and their care providers are critical.

8. **How could plan management and support coordination be more closely aligned and what would the potential benefits and risks be?**

It is important for support coordinators to be able to communicate and regularly check in with plan managers regarding client funding and accounts. Generally, plan managers respond quickly to questions and permit flexible which enables quick responses to the changing needs of people living with younger onset dementia. Effective relationships with plan managers benefit the support coordinator's clients. The role of plan managers is primarily associated with the budgetary components of the plan and defined by the NDIS pricing guides. This enables support coordinators to focus on the provision of person centred support.

Quality of support coordination

9. **Should there be minimum qualification requirements or industry accreditation in place for support coordinators? If so, what might be applicable?**

The majority of Dementia Australia's younger onset dementia support coordinators have Bachelor degrees along with dementia, NDIS and support provision experience. Working in a professional landscape with allied health professionals, clinical staff and other professionals, support coordinators need to be adequately qualified.

There are clear advantages for people with younger onset dementia having the support of dementia qualified support coordinators who understand their changing needs and are connected with younger onset dementia specific supports and services. They also benefit from the dementia resources available and referral to external supports like counselling, support groups and education.

Although we have had staff members join the support coordination team with little dementia and NDIS experience, they have undertaken dementia education and transitioned well to the team, providing a high level of service to people with younger onset dementia.

Continuing professional development on NDIS processes is essential to provide the best service and outcomes for clients. The NDIA recently released online training on support coordination, however these sessions sold out very quickly and many staff members were unable to attend. There have been very few training sessions available in the past and the fact that the NDIA is now providing them is welcomed.

10. **How can the effectiveness of support coordination be measured and demonstrated?**

It is currently difficult to measure the effectiveness of support coordination broadly as there are limited NDIS guidelines for support coordinators. The lack of clearly articulated key performance indicators makes it difficult measure the scope of the role and key activities.

Dementia Australia recommends that the NDIA develop support coordination guidelines and/ or service standards which clearly outline the purpose, scope and outcomes of the coordinator role to improve the ability of all stakeholders – participants, providers and NDIA – to measure and demonstrate the effectiveness of support coordination.

11. **Are there emerging examples of good practice and innovation in support coordination?**

Dementia Australia believes that our support coordination model for people with younger onset dementia is an example of good practice and innovation. Dementia Australia has developed a support coordination manual to guide the delivery of the model and we would welcome the opportunity to discuss our practice with the NDIA.

12. **Are the levels and relativities in the NDIA price limits across different services including support coordination working effectively in the interests of participants and a sustainable, innovative market?**

Dementia Australia did not receive stakeholder feedback specific to this question, but levels and relativities need to be appropriately flexible and sustainable.

13. **Should support coordination pricing be determined, at least in part, based on progression of participant goals and outcomes, and how might this work?**

It is Dementia Australia’s view that it would be difficult for pricing to be determined based on the progression of participant goals and outcomes especially for people with a progressive neurodegenerative disability like younger onset dementia. In addition, we have concerns about how this would work in practice e.g. who would assess the progression of goals and outcomes, how would it be measured and how would it be ensure that the assessment is correct.

Building capacity for decision making

14. **How can a support coordinator assist a participant to make informed decisions and choices about their disability supports? What are the challenges?**

    "We walk beside our clients and carers to support them to build capacity when they can and to be there to provide support during crises and when making challenging decisions. We provide them with resources, information and choices; we connect them to external supports and support collaborative partnerships to allow them to make an informed decision that best meets their personal needs. Dementia is completely unpredictable and the only certainty is that they are not alone with our support." Dementia Australia support coordinator

Building capacity to understand the large range of services and government agencies they made need to navigate is often challenging for people with younger onset dementia. It can also be challenging for their carers, if they have one. In addition to making decisions with and for the person they care for, carers of people with younger onset dementia experience feelings of grief, loss and guilt as dementia progresses. They also often still working and caring for children. With the assistance of a support coordinator, participants and their carers can build their capacity, confidence and understanding of what supports are available and how to access them.

It is challenging for support coordinators though – it takes professional to manage boundaries well in an emotional charged context. Tertiary education and experience as well as good management and support assist younger onset dementia support coordinators to manage these boundaries and ensure clients do not become reliant upon them.

15. **How does a support coordinator build a participant's independence rather than reliance? Should support coordination pricing be determined, at least in part, based on building a participant's capacity for decision making to become more independent?**

As dementia progresses, people gradually lose their decision making capacity. People living with younger onset dementia progressively rely on a supported decision maker and then a substitute decision maker. By the very nature of their disability, people with younger onset dementia struggle to build their independence or capacity for decision making.

Dementia Australia therefore believes it is inappropriate for support coordination pricing to be determined based on building a participant's capacity for decision making to become more independent for people living with younger onset dementia.

16. **How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role? What are the appropriate parameters of the personal advocacy role and the support coordination role?**

It is essential for support coordinators to have clear professional boundaries and know when and how to access advocacy support for participants. Ongoing professional development and training, as well as capacity building resources, enable greater understanding of the need for advocacy.

Conflict of interest

17. **In what circumstances is it more or less appropriate for a participant to receive multiple supports from a single provider?**

Dementia Australia's view is that there is a conflict of interest and therefore not appropriate for participants to receive support coordination from a provider that is also providing SIL, social support, allied health supports etc. With access to technology, location does not need to inhibit access to support coordination from alternative providers. The quality of support that Dementia Australia has been able to provide remotely during the COVID-19 pandemic is evidence of the effectiveness of this approach.

18. **Should the IAC recommendation for the NDIA to enforce an "independence requirement between intermediary and other funded supports at the participant level" be adopted?**

Dementia Australia believes that it would be in the best interests of people with younger onset dementia for this recommendation to be adopted.

19. **What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?**

Stricter conflict of interest requirements would impact providers as it would respond to concerns and require them to provide service based on clients' needs and not their own. The NDIS is intended to inform and adjust the market based on clients' needs and this change would ensure that service providers are not able to take advantage of clients funding. For support coordinators to provide assistance and connect clients to services and supports, they need to make independent recommendations based on what is best for the individual. The choice regarding what services best meet their needs has to be their own and not influenced by the organisation that the support coordinator is employed for.

The ability of organisations to adapt to the changing market is challenging, however it holds a great deal of potential for clients to receive quality specialised support coordination, that is dementia specific and aimed at providing continuously improved service, based on clients outcomes, needs and goals. It is in the best interests of people with younger onset dementia to have an objective and unbiased support coordinator to ensure supports are received based on clients' needs and not convenience or in alignment with targeted business goals of the organisation providing support coordination.

General

20. **What would you identify now as the current critical issues around support coordination?**

Current NDIS guidelines for support coordinators are unclear, making it difficult for providers engaging in these services to communicate the scope and activities of the role to their clients and other service providers. As previously mentioned, Dementia Australia has developed its own support coordination manual to provide our younger onset dementia support coordinators with a framework for the provision of support coordination services under the NDIS. This framework assist staff to accurately define their role, engage in activities that are in-scope and provide a high quality service to their clients.

Dementia Australia are confident in the ability of our staff to deliver excellent support coordination to people living with younger onset dementia, yet we do not know what the quality of support coordination is like for people with younger onset dementia who receive coordination of supports from a generalist disability organisation.

Inadequate and inconsistent information is being provided by the NDIS to enable support coordinators to achieve client outcomes and adapt to their changing needs (including difficulty accessing NDIS forms and reports on the NDIS portal).

There is limited capacity for support coordinators to build relationships with NDIA planners and staff. Fortunately in some cases, Dementia Australia support coordinators have developed relationships with a limited number of planners and SIL contacts who have been helpful. Yet this is the exception not the norm.

A significant challenge in providing support coordination for people with younger onset dementia is finding dementia specific SIL providers to enable us to support the Government's goal of reducing the number of people under 65 years in residential aged care. People with younger onset dementia are being denied SIL options and are having to move into residential aged care due to the limited number of providers offering this support. At a most critical stage in their journey, the NDIS process becomes especially challenging. More often than not they are being forced into residential aged care or a group home that puts financial stress on their family.

Dementia Australia are advocating to increase the number of providers who can provide dementia specific SIL. However, the market is not responding quick enough to demand and, as the needs of people with younger onset dementia, many disability homes are not suitable. Additionally, dementias specific training is required for staff to provide appropriate support.

21. What are the priority actions the NDIA might take to grow an innovative and effective support coordination market in the interests of participants?

The NDIA should continue to provide ongoing and accessible training regarding reports and coordination of supports expectations to ensure the quality of service provided to all participants.

Action should be taken to improve access to planners to allow relationships to develop that enable quicker responses to plan changes as required. People with younger onset dementia are living with a progressive terminal condition. The changes they experience are unpredictable and it is in their best interests for support coordinators to be able to respond quickly to their needs.

Conclusion

For NDIS participants with a complex and progressive neurological disability like younger onset dementia, ongoing support coordination is critical. We hope our submission assists the NDIA to understand the importance of support coordination for people living with younger onset dementia.

Dementia Australia looks forward to further consultation to ensure that support coordination services deliver the best outcomes for people living with younger onset dementia, their families and carers.