

**FIGHT ALZHEIMER'S**  
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**NDIS COSTS AND PRODUCTIVITY**  
**COMMISSION POSITION PAPER**

**SUBMISSION FROM ALZHEIMERS**  
**AUSTRALIA**

**JULY 2017**

## EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide further input to the Productivity Commission's (*the Commission's*) Position Paper on the National Disability Insurance Scheme (NDIS) Costs (*the Paper*).

Alzheimer's Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia. There are over 25,000 people under the age of 65 living with younger onset dementia (YOD), a number that is set to rise to 42,252 people by 2056.<sup>1</sup> The issues raised by the Commission through this study are therefore very relevant to our consumers.

As noted in the Paper, the NDIS is a complex and highly valued national reform that is driving change at a scale and pace that is unprecedented in Australia. If implemented well, it will substantially improve the wellbeing of people with disability and Australians more generally. Alzheimer's Australia has long believed that the NDIS will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception.

However, we share the Commission's concern that the current the speed of the NDIS rollout has put the scheme's success and financial sustainability at risk. It has resulted in the NDIA focusing too much on meeting participant intake estimates and not enough on planning processes, supporting infrastructure and market development. This has had a large impact on our cohort of vulnerable consumers.

As noted in our submission to the Commission in March, the lack of planning and rush to enlist participants has manifested in the progressive and complex needs of people with neurodegenerative diseases like younger onset dementia being overlooked or insufficiently addressed e.g. a lack of understanding of the disease that leads to an attempt to conduct planning sessions over the phone despite communication of cognition challenges, or the creation of plans that do not address key support needs. Thus Alzheimer's Australia welcomes and strongly support the Commission's position that a greater emphasis is needed on pre planning, in depth planning conversations, plan quality reporting, and more specialised training for planners.

We also endorse the Commission's position that the interface between the NDIS and other disability and mainstream services is also critical for participant outcomes and the financial sustainability of the scheme. We are particularly pleased to note the Commission's position that Governments must set clearer boundaries at the operational level around 'who supplies what' to people with disability, and only withdraw when continuity of service is assured.

As noted in our submission to the Commission's Review, Alzheimer's Australia currently delivers programs, supports and services under the NDIS, mainly through the Commonwealth Government funded Younger Onset Dementia Key Worker Program (YODKWP), which provides essential supports to people living with dementia, their families and carers by way of information, linkages and capacity building. It is currently proposed that the YODKWP will transition to the NDIS completely by 30 June 2018; however, our current experience of ongoing transition activities highlight that there are several areas of concern that need to be addressed before the transition can be successfully completed.

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<sup>1</sup> The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). Economic Cost of Dementia in Australia 2016-2056.

Overall, Alzheimer's Australia is broadly supportive of the recommendations made by the Commission in their draft report. In particular, we note and provide further commentary on the following issues:

## **Planning**

It is clear from the Commission's Paper that good quality plans are *a key determinant of the long-term sustainability of the NDIS, because it influences what costs are incurred; the predictability of costs; and the integrity of, and community support for, the scheme as a whole.*

For NDIS participants, a good quality plan is also the lodestone supporting their potential independence, and social and economic participation. There is abundant evidence that a need for refined planning processes will lead to improvements in scheme eligibility and supports, provider, workforce and participant readiness, and ultimately governance and performance of the scheme as a whole.

In Alzheimer's Australia's experience, right now there are substantial variances in what is considered 'reasonable and necessary' in relation to assessment planning. Consumer feedback indicates that plans are based on what people are prepared to ask, and often battle, for rather than being presented with choices from a full suite of clearly explained support options. This has resulted from areas of concern including: phone planning providing limited insight into participant needs; lack of specialist expertise within planning agencies; participants' lack of familiarity with the service offerings, NDIS terminology or experience with making these types of choices; and failure to involve families, carers, support workers and advocates in the planning process.

As demonstrated in this Paper and highlights through our experience with the NDIS, the "investment approach" of the scheme which is focused largely on a model of improved outcomes (particularly education and employment) does not align with the progressive, degenerative, and terminal nature of neurological diseases such as dementia. The limited disability knowledge of NDIS Planners and Local Area Coordinators (LACs) further compounds this issues as they are often unaware of the impact that particular conditions have on people's lives, and they often do not know what supports would be most effective for the participant's disability. This is evidenced in the use of phone planning sessions, which limit the engagement with participants and are demonstrably inappropriate for people with cognitive impairment and neurodegenerative diseases, where loss of speech and communication are one of the initial symptoms. Also, the rigid and opaque nature of the planning review process fails to accommodate the rapid and increasing needs of people living with progressive neurological diseases. This leaves people without adequate supports at their time of greatest need. The resulting increase in requests for plan reviews then also adds to the workload of planners, increasing the administrative costs of the NDIA, as well as costs in other areas.

Alzheimer's Australia continues to receive feedback from consumers that the level of information provided by NDIA and LAC planners is inadequate to support informed

consumer choice and that service quality remains inconsistent. People living with dementia, their families and carers, along with other vulnerable and marginalised groups in society, are likely to have even poorer health literacy, and diminished capacity to identify the services they need in a market-driven system. They are also likely to have difficulty interpreting available data relating to service quality, or using this effectively to make informed health care choices, even where service choice is actually available.

Alzheimer's Australia therefore contends that the following recommended changes to NDIS planning and delivery systems will not only greatly enhance the experience of participants with progressive and degenerative diseases but will also strengthen the system for all participants.

### 1) Pre-Planning Support:

**Pre-planning will lead to lower costs and better outcomes** - The Commission has noted that many participants are ill-prepared for planning conversations (which is affecting the quality of plans). A greater focus on pre-planning will not only reduce the need for time-consuming and costly plan reviews, it will also mean that participants are more likely to be exercising choice and control. An increased focus by the NDIS on the quality of plans will enable more comprehensive performance monitoring against the scheme's objectives.

People with a progressive neurodegenerative disease must consider a number of elements when preparing for NDIS plans. For many, they have only recently been diagnosed and are therefore not yet completely aware of how the disease will progress and how their needs will change. It is essential that individuals have a clear understanding of their anticipated future needs and how the progressive nature of the disease may impact them in the next 12 months (and the years afterwards) when preparing for an NDIS plan. In this case it is clear they would benefit from the assistance of an experienced person who can help them to articulate their aspirations and support needs.

Evidence for this comes from the many reports of people with progressive neurodegenerative disease having advised their NDIS planner of their immediate needs (e.g. social interaction) without considering their greater needs (e.g. occupational or speech therapy) despite having a clear need for them.

#### **Case Study**

*Peter, the carer of a woman with younger onset dementia, felt unprepared when he and his wife attended their first NDIS planning session. Peter and his wife found it difficult and uncomfortable being asked what their needs were as he did not know how to identify or prepare for what their needs were and would be in the future. The NDIS planner had no understanding of dementia and the needs of people living with dementia and as a result the planning session focused on physical needs and solutions. As a result their first NDIS plan provided funded supports totalling \$600.*

*Seeking assistance to address his wife's many unmet needs in this plan, Peter spoke with one of Alzheimer's Australia's Younger Onset Dementia Key Workers who worked with Peter and his wife to better understand their immediate and future needs. The Key Worker assisted Peter*

*in arranging an NDIS plan review and the resulting plan provided funded supports of \$32,000 (including 9 hours of home care and a week of full respite (24/7 care). This was the life-changing NDIS plan Peter and his wife had hoped for when they entered the NDIS.*

Lack of pre-planning can result in ineffective plans which require an NDIS review and/or result in negative health impacts for people with a progressive neurodegenerative disease. Therefore, funding is required either for peak bodies to provide support to people with a progressive neurodegenerative disease as they prepare for NDIS planning sessions or for targeted NDIS education for people with a progressive neurodegenerative disease. This would significantly reduce the risk of inappropriate or insufficient NDIS plans and the need for unscheduled plan reviews.

## **2) Specialised Planning:**

The planning process needs to be sufficiently 'deep' so that planners can obtain sufficient information about a participant for them to make a decision about reasonable and necessary supports. **Involving families, carers, support workers and advocates in the planning process can also improve understanding of the functional impact of the participant's disability, their needs and the supports that they require.**

**Planners need more disability knowledge** – The limited disability knowledge of NDIS Planners is an issue of real concern. An alternative (or complementary) approach would involve leveraging expertise from within the industry – this could include involvement in developing reference packages and advocating for participants needs through systemic feedback to the NDIA and governments, and/or capacity building for NDIS planners, service providers and mainstream services. It could also extend to specialist disability organisations or service providers being more involved in the planning process. Assessment tools in use by the NDIA should be reviewed in conjunction with specialist, expert service providers and published to provide participants with a greater understanding of role of assessment tools in the planning process.

A face-to-face NDIS planning session with an NDIS planner who has a sound knowledge of cognitive impairment and neurodegenerative diseases, such as those in NDIS Complex Care Teams, are considered as best practice and have produced NDIS plans that most appropriately meet the needs of people with a progressive neurodegenerative disease.

Involvement of informal support networks in these specialised planning meetings will provide greater opportunities to advocate for carer respite, which will in turn reduce the requirement for more formal and costly supports in their place. It was for this reason that the Commission in its 2011 Disability Care and Support inquiry recommended that the needs of carers be considered as part of a participant's individualised supports (PC 2011, p. 340).

### **Case Study**

*Leslie called Alzheimer's Australia in a state of distress as she had an NDIS planning session over the phone (with no forewarning) and could not recall who she had talked to or the details of the conversation. It took Leslie, with the help of a YOD Key Worker, over 6 hours to gather the basic information required for Leslie to apply for a review of her NDIS planning session.*

*Chris was asked to complete an NDIS planning session for his wife over the phone with no prior warning and not having done any supported pre-planning. On receipt of the plan, Chris contacted Alzheimer's Australia to discuss plan implementation, however, after discussing his wife's needs for the coming months and Chris's plans to return to part-time work it became clear the \$11,000 provided for 12 months were inadequate to meet his wife's complex needs. Chris is now waiting on a response from the NDIA regarding a review of his wife's plan.*

Feedback from people with progressive neurodegenerative diseases has revealed that Local Area Coordinators (LACs) have also shown insufficient knowledge of their disease, the impact on their lives, most effective service interventions and the degenerative and fatal nature of their disease.

To offer true choice and control in individual plans, NDIS planning sessions must take into consideration the unique needs of all participants by gaining a better understanding of the diseases impacting clients and, mandating face-to-face meeting for people with specialised and complex needs. This specialized gateway model can be expanded to address the needs of various cohorts, including psychosocial, etc.

### **3) Support Coordination:**

AA believes that provision for Support Coordination should be a mandatory element of NDIS plans for participants with complex needs. People with progressive neurodegenerative diseases meet this criteria as they are caught between a changing disability sector and aged care sector and there are limited options available to them within the marketplace.

Coordinators of Support play a vital role in negotiating support costs with providers, making arrangements for support delivery and providing information and ongoing support to providers regarding the specific needs of people with one of these diseases. Without the support and advocacy of a Coordinator of Supports, many people with a progressive neurodegenerative disease will be unable to interact well with the NDIS, then the benefits of the scheme will not be fully realised. This has consequences for the lives of participants and the financial sustainability of the NDIS.

### **Case Study**

*A 58 year-old client Lorraine who was living with her husband Phil in rural NSW, had been with rapidly progressing frontotemporal dementia. Prior to the NDIS she receiving a Level 3 aged care package which was not adequate meeting her changing requirements and there were frustrations with the provider in their understanding of Lorraine's emotional and behavioural needs.*

*Phil approached the Younger Onset Dementia Program to get assistance with preparing for their first NDIA planning meeting, and developing Lorraine's NDIS Plan. Given the extent and number of services required, Phil requested Coordination of Supports by a YOD Key Worker. Over nine months, the key worker spent nearly 50 hours helping Phil and Lorraine to navigate the ever changing and growing service needs. Through this process Lorraine and Phil were linked to fifteen various Allied Health workers, NDIS and mainstream service providers. The YOD Key Worker was able to provide support to Lorraine and Phil in being*

*able to interview and select service providers, self-manage a portion of their plan and develop a communication system between the multiple, varied support providers in assessing and adapting to the changing needs of her condition. The Key Worker also was essential in expediting home modifications after Lorraine broke her arm entering her house and then in preparing and creating a full plan review following the degeneration of Lorraine's condition. Without the assistance of a Support Coordinator, Lorraine and Phil would have remained on an inadequate and inappropriate plan that did not allow them to meet her goals of remaining at home and in her community.*

Coordinators of Support with a good understanding of the unique needs of people with a progressive neurodegenerative disease have proved to be effective advocates who can help to reduce the transaction costs and complexity of the scheme for participants.

In areas of Thin Markets – small cohorts of people with complex, specialised or high intensity needs, or very challenging behaviours – as experienced within the YODKWP, Support Coordination is essential to leverage the Key Worker industry expertise to ensure that appropriate and necessary services are provided.

### **Conflict of Interest Concerns - LACs**

While Alzheimer's Australia is supportive of most of the positions taken by the Commission in its Paper, we do advocate caution around the Commission's recommendation for expanded scope of LAC's.

Twenty per cent of LACs annual funding is for ILC activities. There is an inherent and increasing potential for conflicts of interest that are being created via the ILC and LAC contracts. This has been demonstrated where LACs have proven to be reluctant to fund Coordination of Support for participants with neurodegenerative disease but have been allocating Support Connection to be provided by themselves in their LAC role. These issues are further compounded in an environment where LACs do not have the knowledge or skills required for people with complex needs, and do not have the capacity to perform their ILC roles, particularly in the case of people who are not eligible for NDIS such as carers and families.

The NDIA allowing approval functions to be delegated to LACs could lead to efficiencies in plan administration, however there is significant concern around the potential associated risks particularly the potential for a conflict of interest in the allocation of funds for Support Connection and Coordination of Support, which would need to be provided by a third party to remove the potential for this conflict to occur.

Providing pre-planning services is one of the core functions of LACs. However, the speed of the rollout has meant that this was not possible and LACs have not been performing their pre-planning functions as envisaged). By delegating further responsibilities to LACs, this is likely to be further impacted. It would be essential that pre-planning roles are allocated to other service providers, particularly those with the required specialist knowledge and/or pre-existing relationships with the participant.

## CONCLUSION

Younger onset dementia inevitably results in significant disability and there is a vital need for expert information, care and personal assistance. We are therefore optimistic that the Commission's report will help build an NDIS that can meet the unique and complex needs of younger people living with dementia.

Overall, we agree with the Commission's findings and position. While increased focus on the planning phase may impede meeting of bilateral targets in the short-term, it will reduce the need for time-consuming and costly full plan reviews, managing customer complaints, provide a more accurate picture of the functioning of the scheme and reduce the need for an amended rollout schedule.

The most important benefit of appropriate and effective plans is the increased quality of life, greater social and economic participation, and reduced need for other supports for people with disability and their families. It is the achievement of these goals which will ultimately strengthen the long-term sustainability of the scheme through demonstrated effectiveness in realizing outcomes for people with a disability. As recognised within Section 4(13) of the Act<sup>2</sup>, the role of advocacy in representing the interests of people with disability is to be acknowledged and respected in promoting people with a disability to reach these goals.

We are pleased to note that the Commission's report has reiterated the importance of appropriate planning. Our response to the Paper focusses on the planning support and needs of people living with progressive neurodegenerative diseases and suggestions on how the NDIS can better meet them.

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<sup>2</sup> The National Disability Insurance Scheme Act 2013 (NDIS Act)