



Submission to the Productivity Commission

National Disability Insurance Scheme (NDIS) Costs Issues Paper

March 2017

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OUR VISION

To reduce the incidence and impact of macular disease in Australia

1. Introduction

During the development of the National Disability Insurance Scheme (NDIS), Macular Disease Foundation Australia expressed its concerns to the Productivity Commission and Parliamentary Inquiries about the exclusion from the NDIS of those people who acquire a disability at the age of 65 or over.

The Foundation supported an NDIS without an age limit as an opportunity to streamline all government disability funding into one agency, potentially improving decision-making, efficiency and service quality to consumers. However the NDIS age restrictions were retained.

As a result, the disability and aged care reforms have created three separate support systems for the following groups of people:

1. People who acquire a severe or permanent disability **under the age of 65** - supported under the NDIS;
2. People who acquire a slight or moderate disability **under the age of 65** - supported under state and territory governments' disability care systems; and
3. People who acquire any level of disability **at the age of 65 or over** - supported under the Commonwealth Government's aged care system.

This submission will highlight the inequities between the level of disability support provided in the NDIS and the aged care system, disadvantaging people who acquire a disability at the age of 65 or over.

Rather than creating an additional bureaucracy and system within the aged care system, to accommodate the needs of this group, the Foundation proposes that aged care consumers be allowed to use their aged care funding to access the NDIS. This innovative reform will provide aged care consumers with improved access to specialist disability services and avoid additional costs to the NDIS.

The Foundation also proposes that the NDIS contract specialist disability organisations to conduct the NDIS assessments in order to address issues with the current assessment process.

2. Background - Ageing and disability reform issues

Significant reforms have been introduced to the disability and aged care sectors over the last five years. Despite this, there are still major issues of inequity regarding accessibility of specialist disability services designed to support the independence and quality of life of older people with vision loss or blindness.

People who acquire a disability, such as low vision or blindness, at the age of 65 or older are excluded from the NDIS. However, at the time of the introduction of the NDIS legislation, then Prime Minister Julia Gillard stated in Parliament that, "The scheme to be established by this bill will transform the lives of people with disability, their families and carers. For the first time they will have their needs met in a way that truly supports them to live with choice and dignity. It will bring an end to the tragedy of services denied or delayed and instead offer people with disability the care and support they need over their lifetimes."¹ There was no mention of the exclusion of one group of people from the opportunity to have their lives positively transformed.

Consistently throughout the consultation process leading up to the establishment of the NDIS, the Productivity Commission and the Commonwealth Government both stated that the needs of older Australians aged 65 or over, including those with disabilities such as vision loss or blindness, were most suitably supported under the aged care system.

The decision that older Australians with vision loss or blindness would obtain their support through the aged care system was poorly considered and flawed. Now that these new reforms are being implemented, it is becoming increasingly clear that the aged care system is neither

funded nor designed to provide the supports required by people with a disability from vision loss or blindness.

a. Productivity Commission Reports

Over the last five years significant changes in the disability and aged care areas have resulted in two major Productivity Commission reports, substantial policy review and new legislation:

Productivity Commission Report: *Caring for Older Australians* (June 2011)

The *Caring for Older Australians* report concluded, “The aged care system suffers key weaknesses. It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.”

In response to the Commission’s findings, the then Commonwealth Government introduced the “*Living Longer, Living Better*” reform package in April 2012. This aimed to provide a better, fairer and more nationally consistent aged care system, with amendments to the Aged Care Act passed in June 2013.

Productivity Commission Report: *Disability Care and Support* (July 2011)

The *Disability Care and Support* report concluded, “The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.”

The Commission’s findings led to the development of the NDIS “that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).”

A key aspect of the NDIS was that it provides “reasonable and necessary” supports and services as an entitlement, for life. Critically though, the Commission recommended those who acquired a disability after the age pension age be excluded from fully funded individualised support, and **instead receive equivalent support in the aged care system with co-payments.**

It was anticipated that the reform agenda of successive governments would be inclusive and cater for one of the largest groups with a disability (age-related macular degeneration), and finally address the critical issue of access and affordability of low vision aids, equipment and assistive technologies for those with vision loss and blindness.

However, there continues to be a failure in addressing the lack of disability support for vulnerable older Australians with vision loss or blindness. Even though there are continuing reform arrangements made between the Commonwealth and state and territory governments affecting the disability and aged care systems, measures to adequately address this issue continue to be left out, leaving those in need in a highly disadvantageous, unfair and inequitable position.

b. Impact of reforms on the disability and aged care systems

When the NDIS legislation was enacted, those who acquired a disability after the age of 65 (such as major vision loss or blindness from age-related macular degeneration) were entirely excluded from becoming participants in the NDIS, and were expected to receive their supports and services via the aged care system.

In contrast to the fully funded support that NDIS participants receive, supports and services in the aged care system are means tested and rationed. The subsequent *Living Longer Living Better* aged care reforms did not include any initiatives that would raise the capacity of the aged care

system to provide disability services at the equivalent level of the NDIS. Furthermore, there continues to be significant inconsistency between and within states and territories in the delivery of disability services outside the NDIS. This means many people with vision loss and blindness have continued to fall between the cracks of these two important systems.

The Productivity Commission had previously envisaged that the services available to people who acquired a disability after the age pension age would not differ from those available within the NDIS. They would be funded in accordance with the aged care system, with means-tested co-contributions and payments, reflecting the general capacity of older people to have acquired assets and savings over their working lives.

The Productivity Commission stated: “There should be no artificial barriers to people accessing eligible services, even if those services are notionally identified as primarily serving the demands of the aged care or disability system. Rather, the critical concern is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source.”²

Further reform is required to allow aged care consumers with a disability to access specialist disability support services at an equitable level as their NDIS counterparts.

c. Aged Care system – examples of lack of specialist disability support

The following two examples highlight how the aged care system is presently unable to meet the needs of those over 65 years diagnosed with a disability and the intent of the Productivity Commission’s report on Disability Care and Support in stating that, “There should be no artificial barriers to people accessing eligible services, even if those services are notionally identified as primarily serving the demands of the aged care or disability system”.²

1. The **Commonwealth Home Support Programme (CHSP)** was launched on 1 July 2015. It consolidated four aged care programs, including the Home and Community Care (HACC) program, into one entry-level home support program for older people who need assistance to keep living independently at home and in their community. The Foundation’s advocacy efforts resulted in the CHSP including the new service type ‘Goods, Equipment and Assistive Technology’ which covered low vision aids and technologies. There was, however, no funding allocated towards this service type, even though this was the service stream where funding support was anticipated to be provided.
2. The **Commonwealth Home Care Packages** and **Residential Aged Care Packages** do not specify the provision of aids and technologies. Therefore, the purchase of aids and technologies may only be possible if there is residual funding left in the package and the decision to do so is at the discretion of the package provider. This makes it inconsistent, arbitrary and unlikely, as aged care providers lack knowledge and expertise in the area of low vision aids, equipment and assistive technologies.

3. Enabling aged care consumers to access the NDIS

Recommendation 1

The Foundation recommends that the NDIS develop an interface for all Australians aged 65 years or over to allow the use of aged care funding to access NDIS services.

This section addresses the following questions from the Issues Paper:

- How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved? (pg 16)
- Does the current funding split between the Commonwealth and the States and Territories have implications for the scheme's sustainability? Does it affect the NDIA's capacity to deliver disability care to scheme participants at the lowest cost? Are there any changes that could be made to the funding split that would either improve the financial sustainability or the efficiency of the scheme? (pg 31)

Currently, Australians who acquire a disability at the age of 65 years or over are excluded from the NDIS and have to access their disability support services through the aged care system. The key area of inequity between the two systems is that the aged care system provides limited and inconsistent access to specialist disability support services, whereas the NDIS provides full access to these services.

The Foundation proposes that further reforms be implemented which allow aged care consumers to use their aged care funding to purchase specialist disability services from the NDIS and/or NDIS registered services. From the perspective of reducing the NDIS costs, the introduction of capped means-tested co-contributions will alleviate some budgetary pressure, and allowing aged care consumers to use their aged care funding to access the NDIS will open up a new funding source that supports the NDIS.

From the perspective of aged care consumers with a disability, accessing the NDIS will enable them to get the most appropriate care for their disability needs. The aged care system does not have the expertise or funding mechanisms to adequately provide specialist disability support services to clients. Existing aged care programs do not provide services and packages designed around a person's disability. For example, a person with low vision is unable to be assessed for an aged care program to primarily obtain low vision aids for assistance with reading, even though this is essential for the person to live independently in his/her own home.

The Commonwealth Government's Continuity of Support program, which is meant to continue funding specialist disability services following the cessation of funding from state and territory governments, due to their funding being allocated to the NDIS, is only a temporary measure and will not accept new participants after the full roll-out of the NDIS. Once the NDIS is fully rolled out, all Australians who acquire their disability at the age of 65 years or over will have to receive their disability support needs from the aged care system.

This means that, to cope with the disability needs of the older Australians, there will need to be a new disability sub-system established within the aged care system. Rather than duplicating a disability sub-system within the aged care system, which would be an additional cost to the Commonwealth Government, it would be far more effective and efficient that aged care clients be enabled to use their aged care funding to access specialist disability support services in the NDIS.

4. Contracting specialist disability organisations to conduct NDIS assessments

Recommendation 2

The Foundation recommends that the NDIS contract specialist disability organisations to conduct specialist disability assessments as part of the formal planning process.

This section addresses the following questions from the Issues Paper:

- Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved? (pg 18)
- To what extent does the NDIA's budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made? (pg 21)

As the national peak body representing the macular disease community, the Foundation has ongoing communications with organisations in the low vision area, including specialist low vision service providers who are registered with the NDIS. The Foundation has been advised that the NDIS is utilising generic disability planners who have limited disability knowledge. Whilst it is acknowledged that it is not physically or logistically possible for planners with specialist disability knowledge to be matched with every NDIS participants' disabilities and conditions on a national scale, the NDIS appears to not be effectively leveraging existing expertise from specialist disability organisations.

The Foundation had previously envisioned NDIS planners to be in the role of a coordinator and facilitator, and that they refer NDIS participants to specialist disability organisations for specialist disability assessments. However, the NDIS currently uses in-house planners with generic disability knowledge. These planners may not be experts in the disability area related to the NDIS participants' needs, and as such are guided by NDIS policies including the budget-based approach.

The Foundation previously assisted the NDIS in the development of low vision severity indicators to provide guidance to NDIS planners about matching the support services required with a person's level of vision loss. However, this was supposed to be a way to educate NDIS planners, and not to serve as prescriptive package designs.

As a result, it appears that the planning process has become a negotiation, where the participant is trying to obtain the most appropriate support (regardless of the cost) but the planner is trying to design the support plans as close to the reference packages as possible. This is likely to create inconsistencies where people with similar disability needs are provided with different plans, as the outcome is now based on the participants' negotiation skills with the planner not being able to provide expert opinion.

The NDIS should instead be engaging specialist disability organisations in the assessment process. The Foundation proposes that the NDIS fund these organisations to conduct assessments on a referral basis. The NDIS planner will then serve the role of a coordinator and budget manager, and work with these contracted specialist disability assessors to provide the most appropriate disability services within the budget range.

There is a real concern that, if the current generic assessment process continues, participants will not receive the most appropriate support services during the initial assessment, resulting in the need for reassessments and complaints resolution which incur unnecessary cost to the NDIS. The Foundation's proposed changes would create a more effective and less costly assessment process, as it utilises the specialist disability knowledge that already exists in the disability sector.

5. About Macular Disease Foundation Australia

Macular Disease Foundation Australia is a national, independent charity established in 2001. It is the only organisation in Australia that specifically supports the needs of the macular disease community.

- The Foundation's vision is to reduce the incidence and impact of macular disease in Australia.
- Every day the Foundation is working to save the sight of all Australians and has done so for 16 years.
- The Foundation is recognised nationally and internationally as the Australian peak body for macular disease.
- The Foundation has a national client base of over 53,000 people, across all states and territories, comprising: those at risk of developing, or living with macular disease, their family and carers; eye care and allied health professionals including optometrists, ophthalmologists, orthoptists, occupational therapists, dietitians, pharmacists, GPs, diabetes organisations, residential aged care facilities, university faculties and students, low vision rehabilitation providers; CALD communities; industry groups, key interest and advocacy groups.
- The Foundation's work in education, awareness and support services directly correlates to and supports the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness in Australia*.
- The Foundation has a highly regarded position in representing the views of the client base to government in a collaborative environment in order to make a positive impact on patient outcomes. This is evident in the marked improvements in access to treatment and rehabilitation, support and subsidies for patients, families and carers. Given government's emphasis on chronic disease and improving health outcomes, the Foundation, as a peak body and in its advisory roles, can continue to play a significant role in reducing the incidence and impact of Australia's leading cause of blindness.
- The Foundation has a powerful voice in the eye health sector for its clients, and has developed tools and expertise to ensure it effectively communicates and represents the views of clients.

6. Macular disease in Australia

- It is estimated that there are approximately 8.5 million people at risk of macular disease and over 1.6 million Australians with some evidence of macular disease.^{3,6}
- Macular disease is the greatest contributor to chronic eye disease in Australia.⁴
- Macular disease is a large group of sight-threatening conditions that affect the central retina at the back of the eye, which is responsible for detailed central vision. These diseases include age-related macular degeneration, diabetic retinopathy, retinal vein occlusions and numerous other macular dystrophies.
- Age-related macular degeneration and diabetic retinopathy have been categorised as priority eye diseases for the prevention of blindness and vision impairment by the World Health Organization.
- The most common macular disease in Australia is age-related macular degeneration:
 - Age-related macular degeneration is a chronic disease with no cure.
 - It is the leading cause of blindness and severe vision loss in Australia and is the cause of 50% of blindness in Australia.^{3,5}

- 1 in 7 (1.25 million) people over the age of 50 years have some evidence of age-related macular degeneration.³
 - This is estimated to increase to 1.7 million by 2030, in the absence of adequate treatment and prevention measures.
 - Primarily affects those over the age of 50 and the incidence increases with age.
 - Age-related macular degeneration is a major chronic disease with a prevalence 50 times that of multiple sclerosis and 4 times that of dementia.³
 - The impact of age-related macular degeneration on quality of life is equivalent to cancer or coronary heart disease.⁴
 - Smoking is a key risk factor as it increases the risk of developing age-related macular degeneration by 3 to 4 times and smokers, on average, develop age-related macular degeneration 5 to 10 years earlier than non-smokers³.
- Diabetic eye disease is the leading cause of blindness among working age adults in Australia:⁶
 - Almost 1.1 million Australians have diagnosed diabetes. Of these, over 300,000 have some degree of diabetic retinopathy and about 65,000 have progressed to sight-threatening eye disease.
 - The longer you have diabetes the greater the likelihood of sight threatening eye disease.
 - The expected growth in the number of Australians living with diabetes will lead to a corresponding rise in diabetic eye disease and vision loss – numbers are expected to at least double between 2004 and 2024.
 - Almost everyone with type 1 diabetes and more than 60% of those with type 2 diabetes will develop some form of diabetic eye disease within 20 years of diagnosis. Significantly, many people with diabetes are diagnosed late, by which time retinopathy may already be present.
 - Almost all cases of vision loss from diabetic retinopathy can be prevented with regular eye tests, careful management of diabetes, medication and in some cases, treatment with anti-VEGF agents and/or laser and/or steroids.

Socio-economic costs of vision loss in Australia

- **There is a high cost of vision loss from macular disease to government. Even a modest reduction in the proportion of people who progress to vision loss will generate significant savings.**
- Vision loss from age-related macular degeneration:
 - In 2010, the total cost of vision loss, including direct and indirect costs, associated with age-related macular degeneration was estimated at \$5.15 billion, of which the financial cost was \$748.4 million (\$6,982 per person).³
 - The socio-economic impacts of age-related macular degeneration include:
 - Lower employment rates.
 - Higher use of services.
 - Social isolation.

- Emotional distress.
- An earlier need for nursing home care.
- Vision loss from diabetic retinopathy:
 - As diabetic retinopathy frequently affects people of working age, the social and economic impact of vision loss can be dramatic and long-lasting. People with vision loss from diabetic retinopathy experience higher rates of unemployment and underemployment, reduced safety in the workplace and home, increased rates of depression and greater dependence on carers due to an inability to drive, mobilise independently and undertake common activities. It is clear that even modest reductions in the proportion of people who progress to vision loss will generate significant savings to government.⁶
 - Vision loss from diabetic retinopathy is nearly always preventable; however thousands of Australians continue to lose vision from the disease. Awareness of the risk of blindness from diabetes is low, and compliance to recommended testing regimens, risk reduction strategies and treatment protocols remains unacceptably poor.⁶
 - Vision loss in patients with diabetes also directly interferes with essential tasks to manage diabetes such as insulin administration, glucose monitoring, and exercise, making diabetes progression and other complications more likely.⁷

References

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- ² Productivity Commission Inquiry Report on Disability Care and Support (2011), p. C.7
- ³ Deloitte Access Economics and Macular Degeneration Foundation (2011). *Eyes on the future: A clear outlook on Age-related Macular Degeneration*.
- ⁴ *The Global Economic Cost of Visual Impairment* Access Economics & AMD Alliance international 2010.
- ⁵ Taylor H et al, MJA 2005;182:565-568.
- ⁶ *Out of sight – A report into diabetic eye disease in Australia*, 2013, Baker IDI and Centre for Eye Research Australia.
- ⁷ Leksell JK, Wikblad KF, Sandberg GE. *Sense of coherence and power among people with blindness caused by diabetes*. Diabetes Res Clin Pract. 2005;67:124-129.