Submission to the Productivity Commission

National Disability Insurance Scheme (NDIS) Costs Position Paper

July 2017

OUR VISION

To reduce the incidence and impact of macular disease in Australia

1. Introduction

Macular Disease Foundation Australia was established in 2001 and is the peak national body representing the macular disease community. The Foundation's vision is to reduce the incidence and impact of macular disease in Australia.

Macular disease causes vision loss and blindness. It affects the retina at the back of the eye, which is responsible for central vision. The two macular diseases which have the most significant impact on the Australian population are aged-related macular degeneration (AMD) and diabetic retinopathy. AMD is the leading cause of blindness, contributing over 50% of all severe vision loss and blindness and primarily affects older Australians[1]; Diabetic retinopathy is rising rapidly due to the massive increase in the prevalence of diabetes, where numbers are expected to at least double between 2004 and 2024.[2] Diabetic retinopathy is the leading cause of blindness among working age Australians[2].

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 with a disability:

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.

The Foundation's previous March 2017 submission to the Productivity Commission on the *National Disability Insurance Scheme (NDIS) Costs Issues Paper* highlighted issues around the interface between the NDIS and the aged care system, and the need for the NDIS to better leverage the expertise of the disability support sector. It is acknowledged that these issues have been included in the *National Disability Insurance Scheme (NDIS) Costs Position Paper*.

In this submission, the Foundation provides feedback to the NDIS Costs Position Paper, addressing selected content and recommendations from the Position Paper that significantly affect people with vision loss or blindness from macular disease.

2. Feedback on the Position Paper

a. Page 33 of the Position Paper Overview: "Concerns that some people with disability may be left without services"

The Foundation recommends amending the section "Concerns that some people with disability may be left without services" to include concerns regarding the potential loss of services for the two main groups of people with a disability who have been excluded from accessing NDIS Individually Funded Packages:

- People who acquire a slight or moderate disability under the age of 65, who are meant to be supported under state and territory governments' disability care systems; and
- People who acquire any level of disability at the age of 65 or over, who are meant to be supported under the Commonwealth Government's aged care system.

This section in the Position Paper raises concerns that there will be people with a disability who are not eligible for NDIS Individually Funded Packages may lose their disability support services following the rollout of the NDIS. However, only mental health services are highlighted as an area of particular concern. This is not accurate as government funding for disability programs in all jurisdictions are being redirected to fund the NDIS, which is affecting the sustainability of the disability support services outside of the NDIS.

It would be more accurate to acknowledge that the scale of potential problems is much bigger than just the mental health sector. This section should be amended to acknowledge that the two main groups of people will be affected by the loss of their existing disability support services, as they are ineligible for the NDIS Individually Funded Packages:

- People who acquire a slight or moderate disability under the age of 65, who are meant to be supported under state and territory governments' disability care systems; and
- People who acquire any level of disability at the age of 65 or over, who are meant to be supported under the Commonwealth Government's aged care system.

b. Draft recommendation 4.1:

"The National Disability Insurance Agency should:

- **implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review**
- **review its protocols relating to how phone planning is used**
- **provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options**
- **ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants."**

The Foundation supports this recommendation.

c. Draft recommendation 4.2:

"The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise."

The Foundation supports this recommendation.

As highlighted in the Foundation's previous submission in response to the NDIS Costs Issues Paper, the NDIS needs to be more effective at leveraging existing expertise from

specialist disability organisations. Such arrangements could include the National Disability Insurance Agency (NDIA) contracting specialist disability organisations to conduct specialist disability assessments as part of the formal NDIS planning process.

d. Draft recommendation 5.1:
"Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of $131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach $131 million should be made available from the National Disability Insurance Agency's program delivery budget.
The effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five-yearly review of scheme costs. The ILC budget should be maintained at a minimum of $131 million per annum until results from this review are available."

The Foundation does not support increased funding to the ILC without changes to the ILC to include recurrent funding for disability organisations that provide information, linkages and capacity building services for their respective disability communities.

While the Foundation agrees that the initial funding for ILC is inadequate, it is not appropriate to increase its funding at this time as the ILC does not fund the disability sector to better support people with a disability. It is highlighted that the services initially proposed to be funded under the ILC have changed substantially. Originally in the Productivity Commission's 2011 *Disability Care and Support* report, the ILC was intended to fund "Tier 2" programs including block funding and early intervention programs. The goal of this was to provide access to disability and mainstream services for those who were ineligible for NDIS Individually Funded Packages. However, the ILC now covers time limited and ad hoc projects that provide access to mainstream services.

Currently, the ILC does not provide substantial ongoing support services and will not help ensure support for individuals who fall through the disability service gaps. The Foundation's position is that the ILC should be responsible for funding disability organisations to provide continuing information, linkages and capacity-building services that empower their respective disability communities.

e. Draft recommendation 5.2:
"The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme. The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability."

The Foundation supports this recommendation.

f. Draft recommendation 5.3:
"Each COAG Council that has responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address the provision of those services and how they interface with NDIS

services. This item should cover service gaps, duplications and other boundary issues.
Through the review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreement, parties should include specific commitments and reporting obligations consistent with the National Disability Strategy. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples."

The Foundation supports this recommendation.

Currently the NDIS reforms are impacting services throughout aged care, disability, health and other sectors. However, there does not appear to be a high level of coordination to ensure that people with a disability do not lose services. The Productivity Commission's recommendation for a standing item on each Council of Australian Governments (COAG) Council which has a service area that interfaces with the NDIS is critical to promoting better planning and coordination of reforms, and should be implemented as soon as possible.

As previously raised in the Foundation's submission in response to the NDIS Costs Issues Paper, it is hoped that improved interfaces primarily between the NDIS, aged care, disability and health systems will allow for better equity of support for all people with vision loss or blindness.

g. Draft Recommendation 9.2:
"The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance Scheme. Any decision to join the national scheme should be made public as soon as possible."

The Foundation supports this recommendation.

h. Draft Recommendation 9.3:
"The National Disability Insurance Agency should publicly report on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews."

The Foundation supports this recommendation.

i. Draft Recommendation 9.4:
"The performance of the National Disability Insurance Scheme (NDIS) should be monitored and reported on by the National Disability Insurance Agency (NDIA) with improved and comprehensive output and outcome performance indicators that directly measure performance against the scheme's objectives.
The NDIA should continue to develop and expand its performance reporting, particularly on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities. The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face-to-face, and plan reviews).
The *Integrated NDIS Performance Reporting Framework* should be regularly reviewed by the NDIA and the COAG Disability Reform Council and refined as needed."

The Foundation supports this recommendation.

j. Draft Recommendation 9.5:
"In undertaking its role in delivering the National Disability Insurance Scheme, the National Disability Insurance Agency needs to find a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability."

The Foundation supports a slow-down in the NDIS rollout in order to assist the National Disability Insurance Agency in finding a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability.

However, the Productivity Commission should acknowledge in the Position Paper that slowing down the NDIS rollout will increase the number of people with a disability becoming ineligible for the NDIS due to the age requirement.

The Foundation reiterates its position that the NDIS age requirement be removed, so that all Australians with permanent and significant disabilities, regardless of age, are able to equitably access NDIS funded support.

As highlighted in the Position Paper, there are currently issues with the NDIS that have resulted in poor participant outcomes. Priority should be placed on addressing and resolving these issues to improve participant outcomes. Delaying the rollout may be the best option to prevent further uptake of sub-optimal plans, which not only negatively impact participants' lives, but also waste taxpayers' money and erode public trust in the NDIS.

However, the Productivity Commission needs to acknowledge that slowing down the NDIS rollout will result in more people with a disability becoming ineligible for the NDIS solely because of the 65 years age cut-off. These people will be required to access their disability supports from the aged care system, which is designed to support people with frail ageing needs, and as a result aged care clients can receive inadequate and inappropriate disability services.

The NDIS age requirement should be removed, so that all people with permanent and significant disabilities, regardless of age, are able to access NDIS Individually Funded Packages once participant outcomes have improved.

3. 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.
- The Foundation is recognised nationally and internationally as the Australian peak body for macular disease.
- The Foundation has a national client base of over 54,000 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.

4. 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.[1,2]
- Macular disease is the greatest contributor to chronic eye disease in Australia.[3]
- 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.[1,4]
    - 1 in 7 (1.25 million) people over the age of 50 years have some evidence of age-related macular degeneration.[1]
    - 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.[1]
    - The impact of age-related macular degeneration on quality of life is equivalent to cancer or coronary heart disease.[3]
    - 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-smokers[1].
- Diabetic retinopathy is the leading cause of blindness among working age adults in Australia:[2]
    - 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 retinopathy 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 retinopathy 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).[1]
    - 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.[2]
    - 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.[2]
    - 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.[5]

5. References

[1] Deloitte Access Economics and Macular Degeneration Foundation (2011). *Eyes on the future: A clear outlook on Age-related Macular Degeneration*.
[2] *Out of sight – A report into diabetic eye disease in Australia*, 2013, Baker IDI and Centre for Eye Research Australia.
[3] *The Global Economic Cost of Visual Impairment* Access Economics & AMD Alliance international 2010.
[4] Taylor H et al, MJA 2005;182:565-568.
[5] 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.