Macular Disease Foundation AUSTRALIA™

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Submission to the Senate Community Affairs Legislation Committee

Feedback on the *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*

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Macular disease is the leading cause of blindness and severe vision loss in Australia

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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].

The Foundation has actively engaged in the consultations relating to the development of the National Disability Insurance Scheme (NDIS). It supports a strong quality assurance and safeguards system in the NDIS. However, it is also concerned that people who acquire a disability at the age of 65 years or over are excluded from becoming NDIS participants. The Foundation's position is that older Australians who are excluded from the NDIS need to receive an equitable level of disability support.

2. The Foundation's feedback on the *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*

The Foundation welcomes the establishment of the National Quality and Safeguards Commission. The new regulator's independence from the National Disability Insurance Agency (NDIA) is important as it ensures that there is a dedicated institution focused on overseeing and enforcing provider compliance, to protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services under the NDIS.

However, the Foundation remains concerned with the lack of detail in the legislation about the Commission's jurisdictional authority over unregistered providers. The *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017* (Amendment Bill) only adds the following broad statement to the *National Disability Insurance Scheme Act 2013*, "(The Commission) also regulates supports and services provided outside the National Disability Insurance Scheme in certain circumstances."[3] **The Foundation recommends further legislative amendments be made to clarify the process in which the Commission can direct unregistered providers to adhere to regulatory requirements and directions.**

The Foundation is also supportive of the amendments which more appropriately describe the purposes of funding the Information, Linkages and Capacity-Building (ILC) Framework. In the Amendment Bill, the ILC funding is for the purposes of enabling the provision of information in relation to disability and disability supports and services; assistance in building capacity within the community in connection with the provision of goods and services to people with disability and their families and carers; assist people with disability to realise their potential for physical, social, emotional and intellectual development; or assist people with disability, and their families and carers, to participate in social and economic life.[4]

However, the Foundation highlights to the Committee that despite the broad scope of the ILC as described in the Amendment Bill, the current ILC Commissioning Framework applies

a number of limitations to funding which do not appropriately support the work of disability organisations. First, the ILC does not fund activities which duplicate the work of NDIS Local Area Coordination (LAC), thereby limiting funding for disability organisations to provide information and linkage services. Second, ILC does not provide recurrent core funding, which means only short-term projects are likely to be funded. Third, ILC prioritises funding for people with a disability under the age of 65 years, even though people who acquire a disability aged 65 years or over are in greater need of support as they are ineligible for NDIS Individually Funded Packages.

It is noted that the ILC has changed significantly since it was initially proposed. 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. This would provide access to disability and mainstream services for those who were ineligible for NDIS Individually Funded Packages. However, other than funding for LAC activities, the ILC now only covers time limited and ad hoc projects.

As a result, the ILC does not provide funding for substantial ongoing services and will not ensure support for individuals who fall through the disability service gaps. **The Foundation recommends the ILC be made responsible for funding disability organisations to provide sustainable information, linkages and capacity-building services that support and empower their respective disability communities.**

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 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.[5]
- 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.[1,6]
    - 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.[5]
    - 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.[7]

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] *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*, pages 3-4.
[4] *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017*, pages 81-82.
[5] *The Global Economic Cost of Visual Impairment* Access Economics & AMD Alliance international 2010.
[6] Taylor H et al, MJA 2005;182:565-568.
[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.