



**Submission on the Independent
Review of the Operation of the
*National Disability Insurance
Scheme Act (Cth)* Discussion Paper**

October 2015

OUR VISION

To reduce the incidence and impact of macular disease in Australia

About Macular Disease Foundation Australia

Macular Disease Foundation Australia is a charity established in 2001 and is the only national organisation committed to working on behalf of the entire macular disease community.

The Foundation's mission is to reduce the incidence and impact of macular disease in Australia through five major areas of activity:

- 1) Education: Provide accurate, specific, current and ongoing information
- 2) Awareness: Increase awareness of macular disease
- 3) Support services: Provision of support to clients and facilitation of access to relevant support
- 4) Research: Support and pursue research
- 5) Representation: Advocate for the best interests of the macular disease community

The Foundation's activities and programs are guided by four overarching strategic pillars:

- 1) Building healthy communities
- 2) Building strong positioning in the development of public policy
- 3) Building a sound knowledge base
- 4) Building strong relationships and partnerships

The Foundation is the voice of patients, families and carers, and all people at risk of developing macular disease. The Foundation also supports healthcare professionals through professional development, information and resources.

The Foundation's work encompasses macular degeneration, diabetic eye disease, retinal vein occlusion and a range of other macular diseases. Macular degeneration is the Foundation's primary focus, and the Foundation has provided outstanding measured health outcomes for the Australian public in addressing macular degeneration. The Foundation is involved in all aspects of the continuum of care for people with macular disease including prevention, early detection, timely access to affordable, effective treatment and rehabilitation.

For over 14 years, the Foundation has a proven track record of outcomes for public health in Australia and has been recognised internationally, with published work in the prestigious *American Journal of Public Health* (AJPH)¹, *Aging and Mental Health*² and *Value in Health*³, collaborations with internationally renowned organisations such as The Angiogenesis Foundation, and sharing the Foundation's work at international forums in Europe, South America and Asia Pacific.

¹ Heraghty J, Cummins R. A layered approach to raising public awareness of macular degeneration in Australia. *American Journal of Public Health*. 2012;102(9):1655-1659.

² Gopinath B et al. Predictors of psychological distress in caregivers of older persons with wet age-related macular degeneration. *Aging & Mental Health*. 2014. Available from: <http://dx.doi.org/10.1080/13607863.2014.924477>.

³ Varano M, Eter N, Winyard S, Wittrup-Jensen K, Heraghty J, *Value in Health* 2014;17:A612.

Given the recognition in its best practice approach to public health in relation to macular degeneration, the Foundation organised and co-hosted the first-ever Global Ageing and Vision Advocacy Summit held on 17–18 April 2013 in Barcelona, Spain in collaboration with the International Federation on Ageing.

Introduction

Macular Disease Foundation Australia is primarily concerned that the NDIS is excluding those who acquire a disability at the age of 65 or over from becoming participants. The NDIS should support people with a disability on the basis of the severity of their functional impairment, and to treat them differently due to old age is unfair and discriminatory. The Foundation provides recommendations on amending the NDIS Act to make the scheme inclusive of this group of people.

The Foundation also recommends that an independent expert audit and risk group be created to advise the NDIA Board on the financial aspects and sustainability of the NDIS, and that attention be brought to people losing their state or territory disability support services due to the transfer of resources and responsibilities to the NDIS.

Responses have been provided to selected questions from the Discussion Paper

Question 1: Do the Objects and Principles of the NDIS Act provide a sufficient basis for giving effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities?

The Foundation is highly concerned that the age discrimination in the NDIS Act is in contravention of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which the Australian Government signed up to in 2007.

The UNCRPD makes no qualification or restriction relating to age and states that all people with disability should be treated equally in law. As Article 5(1) of the UNCRPD is written, "States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law."

Section 22(1) of the NDIS Act clearly contravenes this Article by excluding people who acquire a disability at the age of 65 and over, through establishing an age requirement to become an NDIS participant where "the person was aged under 65 when the access request in relation to the person was made".

It is of major concern that Australia has signed up to UNCRPD but as soon as the practical implementation of these rights became apparent, the Commonwealth Government passed legislation which negated the rights of those who acquire a disability at the age of 65 or over.

This raises the question of genuine commitment by the Commonwealth Government to the UNCRPD.

Australia needs to demonstrate that its commitment is not only in name, otherwise Australia's signature to this Convention is meaningless if it can be so easily negated by the Government of the day.

The Foundation recommends

1. The immediate removal of the age requirement from the NDIS Act, so as to align with the United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory.

Question 3: How well do the access criteria enable government to further the objects and principles of the NDIS Act? With particular reference to the following principles:

- **People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development**
- **People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability**
- **People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.**

The NDIS discriminates against people with disability based on their age.

The age requirement in the NDIS Act (section 22(1)) does not enable government to further the objects and principles of the NDIS Act as it specifically excludes older people who acquire a disability at the age of 65 or over from becoming NDIS participants. These people with disability:

- will not have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development
- will not be supported to participate in and contribute to social and economic life to the extent of their ability
- (and their families and carers) will not have certainty that they will receive the care and support they need over their lifetime.

It is highly inequitable for people with disability aged 65 or over to be excluded from access to the NDIS even though they have the same level of functional impairment as people under the age of 65.

People who acquire a disability at the age of 65 or over are expected to receive their disability supports from the aged care system. However the aged care system is only able to provide extremely limited supports for people with a disability as it primarily focuses on supporting those with frail ageing needs. Services in the aged care system lack specialist disability knowledge, skills and resources. In addition, aged care services require co-payments from clients, in contrast with the fully funded individual support packages that NDIS participants receive.

Despite recent minor amendments in the Commonwealth Home Support Program, there remains an enormous gap in the supports and services available to older people with vision loss who are excluded from the NDIS due to their age. Older people with a disability, such as major vision loss, who are living in residential aged care facilities are in an even more difficult position as there are virtually no supports, such as low vision aids and technologies, provided in this system.

On 18 June 2013, the Foundation wrote to the Parliamentary Joint Committee on Human Rights to highlight the limited disability support in the aged care system. The Foundation also expressed concern that the NDIS Act is exempt from the Age Discrimination Act 2004.

The Committee, in section 3.28 of its 10 December 2013 report⁴, recommended that inequity in disability support between the NDIS and the aged care system be evaluated in this Independent Review, in accordance with section 208 of the NDIS Act. The Committee stated it was concerned that “there may be substantial differences between the supports provided to individuals in the aged care system compared to those on the NDIS, which could result in the inequitable treatment of people over 65 years old who acquire a disability.”

It is important to highlight that people aged 65 or over who pay taxes directly fund the NDIS through the Medicare Levy. As an insurance scheme, it is extremely unfair that they are not covered by the NDIS should they acquire a disability, even though they contribute to it.

It is currently not known if those who acquire a disability at the age of 65 or over will be supported under the Information Linkages and Capacity Building Policy (ILC). Even if that is the case, they would still not be considered NDIS participants based on the NDIS Act.

The NDIS should provide individual funded packages to anyone who meets the disability or early intervention requirements, and there should not be discrimination based on age. It is unfair and inequitable if a person who acquires a disability at the age of 65 or over, with the same level of severe functional impairment as a person aged under 65, receives a lower level of support.

The Foundation recommends

2. The Independent Review follows up on the concerns expressed by the Parliamentary Joint Committee on Human Rights, and the recommendation in its 10 December 2013 report, by investigating the substantial differences between the supports provided to individuals with a disability in the aged care system compared to those on the NDIS, which could result in the inequitable treatment of people who acquire a disability at the age of 65 and over.
3. The NDIS Act no longer be exempted from the Age Discrimination Act 2004.

Question 4: How clearly defined are the access criteria?

For people with macular disease, the access criteria can cause a degree of uncertainty over eligibility, as vision loss progresses over a period of time.

The age requirement (section 22(1)) states the person has to be under the age of 65 when the access request is made, and the disability requirement (section 24 (1)) states the impairment has result in substantially reduced functional capacity.

For a person with macular degeneration, he/she could be diagnosed with the disease at the age of 50, apply for the NDIS and be rejected because the minimum vision loss does not meet the disability requirement. That same person could become legally blind at the age of

⁴ The document is located at:

http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/Completed_inquiries/2014/144/index

70, and then be ineligible when he/she reapplies again for the NDIS due to the age requirement.

People with macular degeneration would also not be eligible under the early intervention requirements, as there is no certainty that disease progression would result in substantial vision loss.

Ideally, removing age requirement from the access criteria would be the most direct way of removing uncertainty over eligibility and be consistent with the objects and principles of the NDIS Act, as people could apply for the NDIS at whatever age substantial vision loss occurs and receive the supports they need.

The Foundation recommends

4. The removal of the age requirement from the access criteria as it currently causes uncertainty over NDIS eligibility for people with disabilities that develop over a period of time.

Question 16: How well do the governance arrangements enable government to further the objects and principles of the NDIS Act?

The Foundation proposes that the responsibilities for financial oversight be delegated from the NDIA Board by forming a qualified independent advisory audit and risk group.

This expert group would independently monitor the financial aspects and sustainability of the NDIS and advise the NDIA Board accordingly.

This separation of roles would allow the NDIA Board to better focus on setting the strategic direction of the organisation, maintaining stakeholder relationships with all other governance stakeholders, and ensuring NDIA compliance with statutory requirements.

The Foundation recommends

5. The creation of an independent expert audit and risk group to advise the NDIA Board on the financial aspects and sustainability of the NDIS.

Question 18: Are there any other aspects of the NDIS legislative framework that you believe are impacting on:

d. Other legislation, including State and Territory legislation?

The Foundation is concerned that aspects of state and territory legislation, in conjunction with bilateral agreements between the Commonwealth and State and Territory Governments, relating to the roll-out of the NDIS may result in changes to funding that will create gaps in disability services and programs.

It is a particular concern that State and Territory Governments will lack funding for their own disability services as they contribute funding and redirect disability resources to the NDIS. For example, the Queensland Government's 'Investing in Queenslanders: Social and human services investment blueprint 2014–2019' states that, "Once the NDIS is fully implemented,

the department will no longer directly deliver disability services”⁵, and the NSW Government has already authorised the transfer of its disability resources to the NDIS through the ‘National Disability Insurance Scheme (NSW Enabling) Act 2013’⁶.

However, people with disability who received state and territory support may not qualify for support under the NDIS (i.e. those who acquire a disability at the age of 65 or over, and those who do not have functional impairment at a substantial level). They would lose their supports should the state or territory disability program they depend on be discontinued.

In essence, there is the strong possibility that people are falling through the gaps during the reform process and the transfer of disability resources and responsibility from the States and Territories to the NDIA. Vulnerable people with all different types of disabilities are affected and have limited opportunity to raise the profile of the loss of their disability support services.

When all the disability resources around the country are being invested into the NDIS, it is conceivable that people with disability needs who do not qualify for the NDIS will lose their disability support services. This issue needs to be investigated and addressed.

The Foundation recommends

6. The Independent Review investigates the impact of the NDIS Act on state and territory disability legislation and services, as there is concern that the NDIS creating a situation where people are losing their existing state/territory disability support services, yet are unable to access the NDIS.

⁵ The document is located at: <http://qada.org.au/sites/default/files/investing-in-queenslanders-2014-19.pdf>

⁶ The document is located at: http://www5.austlii.edu.au/au/legis/nsw/consol_act/ndisea2013450/