



# **Submission to the Productivity Commission**

## **Response to the National Disability Agreement Review Issues Paper**

**August 2018**

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

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# 1. Introduction

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

Macular disease includes a range of conditions that affect the central retina (the macula) at the back of the eye. It is the leading cause of blindness and severe vision loss in Australia. It is estimated that there are approximately 8.5 million people at risk of macular disease and over 1.7 million Australians with some evidence of macular disease.<sup>1,2</sup>

The two macular diseases which have the most significant impact on the Australian population are aged-related macular degeneration (AMD) and diabetic retinopathy. AMD alone accounts for 50% of blindness and primarily affects older Australians<sup>1</sup>; 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.<sup>3</sup> Diabetic retinopathy is the leading cause of preventable blindness among working-age Australians<sup>3</sup>.

The Foundation's submission primarily calls for the development of a new National Disability Agreement (NDA) which addresses the current and future issues affecting support services for people with a disability. These issues include:

- The transition of state and territory governments away from funding and direct delivery of disability support services;
- The limited and inconsistent support for people with a disability who are not National Disability Insurance Scheme (NDIS) participants; and
- The lack of access to low vision aids and technologies for people with vision loss or blindness.

These three issues will be discussed when addressing selected questions from the Productivity Commission Issue Paper.

## 2. Response to page 9 questions from the Issues Paper

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### 2.1. Questions

- In light of developments in the disability policy landscape and intergovernmental funding arrangements, is an NDA still required?
  - If not, by what mechanism would outcomes for people with disability not covered by the NDIS (or related continuity of support arrangements) be achieved?
  - If so, how can the NDA remain policy relevant in an evolving policy environment?
- What should be the scope of the NDA? Should it continue to cover all people with disability? What services should it cover (such as specialist disability services and/or mainstream services, including mental health, healthcare, aged care, education, transport, housing and justice)?
- Is there a coherent link between the NDA and other related agreements, strategies and policies, such as the NDS, the NDIS and State and Territory disability strategies?
  - If not, what should be the relationship between each of these strategies and agreements? Is it necessary to have both an NDA and an NDS, and if so, why?

### 2.2. Response

#### **Recommendation 1**

The Commonwealth, state and territory governments develop a new NDA that clearly defines their roles and responsibilities in funding and delivery of disability support services in Australia, and close the gaps in funding to ensure that all Australians with a disability are able to equitably access disability support services.

#### **Recommendation 2**

The NDA serves as an overarching document for government funding of disability support services in all jurisdictions, with primary focus on establishing funding arrangements that cover the support needs of non-NDIS participants.

The NDA is fundamentally essential in allocating resources to support people with a disability across the nation. The National Disability Strategy is a different type of document, containing the vision and desired outcomes for supporting people with a disability, but does not detail the roles and responsibilities of the Commonwealth, state and territory governments. The National Disability Insurance Scheme (NDIS) only supports the disability needs of its participants, who are only eligible if they have permanent and severe disabilities, or have selected diseases, and are under the age of 65 years old.

In the current policy environment, non-NDIS participants only have access to less equitable levels of support, under programs such as the Continuity of Support (CoS) program, the NDIS Information Linkages and Capacity Building (ILC) program and the aged care system. Some

state and territory governments still directly deliver disability services, however it is likely these services may cease following the full roll-out of the NDIS.

The two main groups of people who are negatively impacted are all people with a disability aged 65 years old and over, and people with a disability under the age of 65 who are ineligible for the NDIS.

It is important to note that the NDIS eligibility requirements for people with vision impairment, as stated in the NDIS operational guidelines<sup>4</sup> is very high, with permanent blindness in both eyes being the standard requirement unless the individual has one of a number of selected genetic eye diseases.

The NDA should continue to serve as an overarching document which clarifies the roles and responsibilities of the Commonwealth, state and territory governments in funding disability support services. The NDA should be comprehensive and cover the funding arrangements to address all aspects of support needs for people with a disability. It should primarily cover the support needs of non-NDIS participants, but also address any gaps in support for NDIS participants. It also should incorporate other disability related agreements to prevent duplication, and be used to establish interfaces and linkages with the health and aged care systems.

### 3. Response to page 13 questions from the Issues Paper

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#### 3.1. Questions

- How have the roles and responsibilities of Governments changed since the NDA was updated in 2012? Are roles and responsibilities clear?
- In light of the changing policy landscape (particularly with respect to the NDIS), do the roles and responsibilities of Governments in the NDA need to change? How?
  - What role should the NDA play in assigning responsibilities for all disability services between governments? How should this relate to the responsibilities set out in the NDIS bilateral agreements?
  - Should the roles and responsibilities of mainstream services to people with a disability be more clearly outlined in a national agreement?
- How has the introduction of the NDIS impacted on access to services for people not eligible for the NDIS?
  - Where are the main gaps in services outside the NDIS? What are the problem areas?
  - To what extent does the NDIS (for example, through the provision of ILC activities and Local Area Coordinators) cater to people outside the NDIS?
  - What role could the NDA play in assigning responsibilities for addressing service gaps identified in the current arrangements?
- Should the agreement have regard to the way States and Territories are delivering services to people with a disability outside the NDIS (for example, through mainstream services or through specialist disability services)? If so, why?

#### 3.2. Response

##### **Recommendation 3**

The Commonwealth, state and territory governments reform the disability and aged care systems to ensure that all non-NDIS participants have access to appropriate and adequate disability support services, and at an equitable level with those in the NDIS.

The most significant issue concerning people with a disability is the lack of clarity relating to the roles and responsibilities of Commonwealth, state and territory governments, which is affecting the funding and delivery of support services.

In general terms, under the NDA the state and territory governments are responsible for funding disability services for people under the age of 65 years old, and the Commonwealth Government is responsible for funding disability services for people aged 65 years old and over.

However, an example of the lack of clarity in the NDA is support for people with a disability who are under the age of 65 years old and are not eligible for the NDIS. Paragraph 18b of the NDA states, "All State and Territory governments are responsible for: (except for Victoria and Western Australia) funding and regulating basic community care services for people under the age of 65 years in line with their principal responsibility for delivery of other disability services

under this Agreement, except Indigenous Australians aged 50 years and over for whom the cost of care will be met by the Commonwealth.”

Despite this statement, state and territory governments are in the process of ceasing direct delivery of support services for people with a disability under the age of 65 years old, with the NSW government closing its Ageing, Disability and Home Care (ADHC) office and outsourcing some of its functions from July this year.

Another example of the lack of clarity in the NDA relates to the funding responsibility for aids and equipment programs, which are currently being funded and delivered by state and territory governments. Paragraph 17d of the NDA states that, “The Commonwealth undertakes responsibility for: funding disability services delivered by the States in accordance with their responsibilities under this Agreement for people aged 65 years and over (50 years and over for Indigenous Australians).”

Despite this statement, the state and territory governments still have full responsibility over their respective programs. As a result, the types of aids and equipment and the level of subsidies provided are different in every jurisdiction, with only a few jurisdictions providing subsidised low vision aids and technologies. Without Commonwealth government funding, it is feared that with significant levels of state and territory government responsibility and funding being transferred to the NDIS, these aids and equipment programs may implement age limits; provide only medical, and not disability aids and equipment; or even cease to exist.

### **3.3. Additional comments supporting the establishment of a national aids and equipment program**

#### **Recommendation 4**

Through the NDA, establish a nationally funded, accessible, affordable and consistent low vision aids and equipment program, to replace the current state/territory government programs.

The cost of low vision aids and equipment, and the associated training to use them effectively, can be prohibitive to individuals. For example, a person with slight vision loss may use an optical magnifier which costs between \$7 to \$530. However, that optical magnifier may not be appropriate once that person’s vision loss becomes more severe, and an Electronic Desktop Magnifier, costing between \$3,000 to \$7,000, will then be needed.<sup>5</sup>

Government subsidies for low vision aids and technologies exist, however they are inconsistently provided across the country. Low vision aids are not covered under Medicare, therefore people who cannot afford to purchase devices privately, rely on either national or state and territory based subsidies to cover the cost.

On the national level, people with vision loss or blindness may seek to access subsidised low vision aids and technologies through one of two systems; the NDIS or the aged care system, depending on whether they are diagnosed before or after the age of 65 years old.

Those who are diagnosed under the age of 65 years old and meet the other eligibility requirements are able to access fully funded low vision aids and technologies from the NDIS.

Those diagnosed at the age of 65 years old or over are excluded from the NDIS and have limited access to subsidies in the aged care system, as there is a lack of inclusion of disability support in aged care policy and legislation.

The existing aged care programs do not provide services and packages based primarily on a person's disability. For example, a person with vision loss or blindness aged 65 or over will not be able to access the aged care system solely to 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 Home Support Programme (CHSP) has a policy which is meant to provide low vision aid subsidies, however this policy currently remains unfunded. The provision of low vision aids through the Home Care Packages program and residential aged care facilities is inconsistent as it is dependent on negotiations between the consumer and the provider.

On the state and territory level, government subsidies are inconsistent as they are limited to the respective jurisdictions. State and territory government aids and equipment programs have different budgets, scope, eligibility requirements and levels of subsidy. Some schemes require no consumer co-payments but limit eligibility and scope, while others have broader eligibility and scope but require user co-payments. The provision of low vision aids and technologies is excluded from the main aids and equipment programs in Tasmania, South Australia and Western Australia, but may be provided through other state-funded agencies at a different level of subsidy or at cost to the consumer.

Accessing certain Commonwealth Government programs, such as the Home Care Packages and residential care, will also render consumers ineligible for many of the state and territory based aids and equipment programs.

The inconsistent policies for aids and equipment subsidies by Commonwealth, state and territory governments, and the separation between state/territory and Commonwealth program funding and policies, have created barriers which prevent vulnerable people with vision loss or blindness from accessing low vision aids and technologies.

The current NDA has not clearly addressed which level of government funds disability aids and equipment. As a result, developing policies to create national consistency have been challenging. There is also concern that state and territory governments will stop providing disability aids and equipment due to the lack of clear responsibility in the NDA and given that they have significant funding commitments to the NDIS based on their respective NDIS bilateral agreements.

To equitably provide appropriate support to all Australians with vision loss or blindness, there is an urgent need to fund and standardise the eligibility, access and co-payment requirements for low vision aids and technologies across the country. However, given the significant differences in the provision of low vision aids and technologies subsidies amongst the different existing Commonwealth, state and territory government programs, the most effective course of action may be to separately establish a new national low vision aids and equipment program.

In comparison with the Hearing Services Program<sup>6</sup>, which costs the Federal Budget over \$500 million a year<sup>7</sup>, Macular Disease Foundation Australia has developed its own cost modelling, and estimates that an initial national low vision aids and equipment program would cost \$30-\$50 million a year<sup>8</sup>.

#### 4. Reference List

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<sup>1</sup> Deloitte Access Economics and Macular Degeneration Foundation (2011). *Eyes on the future: A clear outlook on Age-related Macular Degeneration*.

<sup>2</sup> Gopinath B et al. *BMJ Open* 2017;7:e018204. doi:10.1136/bmjopen-2017-018204

<sup>3</sup> *Out of sight – A report into diabetic eye disease in Australia*, 2013, Baker IDI and Centre for Eye Research Australia.

<sup>4</sup> National Disability Insurance Scheme (2015). *Operational Guideline – Access – Disability Requirements*. Accessed at: [https://www.ndis.gov.au/html/sites/default/files/OGs-access-disability-requirements\\_0.pdf](https://www.ndis.gov.au/html/sites/default/files/OGs-access-disability-requirements_0.pdf)

<sup>5</sup> Macular Disease Foundation Australia and The George Institute for Global Health (2017). *Low vision, quality of life and independence: A review of the evidence on aids and technologies*.

<sup>6</sup> Austroads. *Assessing Fitness to Drive for Commercial and Private Vehicle Drivers: Medical Standards for Licensing and Clinical Management Guidelines: Guidelines and Standards for Health Professionals in Australia*: Austroads; 2003.

<sup>7</sup> McCarty CA, Fu CL, Taylor HR. *Predictors of falls in the Melbourne visual impairment project*. *Australian and New Zealand journal of public health* 2002; 26(2): 116-9.

<sup>8</sup> Macular Disease Foundation Australia (2017). *Cost estimate of a federally funded low vision aids and technology program*. Unpublished.