

15 February 2024



Department of Health and Aged Care – New Aged Care Act Consultation

Via email - [AgedCareLegislativeReform@health.gov.au](mailto:AgedCareLegislativeReform@health.gov.au)

Dear Aged Care Legislative Reform team,

Macular Disease Foundation Australia appreciates the opportunity to provide this submission in response to the *New Aged Care Act Consultation*.

### **About Macular Disease Foundation Australia**

Macular Disease Foundation Australia is the national peak body representing people living with macular disease and their carers. Our purpose is to reduce the impact of macular disease through (i) supporting and caring for people living with macular disease; (ii) engaging with healthcare organisations and providers; (iii) advocacy; (iv) research and (v) community awareness and early detection.

We currently engage directly with 75,000 members of the community across Australia.

### **About Macular Disease**

Macular disease is the collective term used for eye diseases and conditions affecting the macula, which is the part of the retina at the back of the eye responsible for central vision. Macular disease is the leading cause of blindness and severe vision loss in Australia.<sup>1</sup>

In 2024, it is estimated there are over 1.9 million Australians with some evidence of macular disease.<sup>1,2</sup> Age-related macular degeneration (AMD) is the leading cause of blindness and irreversible vision loss in Australia among older Australians.<sup>3,4</sup> There are an estimated 1.5 million Australians living with some evidence of AMD.<sup>2</sup>

Vision loss in Australia has significant impacts on individuals, their families and carers, and also has wide-ranging implications for health, aged care and disability services.

Vision loss in general is associated with a 50% decline in social independence; three-fold increase in the risk of depression; two-fold increased risk of falls; four-to-eight-fold increased risk of hip fractures; increased risk of medication dosing errors; two-to-three years earlier admission into nursing homes; and greater all-cause mortality.<sup>5</sup>

Vision loss is extremely costly at both the individual and government level. The total economic cost of vision loss in Australia is estimated to be \$16.6 billion or \$28,905 per person with vision loss aged over 40.<sup>3</sup> This is made up of:<sup>3</sup>

- Total health system costs of \$2.98 billion
- Total other financial cost of vision loss of \$4.2 billion or \$7,373 per person aged over 40 with vision loss including:
  - \$2.28 billion in estimated productivity losses of those with vision loss
  - \$869 million in estimated deadweight losses from transfers and lost taxation
  - \$839 million in estimated other indirect costs (aids, modifications, other carer and bring forward of funeral expenses)
  - \$251 million in estimated carer (opportunity) costs
- Loss of wellbeing of \$9.4 billion, a cost of \$16,360 per person with vision loss aged over 40.

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[Macular disease is the leading cause of blindness and severe vision loss in Australia](#)

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## **The New Aged Care Act – areas that Macular Disease Foundation supports**

Macular Disease Foundation supports the development of a new Aged Care Act. The current *Aged Care Act 1997* is outdated and not able to adequately or appropriately support older Australians, especially those living with disabilities such as vision loss and blindness.

With the exclusion of older people with a disability from the National Disability Insurance Scheme (NDIS), they have no choice but to depend on funded aged care services for disability needs.

In particular, in this Exposure Draft, we support its alignment with the United Nations *Convention on the Right of Persons with Disabilities* (Chapter 1, Part 1, Section 5, Paragraph a).

We support this Exposure Draft enabling older Australians accessing funded aged care services to exercise choice and control in the planning and delivery of those services (Chapter 1, Part 1, Section 5, Paragraph c).

We also support the establishment of an aged care worker screening scheme which will facilitate mutual recognition of worker screening across both the aged care and disability sectors (Chapter 3, Part 1, Section 65), as this would help increase the size of the aged care workforce and the level of skills in supporting older people with a disability in the aged care system.

## **The New Aged Care Act – areas that Macular Disease Foundation recommends need to be strengthened**

Macular Disease Foundation strongly recommends the following amendments to areas within the Exposure Draft to strengthen its support for older Australians:

1. Chapter 1, Part 1, Section 5, Paragraph f states that one of the Objects of the Act is to “provide and support education and advocacy arrangements that can assist individuals accessing funded aged care services to understand their rights, make decisions and provide feedback on the delivery of their services without reprisal”.

This should be expanded to include the provision of support for people to understand and navigate funded aged care services. The aged care system is complex, and the Act needs to acknowledge that funding should go to establishing programs that help older Australians navigate the system, as evidenced by the need for the Aged Care Navigators Trial<sup>6</sup> and Star ratings system<sup>7</sup>.

2. In general, the Exposure Draft needs to be strengthened to clarify that older Australians with a disability will be supported in the aged care system, and that funded disability services in the aged care system need to be made available to them.
3. The Royal Commission into Aged Care Quality and Safety 2021 report Recommendation 72 highlighted the need for equity for people with disability receiving aged care, stating:<sup>8</sup>

*... every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions.*

It is essential that the new Aged Care Act ensures that older Australians with a disability are eligible for the aged care system because of their disability needs.

Due to the age limit established in the *National Disability Insurance Scheme Act 2013*, people who acquire a disability at the age of 65 years and over are excluded from the NDIS.<sup>9</sup> The bilateral NDIS agreements between the Australian Government and all the

States and Territories establish that the Australian Government is responsible for the supporting the disability needs of these older Australians.<sup>10</sup>

The new Aged Care Act must allow older Australians with disability needs, including low vision and blindness, to access the aged care system. This can be supported by amending the sections outlining the eligibility and assessment criteria (Chapter 2, Part 2, Divisions 2 and 3) to include providing access to individuals who simply require the assistance of one or more aids to maintain their physical, mental or social capacity to function independently.

With the Australian Government Department of Health and Aged Care developing the new “Support at Home” program<sup>11</sup>, including the introduction of a new goods, equipment and assistive technology (GEAT) program within it, there needs to be clear language in this new Aged Care Act to include disability services, which support people aged 65 years old and over. The legislation should also guarantee access to low vision aids and technology to aged care clients in all care settings, regardless of whether they are in home care or residential care.

Although the Exposure Draft includes “the individual requires... the assistance of one or more aids, to maintain their physical, mental or social capacity to function independently” as part of its definition for “care needs” (Chapter 1, Part 2, Division 1, Section 7), it is not included or clearly referenced in the sections about eligibility (Chapter 2, Part 2, Division 2) or assessment (Chapter 2, Part 2, Division 3) for the aged care system.

4. The Exposure Draft lacks formal timeframes for the System Governor to implement procedures and actions. Where timeframes are mentioned, they only begin **after a decision is made** by the System Governor.

If older Australians are to truly be at the centre of this new Act, timeframes for correspondence, procedures and actions should instead begin **after formal correspondence/request is received** by the System Governor and delegates.

Should you require further information, please do not hesitate to contact me at

[REDACTED]

Yours sincerely,

[REDACTED]

Dr Kathy Chapman  
CEO

## References

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- <sup>1</sup> Australian Government Department of Health (2019). *National Strategic Action Plan for Macular Disease*. Accessed at [www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-action-plan-for-macular-disease\\_1.pdf](http://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-action-plan-for-macular-disease_1.pdf).
- <sup>2</sup> Deloitte Access Economics and Macular Degeneration Foundation (2011). *Eyes on the future - A clear outlook on age-related macular degeneration*. A report for Macular Disease Foundation Australia. Accessed at [www.mdfoundation.com.au/resources/eyes-on-the-future/](http://www.mdfoundation.com.au/resources/eyes-on-the-future/).
- <sup>3</sup> Deloitte Access Economics and Vision 2020 Australia (2010). *Clear Focus - The Economic Impact of Vision Loss in Australia in 2009*. Accessed at [www.vision2020australia.org.au/resources/clear-focus-the-economic-impact-of-vision-loss-in-australia-in-2009/](http://www.vision2020australia.org.au/resources/clear-focus-the-economic-impact-of-vision-loss-in-australia-in-2009/).
- <sup>4</sup> Taylor H et al. (2005). Vision loss in Australia. *MJA*. 2005;182:565-568. Accessed at [www.pubmed.ncbi.nlm.nih.gov/15938683/](http://www.pubmed.ncbi.nlm.nih.gov/15938683/).
- <sup>5</sup> Access Economics and AMD Alliance International (2010). *The Global Economic Cost of Visual Impairment*.
- <sup>6</sup> COTA Australia. *Aged Care Navigators*. Accessed on 7 February 2024 at [www.cota.org.au/information/aged-care-navigators/](http://www.cota.org.au/information/aged-care-navigators/).
- <sup>7</sup> Aged Care Quality and Safety Commission. *Star ratings*. Accessed on 7 February 2024 at [www.agedcarequality.gov.au/providers/assessment-monitoring/star-ratings](http://www.agedcarequality.gov.au/providers/assessment-monitoring/star-ratings).
- <sup>8</sup> Royal Commission into Aged Care Quality and Safety (2021). *Final Report - List of Recommendations*.
- <sup>9</sup> Parliament of Australia (2013). *National Disability Insurance Scheme Act 2013*. Accessed at [www.legislation.gov.au/C2013A00020/latest/text](http://www.legislation.gov.au/C2013A00020/latest/text).
- <sup>10</sup> National Disability Insurance Scheme (2022). *Intergovernmental agreements*. Accessed at [www.ndis.gov.au/about-us/governance/intergovernmental-agreements](http://www.ndis.gov.au/about-us/governance/intergovernmental-agreements).
- <sup>11</sup> Australian Government Department of Health and Aged Care (2022). *A new program for in-home aged care – Discussion paper*. Accessed on 6 August 2023 at [www.health.gov.au/resources/publications/a-new-program-for-in-home-aged-care-discussion-paper?language=en](http://www.health.gov.au/resources/publications/a-new-program-for-in-home-aged-care-discussion-paper?language=en).