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Macular Disease Foundation AUSTRALIA™

Our focus is your vision

Submission to the Senate Community Affairs Legislation Committee

Inquiry into the *Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016*

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OUR VISION

To reduce the incidence and impact of macular disease in Australia

Key concerns regarding the *Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016*

The *Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016* will negatively impact certain people with a disability who wish to continue working or studying.

If this Bill is passed by Parliament, two groups of people will be significantly affected by these legislative amendments:

1. Those under 65 years of age who do not qualify for the National Disability Insurance Scheme (NDIS) based on the level of severity of their disability; and
2. Those who are aged 65 years or over with a disability.

These two groups will no longer receive the Mobility Allowance if they are new or returning applicants from 1 January 2017.

In contrast, those who qualify for the NDIS will be entitled to receive comparable transportation allowances provided through the NDIS.

However, from 1 July 2020, even existing recipients would lose this benefit, increasing the financial burden on already vulnerable people who wish to continue to study or work. These changes are most inequitable for people aged 65 years or over, who have to contribute co-payments for services in an aged care system that has rationed packages and does not provide support services based on their disability needs. This is in contrast to the NDIS, where participants receive fully funded support services planned around their disability needs.

As the disability reforms are ongoing, it is not known what will be included in state and territory disability programs from 1 July 2020. However, as they are planned and managed by respective state or territory governments, it can reasonably be assumed that the consumers of these programs will experience separate and inconsistent program policies in each state and territory, resulting in inequities in the eligibility requirements, types of support offered and level of funding offered. This is in contrast to the NDIS where there is national consistency.

Given the lower level of support for Commonwealth aged care system consumers and state/territory disability system consumers, they will be more disadvantaged than NDIS participants when the Mobility Allowance program closes.

As such, Macular Disease Foundation Australia proposes that the Mobility Allowance program be retained in its current form, except for NDIS participants as they will be supported through that system. This will allow those with a disability, illness, or injury, who cannot use public transport without substantial assistance, to continue receiving financial support for travel to work or study.

Recommendation

Macular Disease Foundation Australia recommends that the *Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016* be rejected by Parliament. In its place should be a Bill which ensures that people who are unable to use public transport without substantial assistance due to a disability, illness or injury, and do not qualify for the NDIS, can continue to receive the Mobility Allowance on an ongoing basis.

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.

- Every day the Foundation is working to save the sight of all Australians and has done so for 15 years.
- The Foundation is recognised nationally and internationally as the Australian peak body for macular disease.
- The Foundation is a robust organisation with a strong governance model:
    - An experienced Board of Directors set the strategic direction of the organisation
    - State Chairs represent the macular disease community in their respective states.
    - Four expert Committees including a Medical Committee, comprising 11 of Australia's leading retinal specialists who provide expertise across all macular diseases, guiding the Foundation on major matters related to prevention, treatment and patient outcomes.
    - The Foundation's National Research Advisor, Professor Paul Mitchell, Professor of Ophthalmology University of Sydney, is a world expert on macular disease and is a key source of information and support.
    - The Foundation has experienced senior staff with backgrounds in science, education, communications, pharmaceutical and medical industries, government policy, media and business. The CEO was a recipient of a Harvard Fellowship in 2013 to study *Strategic Perspectives in Non-Profit Management*.
- The Foundation has a broad national membership of almost 52,000, 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 membership 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 members, and has developed tools and expertise to ensure it effectively communicates and represents the views of members.
- The Foundation has a proven track record of outcomes for public health in Australia which has been recognised on the world stage, with the publication of its work in leading international, peer-reviewed journals: *Aging and Mental Health*[i], *American Journal of Public Health* (AJPH)[ii], *Clinical Ophthalmology*[iii], *Eye*[iv] and *Value in Health*[v].

- The Foundation has been regularly invited to share its outstanding achievements in local and international fora, including at major international conferences and events in Europe, South America and Asia Pacific. Given the recognition of 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* in April 2013 in Barcelona, Spain in collaboration with the International Federation on Ageing.

Macular disease in Australia

- It is estimated that there are approximately 8.5 million people **at risk** of macular disease and over 1.19 million Australians with **some evidence** of macular disease.[vi]
- Macular disease is the greatest contributor to chronic disease in eye health in Australia.[vi]
- Macular disease is a large group of sight-threatening diseases that affect the central retina at the back of the eye, which is responsible for detailed central vision. These diseases include macular degeneration, diabetic retinopathy, retinal vein occlusions and numerous other macular dystrophies.
- Macular degeneration and diabetic retinopathy have been categorised as priority eye diseases for the prevention of blindness and vision impairment by the World Health Organisation.
- Early detection of macular disease is vital. Treatment, along with diet and lifestyle measures, can slow progression of macular disease and, in the case of treatment, save sight.[vi]
- The most common macular disease in Australia is macular degeneration:
    - **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. [vi]
    - 1 in 7 (1.19 million) people have some evidence of macular degeneration.[vi]
    - **This is estimated to increase 70% to 1.7 million by 2030**, in the absence of adequate treatment and prevention measures.[vi]
    - Primarily affects those over the age of 50 and the incidence increases with age. [vi]
    - Macular degeneration is a major chronic disease with prevalence 50 times that of multiple sclerosis and 4 times that of dementia.[vi]
    - The impact of macular degeneration on quality of life is equivalent to cancer or coronary heart disease.[vii]
    - Smoking is a key risk factor as it increases the risk of developing macular degeneration by 3 to 4 times and smokers, on average, develop macular degeneration 5 to 10 years earlier than non-smokers[vi].
- Diabetic eye disease is the leading cause of blindness among working age adults in Australia:[viii]
    - 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.

- One in three people over the age of 50 with diabetes has diabetic retinopathy.
- The expected growth in the number of Australians living with diabetes will lead to a corresponding rise in diabetic eye disease 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 eye disease 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, the use of certain medications such as fenofibrate, 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.**
- Visual impairment prevents healthy and independent ageing and is associated with[6]:
  - Risk of falls increased by two times.
  - Risk of depression increased by three times.
  - Risk of hip fracture increased by four to eight times.
  - Admission to nursing home three years earlier.
  - Social independence decreased by two times.
- Vision loss from macular degeneration:
  - In 2010, the total cost of vision loss, including direct and indirect costs, associated with macular degeneration was estimated at $5.15 billion, of which the financial cost was $748.4 million ($6,982 per person).[vi]
  - The socio-economic impacts of 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.[8]

- 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.[8]

- 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.[ix]

References

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