Response to the Inquiry into the Living Longer Living Better Legislative Reforms

April 2013

Macular Disease Foundation AUSTRALIA™

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22 April 2013

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600, Australia

Dear Committee Secretary,

Re: Response to the Inquiry into the *Living Longer Living Better* legislative reforms

The Macular Disease Foundation Australia welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs on the inquiry into the *Living Longer Living Better* legislative reforms, namely the *Aged Care (Bond Security) Amendment Bill 2013*, the *Aged Care (Bond Security) Levy Amendment Bill 2013*, the *Aged Care (Living Longer Living Better) Bill 2013*, the *Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013*, and the *Australian Aged Care Quality Agency Bill 2013*.

With the exclusion of people who acquire a disability aged 65 and over from DisabilityCare Australia, it is essential and imperative that the *Living Longer Living Better* reforms create mechanisms in the aged care system to support the needs of older people with vision impairment and blindness. Macular degeneration is the leading cause of legal blindness and major vision loss in Australia, with 50 per cent of all legal blindness in Australia due to macular degeneration.

In addition, the Foundation requests that it be able to present its position on the *Living Longer Living Better* legislative reforms to the Senate Standing Committee on Community Affairs. I can be contacted in response to this request .The Foundation looks forward to continuing to work with the Commonwealth Government in the interest of the macular degeneration community.

Please find a copy of the submission enclosed.

Yours sincerely,

Julie Heraghty
Chief Executive Officer
Macular Disease Foundation Australia

About the Macular Disease Foundation Australia

The Macular Disease Foundation Australia (formerly known as the Macular Degeneration Foundation) is a charity established in 2001 and is the only national charity committed to working on behalf of the entire macular disease community.

The Foundation represents patients, families and carers, and people at risk of developing macular diseases. The Foundation also serves healthcare professionals, providing them with professional development, information and resources.

The vision of the Foundation is to reduce the incidence and impact of macular disease in Australia through five major objectives:

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

The Foundation's activities encompass all macular diseases, including diabetic retinopathy, retinal vein occlusions, and macular dystrophies. Macular degeneration is the Foundation's primary focus.

About macular degeneration

Macular degeneration is a progressive, chronic disease of the macula. It leads to loss of central vision, affecting the ability to read, drive, recognise faces and perform activities requiring detailed vision.[i]

Macular degeneration is the leading cause of legal blindness and major vision loss in Australia,[ii,iii] 50 per cent of all legal blindness in Australia is due to macular degeneration. The prevalence of macular degeneration is four times that of dementia and more than half that of diabetes.[iv] Over one million people in Australia have some evidence of macular degeneration. In the absence of effective prevention and treatment measures, this number will increase to over 1.7 million by 2030.[v] Macular degeneration has been categorised as a priority eye disease for the prevention of blindness and vision impairment by the World Health Organisation.[vi]

Vision impairment and legal blindness

Macular degeneration is the leading cause of legal blindness and major vision loss in Australia. While many people with macular degeneration receive an initial diagnosis

before 65, virtually all of the estimated 167,000 people with vision impairing late macular degeneration in either eye are aged over 65[vii].

It is estimated that between 39,000 and 73,000 Australians are legally blind in both eyes due to macular degeneration. In 2007, a highly effective treatment became available for neovascular (or 'wet') macular degeneration, the most common cause of serious vision loss and blindness with this disease. This treatment has changed the landscape of ophthalmology and is expected to result in a progressive reduction in blindness from this type of the disease. However not all people with wet macular degeneration benefit from treatment, many became blind before treatment was introduced, and many others experience late 'dry' macular degeneration or geographic atrophy, for which there is currently no effective treatment.[viii]

Cost of macular degeneration in Australia

The total cost of vision loss associated with macular degeneration was estimated at approximately $5 billion in 2010.[ix] The socio-economic impacts of macular degeneration include lower employment rates, higher use of services, social isolation, emotional distress and an earlier need for nursing home care.[x] The impact of macular degeneration on quality of life is equivalent to cancer or coronary heart disease[xi]. Visual impairment prevents healthy and independent ageing and is associated with the following:[xii]

- Risk of falls increased two times
- Risk of depression increased three times
- Risk of hip fractures increased four to eight times
- Admission to nursing homes three years earlier, on average
- Social independence decreased two times

Introduction

On 21 March 2013, the National Disability Insurance Scheme (DisabilityCare Australia) legislation passed through Parliament excluding people who acquire a disability aged 65 and over from the scheme. This exclusion has made it all the more essential and imperative that the *Living Longer Living Better* legislative reforms create mechanisms to support the needs of older people with vision impairment and blindness, and will now have to be accommodated in the aged care system. In addition, the aged care system will be required to integrate awareness, early detection and education programs for both older Australians and professionals into the aged model in both residential and home care settings.

The aged care system does not have the required level of capacity, expertise and funding to support people with a disability, which will result in people with vision

impairment and blindness falling through the cracks of this reform agenda, and in effect having to pay for their own disability support services.

It is inequitable and unacceptable that people who acquire their vision impairment at the age of 65 or older will be relegated to accessing an aged care system that provides a significantly lower standard of care than the disability system, and one which requires co-contribution. There is also the need to overcome the pervasive myth that vision impairment and blindness are natural consequences of the ageing process.

In light of DisabilityCare Australia's age discrimination, the *Living Longer Living Better* legislative reforms must include the support needs of people with vision impairment or blindness, in a manner that is equitable with DisabilityCare Australia, which will provide support services for people who acquire a disability under the age of 65.

In this submission, the Foundation will propose its primary recommendation that 'people who are vision impaired or blind' be listed as a special needs group in the *Aged Care (Living Longer Living Better) Bill 2013*. Other recommendations are the inclusion of 'low vision supplement' as a primary supplement for all care recipients in the legislation, and including references to disability care and support for people with a disability aged 65 and over in the aged care legislation.

'People who are vision impaired or blind' as a special needs group

Recommendation 1
The Foundation recommends the inclusion of 'people who are vision impaired or blind' as a special needs group in the *Aged Care (Living Longer Living Better) Bill 2013*, schedule 1, part 1, item 6.

The Foundation's key recommendation is for the inclusion of 'people who are vision impaired or blind' as a special needs group in the legislation.

Vision impairment is more common in older people, increasing three-fold with every decade of life after the age of 40.[xiii] Australia has an ageing population, with approximately three million people aged 65 or over in 2011, increasing to six million by 2031.[xiv] The aged care system should be set up to support people with vision impairment or blindness in the long term. However it is currently not designed to provide support for many disabilities. It lacks the funding, capacity and expertise to deliver much needed services, resulting in people with vision impairment or blindness having to pay for their own disability support needs including low vision aids and technology. This

creates issues around access and affordability of low vision aids for the individual, which can impact on their ability to continue to live independently and maintain a good quality of life.

The lack of acknowledgment for people with disabilities, especially vision impairment and blindness, in aged care legislation is discriminatory, inequitable and obstructs access to specialist disability services, which goes against the principles of the United Nations Conventions on the Rights of Persons with Disabilities. The designation of special needs status would encourage aged care service providers to take into account specialist needs, provide greater training for aged care staff on individual and complex requirements, allow for more targeted funding initiatives, support people to remain in their own homes and out of residential care for significantly longer, and most importantly, provide enormous quality of life benefits for older people who are vision impaired or blind.

In preparing its March 2013 *The Gateway Service Delivery Model Advisory Paper* for the Department of Health and Ageing, the National Aged Care Alliance (NACA), of which the Foundation is a member, recognised "people who are blind or vision impaired" as a special needs group. The Minister and the Department need to follow the lead of the sector's key stakeholders and recognise 'people who are vision impaired or blind' as a special needs group.

Once 'people who are vision impaired or blind' is designated as a special needs group, long term policy decisions can be made to allocate funding to supplement specialist care, community care and residential care services providers in providing specialist care and support for these people.

Low vision supplement

Recommendation 2
The Foundation recommends the inclusion of a 'low vision supplement' as a primary supplement for all care recipients in the *Aged Care (Living Longer Living Better) Bill 2013*, sections 44-5 and 48-3.

The inclusion of a 'low vision supplement' as a primary supplement in the aged care legislation would remove cost barriers and improve access to low vision services for older people with vision impairment or blindness. The supplement could be used to fund the provision of specialist assessments and support including mobility aids and training, and low vision aids and technology (including training, servicing, etc).

The cost of low vision aids can be prohibitive to individuals, but is relatively low cost for the Commonwealth Government to provide. For example, aids can cost as low as $40 for a walking cane and as high as $6,000 for a CCTV (closed circuit television). These can, however, yield high return for people with vision impairment or blindness in terms of improving their quality of life and independence. Low vision aids allow people to remain living in their own homes for longer and delay entry into residential care. For people who have already entered residential care, aged care facilities could be funded through the supplement to provide access to aids and allow residents with vision impairment or blindness to maintain a good quality of life by participating in social and recreational activities.

Another area that can be funded by supplements is specialist assessment and support. Generic assessment tools can be inadequate in determining the complex support needs of people with vision impairment or blindness. Specialist assessments may be required to determine the most appropriate support needs for individuals, including the provision of low vision aids and low vision training for independent living. Currently, most people who are vision impaired or blind and access specialist services receive them through specialist blindness agencies rather than through the aged care sector. Should supplements be made available, the costs to the individual and agencies could be mitigated and therefore made more accessible.

A specialist assessment should be performed by highly skilled and qualified individuals with extensive knowledge of conditions resulting in vision impairment, working within or in collaboration with low vision service provider and include eye health professionals such as ophthalmologists, optometrists, orthoptists, and occupational therapists.

Home care example

What often happens now

Anne is a 70 year old who lives alone at home. Despite appropriate treatment, she loses vision rapidly in both eyes from 'wet' macular degeneration. She receives a generic assessment from the Aged Care Assessment Team (ACAT), which recommends daily personal care support, to do such tasks as shopping, preparation of meals, cleaning and reading out her mail. Despite the care, costing thousands per month, she remains unable to use public transport and feels highly vulnerable venturing outside the house. She remains unable to read, and is still incapable of using her computer or doing the arts and crafts that she once loved. Anne becomes depressed as she feels helpless, worthless and bored.

What should happen now

ACAT refers Anne to a specialist blindness agency for a specialist assessment. The specialist assessment identifies Anne's specific needs and recommends a one-off purchase of a CCTV for reading bills, screen magnification and a screen reader for her computer, some portable magnifiers for reading and shopping, improved lighting and some minor home modifications to improve safety. Some specialist mobility training, including the use of a white cane enables Anne continue to independently use public transport, visit family and friends and go shopping. For a fraction of the cost of providing a daily carer, Anne feels empowered and is able to care for her own needs, and continue to remain fully independent and living in her own home. Currently, Anne has to pay for the equipment herself. If she is unable to pay, she either goes without, or is dependent on donations from the low vision agency (usually a charity.)

What should happen in the future

Similar to the situation above, ACAT refers Anne to a specialist blindness agency for a specialist assessment. Following the assessment, she is able to obtain enabling aids and technology, as well as essential training and servicing, through a person-centred aged care package that is similar to what would be available to someone aged under 65 via the NDIS.

Residential care example

What typically happens now

Mary is an 80 year old who lives residential care facility. She is frail, has difficulty walking, and has lost some vision from 'dry' macular degeneration. One day, she suddenly loses vision in both eyes from 'wet' macular degeneration. The residential care facility's staff is untrained in the consequences of her sudden vision loss and do not send her to the ophthalmologist immediately. As a result she becomes legally blind in both eyes. The facility management is unable to provide extra support as she is on the basic package. She cannot afford to purchase her own low vision aids as she is a full pension retiree and all of her money is spent on treatment and her residential fees. She becomes isolated and depressed from a poor quality of life.

What should happen in the future

The staff members at the residential care facility are trained in supporting residents with eye conditions. When she does get wet AMD, the staff know to send her to an ophthalmologist for treatment immediately, thereby preserving her vision. In the event that she continues to lose vision and becomes seriously impaired or legally blind, she is referred to a specialist low vision agency and is able to obtain a CCTV and/or other aids and technology, as well as mobility training via a package similar to what would be available to someone aged under 65 via the NDIS. Mary is happy as she feels supported by the staff members, who are trained to provide her the appropriate type of care as her condition changes.

Equitable access to disability services in the aged care system

Recommendation 3

The Foundation recommends that the aged care legislation include references to disability care and support for people with a disability aged 65 and over.

Whilst the Commonwealth Government has made a clear decision to separate the disability and aged care systems, there needs to be mechanisms built into the aged care system to ensure that people aged 65 and over will have their disability needs accommodated.

Unfortunately the political rhetoric does not match reality. Currently there is no mechanism in the aged care system to support disability needs, and people with a disability in the system simply 'fall through the cracks'.

It is the Foundation's position that all people with a disability, regardless of their age, should have their disability needs covered under DisabilityCare Australia. As this is not the direction the Commonwealth Government has taken at this stage, there needs to be either the creation of a duplicate disability system within the aged care system, or a flexible and comprehensive interface mechanism with DisabilityCare Australia. Whatever initiative the Commonwealth Government adopts, it needs to be enshrined in legislation to ensure that discrimination does not occur against older people with a disability and that unnecessary and costly duplication does not arise.

Conclusion

As the aged care reform legislation is currently written, it will not accommodate the support required in the aged care system for older people with a disability, including people who are vision impaired or blind. In fact, by omission it is discriminatory. In light of the exclusion of people who acquire a disability at the age of 65 or over, the Foundation strongly urges Parliament to give proper examination and consideration to these crucial legislative amendments, so that all older people with a disability who are in the aged care system will be able to access much needed disability support services.

The Foundation would like to thank the Senate Standing Committee on Community Affairs for the opportunity to provide feedback on the *Living Longer Living Better* legislative reforms.

Yours sincerely,

Julie Heraghty
Chief Executive Officer
Macular Disease Foundation Australia

End notes

[i] Deloitte Access Economics (2011). *Eyes on the future: A clear outlook on Age-related Macular Degeneration*. Barton: Deloitte Access Economics and Professor Paul Mitchell.
[ii] Ibid.
[iii] Taylor H et al, MJA 2005;182:565-568.
[iv] Deloitte Access Economics (2011). *Eyes on the future: A clear outlook on Age-related Macular Degeneration*. Barton: Deloitte Access Economics and Professor Paul Mitchell.
[v] Ibid.
[vi] www.who.int/blindness/causes/priority/en/index8.html, accessed on 19 April 2013.
[vii] Deloitte Access Economics (2011). *Eyes on the future: A clear outlook on Age-related Macular Degeneration*. Barton: Deloitte Access Economics and Professor Paul Mitchell.
[viii] Ibid.
[ix] Ibid.
[x] "*The Global Economic Cost of Visual Impairment*", Access Economics & AMDAI 2010.
[xi] Ibid.
[xii] Ibid.
[xiii] www.who.int/ncd/vision2020_actionplan/documents/ReportonWorldSight2002.pdf, accessed on 19 April 2013.
[xiv] www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129542765, accessed on 19 April 2013.