Low vision, quality of life and independence

A review of the evidence on aids and technologies
Macular Disease Foundation Australia commissioned The George Institute for Global Health to conduct a literature review of the current evidence relating to low vision aids and technologies.

This report was written with input from the following:

**Associate Professor Lisa Keay**  
Senior Research Fellow  
The George Institute for Global Health  
University of Sydney

**Julie Heraghty**  
Chief Executive Officer  
Macular Disease Foundation Australia

**Anna Palagyi**  
Research Fellow  
The George Institute for Global Health  
University of Sydney

**Rob Cummins**  
Director Research and Policy  
Macular Disease Foundation Australia

**Dr Nina Tahhan**  
Research Associate  
The George Institute for Global Health  
University of Sydney

**Aryati Yashadhana**  
Research Associate  
The George Institute for Global Health  
University of Sydney

Thank you to all those who shared their story for this report on the importance of low vision aids and technologies in enhancing quality of life and independence.

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“It is so important for us to keep living independently in our own home, to stay active and engaged socially, rather than depending on others.”
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This report aims to ensure all Australians with low vision and blindness, regardless of their financial means, can access appropriate aids and technologies to maintain independence and quality of life.

It has been compiled from an evidence base, to inform more effective and efficient strategies for managing vision loss in Australia.

Although randomised clinical trials are generally considered gold standard to demonstrate the value of an intervention, in the case of low vision aids and technologies, the rapid pace of product development does not provide the time required to conduct such trials.

Therefore, this report draws on quality studies that have been undertaken, along with strong anecdotal evidence, to demonstrate the significant opportunities that aids and technologies provide for people with low vision to maintain independence and quality of life.

Key Recommendations

The report strongly recommends:

1. Increased investment in research to accurately quantify the impact low vision aids, technologies and services can have on quality of life and independence for people with low vision and blindness. Particular emphasis should be given to new technologies.

2. The establishment of a nationally funded, accessible, affordable and consistent low vision aids and equipment program to replace the current state/territory government programs.

3. That financial support for aids, demonstrated to improve quality of life for people with functional vision loss, is established in private health insurance policies.

Introduction

Low vision is both a clinical condition and a lived experience that impacts a person’s quality of life. It is the absence of normal ocular function, which involves irreversible vision loss. Low vision interferes with daily functioning and cannot be adequately corrected by medical therapies or standard vision-correcting devices.
In Australia in 2016, low vision and blindness impacts a conservative estimate of 100,000 people aged over 50. The older population are disproportionately affected, with the primary causes of vision loss being age-related macular degeneration, diabetic eye disease and glaucoma.

Although early detection and medical management of these three primary causes of vision loss is critical to saving sight, the current focus on a medical model of care for vision loss prevents many people living with low vision from receiving the support necessary to maintain functional independence.

People with low vision are in effect ‘caught between two systems’ - a medical model and a disability model. It is estimated that only 15% of people with low vision receive appropriate assessment and access to low vision aids.

An individual with vision loss not only experiences loss of sight, but is susceptible to negative functional, social, economic and psychological consequences. The economic consequences of low vision affect the individual, family, community and the broader economy.

Advantages of Aids and Technologies
There is clear evidence that low vision interventions, including suitably timed low vision assessment and the provision of low vision aids, equipment and assistive technologies appropriate to an individual’s needs, enhance visual performance and assist in maintaining independence and quality of life.

Low vision aids can provide the opportunity to read essential communications, participate in paid work and/or volunteering, social interaction, hobbies and sport and engage in everyday activities such as housework, cooking and gardening. Such interventions provide a greater sense of self-worth, reduce anxiety and depression, and enable people to function independently while reducing the need for in-home or residential care. Low vision services can also include orientation and mobility training, but given the specific nature of these programs they have not been covered in this report.

Barriers to Entry
Best practice models of low vision care are multi-disciplinary, extending beyond the involvement of just eye health practitioners and bringing together relevant support services including low vision practitioners, counselling, occupational therapy, and orientation and mobility training.

Yet services for people with vision loss in Australia are presently highly fragmented, with the majority of low vision services being provided within the non-government sector. Referral pathways and co-management plans between eye care practitioners and specialist low vision services are typically inadequate. Further, although low vision assessment and training in the use of low vision aids in many cases may be provided at no-cost, low vision aids themselves can comprise a considerable out of pocket expense to a person with low vision.

Barriers to the access of low vision services in Australia lie not only at the service model level. Personal attitudes towards low vision, poor knowledge of available services, problems with physical access to often urban-based low vision facilities, and issues around cultural appropriateness may present further obstacles to a person with low vision accessing services appropriate to their functional needs.

International Focus
Low vision and its causative conditions are gaining increasing attention around the world, particularly in economically advanced countries like Australia where changing demographics are leading to a rise in the burden of age-related health conditions.

Systems of care are being critically reviewed and new policies emerging in an effort to support health systems to manage the pressures of an ageing population in the coming decades.

The World Health Organization is presently establishing an international standard of services for low vision rehabilitation. This will provide an important benchmark for minimum services in Australia.
Pam and Noel’s story
Quality of life and independence

Pam and I are both legally blind and live on our own. Pam is 73 years of age and has aniridia which is the lack of an iris in both eyes. She has less than 1% sight and sees everything through a blur. I am 82 years old and have retinitis pigmentosa and I have no sight.

Pam uses her closed-circuit television to enlarge print, and I use a scanner to read items at home, but this technology is not designed nor intended for helping us when we’re out and about.

Recently we were introduced to a very new piece of innovative low vision assistive technology. This device can read clearly printed material, and even text on a computer or smartphone screen, in a voice that can be adjusted for speed and volume. It can also be programmed to recognise people’s faces and discreetly speak the name through an earpiece when requested to do so. It is extremely portable and convenient, using a spectacle mounted camera to capture whatever is sought. Once again we can be connected to the social world!

The device very much appeals to us because it is so easy to use and it meets a very big need in supporting our independence. However, the cost for both of us to have one is a challenge. Given our age, we have to consider other things in our life. We are very mindful of our financial situation and the need to plan to pay for our aged care if that becomes necessary.

We understand that people under 65 years of age can now tap into disability funding for low vision aids and technologies through the National Disability Insurance Scheme (NDIS).
However, the NDIS is not available to the majority of people who need aids and technologies like Pam and me. We have lived with our disability of blindness for many years and when the NDIS was implemented, we were excluded from the scheme, solely because we were over 65 years of age.

Moreover, our experience has been that the available funding for us is limited and does not offer the same level of affordability, access and choice for low vision aids and technologies as the NDIS.

Most people in the vision impaired community are over the age of 65 years. Many of these older people experience great difficulty in coming to terms with their changed circumstances and lose confidence in themselves. Low vision aids and technologies can assist them to overcome challenging situations in their daily lives, but in many cases older people cannot afford these devices.

Pam and I have met with our local Federal Member of Parliament and we demonstrated to him the benefits of low vision technology. We were able to bring to his attention the vast difference between the little assistance available to people with a disability over 65 years of age, compared to those who are under that age.

In essence, a small investment in technology can mean a large saving for government. It can mean quality of life is preserved for those with blindness or vision loss. It can keep people like Pam and me living independently in our own home, staying active and engaged socially, rather than depending upon others.

We hope the Federal Government will respond by supporting access and affordability of such technology.
1 Background

In 2016 Macular Disease Foundation Australia commissioned The George Institute for Global Health to conduct a literature review on the current evidence relating to low vision aids, equipment and assistive technology.

This review examines:

- the impact of low vision on individuals, their families and the broader community;
- options available to improve or enhance visual performance and assist in maintaining independence and quality of life;
- the evidence on the costs, benefits and cost-effectiveness of low vision aids, equipment and assistive technology; and
- access to low vision aids, equipment and assistive technology for people with low vision in Australia.

The scope of low vision services is broad. In addition to the provision of low vision aids, equipment and assistive technology to enhance visual performance, it may also include environmental adaptations, skills training for improved orientation and mobility, other occupational therapy or a combination of services through either a single health professional or a multi-disciplinary team.

The scope of the review was limited to low vision aids, equipment or assistive technology that are aimed at enhancing visual performance and maintaining independence. It does not include interventions designed to improve orientation and mobility such as the use of an identification cane, guide dogs, skills training, environmental adaptations or occupational therapy.

The report was motivated by evidence of under-utilisation of low vision aids by those who would benefit, despite the wide array of options available. This report describes the potential barriers to access of low vision aids, maps existing service pathways for low vision services in Australia, and describes the relevant government policies and provisions.

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Val’s story

Losing vision was devastating for Val who was diagnosed with dry age-related macular degeneration and is now legally blind. Having been an avid reader all her life, she couldn’t imagine a future without access to books.

“I’m a huge reader and as an adult I was always studying. My family said I always had my head in a book and when I wasn’t reading, I was doing the cryptic crossword,” says Val.

Fortunately, Val discovered the Navigator Audio Book program, which has become integral to her daily life. The Navigator covers everything in terms of genres and once charged it lasts a long time, which means Val can read with complete independence.

“I used to go to bed and read all night sometimes, now I take the Navigator and when I go to sleep, it turns itself off. Recently I spent two days in hospital and so I took my Navigator and a small digital radio, that’s all I needed. Without the Navigator there would be a huge hole in my life.”
1.1 Broad policy context – equity across aged care and disability system

Significant reforms have been introduced to the disability and aged care sectors over the last five years. Despite this, there are still major issues of inequity regarding accessibility and affordability of aids and technologies designed to improve independence and quality of life of older people with disability. Access to specialist low vision services by older people is also limited and inequitable.

People who acquire a disability such as low vision at the age of 65 or older, are excluded from the National Disability Insurance Scheme (NDIS). They are required to obtain their support through the aged care system, yet the aged care system is neither funded nor designed to provide the supports that people with disability require.

Additionally, many younger people with vision less than legal blindness are excluded from the NDIS. These people have significant impairment to their functional vision and could also benefit from additional services and supports relating to their low vision.

Over the last five years significant changes in the aged care and disability areas have resulted in two major Productivity Commission reports, substantial policy review and new legislation. It was anticipated that the reform agenda of successive governments would finally address the issue of access and affordability of low vision aids, equipment and assistive technologies for those with vision loss and blindness. Unfortunately, this issue continues to fall between the silos of disability and aged care, leaving those in need in a highly disadvantageous, unfair and inequitable position.

Productivity Commission Reports

**Caring for Older Australians (July 2011)**

The *Caring for Older Australians* report concluded, “The aged care system suffers key weaknesses. It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.”

In response to the Commission’s findings, the then Federal Government introduced the “Living Longer, Living Better” reform package in April 2012. This aimed to provide a better, fairer and more nationally consistent aged care system, with amendments to the Aged Care Act passed in June 2013.

**Disability Care and Support (July 2011)**

The *Disability Care and Support* report concluded, “the current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.”

The Commission’s findings led to the development of the National Disability Insurance Scheme (NDIS) “that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).”

A key aspect of the NDIS was that it provides “reasonable and necessary” supports and services as an entitlement, for life. Critically though, the Commission recommended those who acquired a disability after the age pension age be excluded from fully funded individualised support, and instead receive equivalent support in the aged care system with co-payments.
Impact of reform – aged care and disability systems

When the NDIS legislation was enacted, those who acquired a disability after the age of 65 (such as major vision loss from age-related macular degeneration) were entirely excluded from becoming participants in the NDIS. Instead, they were expected to receive their supports and services via the aged care system.

In contrast to the fully funded support that NDIS participants receive, supports and services in the aged care system are means tested and rationed. The subsequent Living Longer Living Better aged care reforms did not include any initiatives that would raise the capacity of the aged care system to provide disability services at the equivalent level of the NDIS. Furthermore, there continues to be significant inconsistency between and within states and territories in the delivery of disability services outside the NDIS. This means many people with vision loss continue to fall between the cracks of these two important systems.

The progressive implementation of the NDIS, through legislation and policies, has further defined the limits being placed upon access to the NDIS for people who acquire a disability before the age of 65, with eligibility of applicants assessed according to disability, early intervention and residency requirements. Those that do not qualify for the NDIS must receive support from inconsistent and limited state and territory government disability programs, which vary depending on the jurisdiction in which the person resides.

For example, many younger people with mild to moderate vision impairment who do not qualify for supports and services through the NDIS, are dependent on low vision programs operated by their respective state and territory government to provide low vision aids, equipment and assistive technologies. Provision under these programs is inadequate, inconsistent, and in some cases, non-existent (Section 5 has further information on low vision services).

In its report Disability Care and Support (2011), the Productivity Commission accepted the then Federal Government’s position on defining roles and responsibilities of service systems based on age, in order to achieve a unified and consistent aged care system. It recommended that disability services be delivered through the NDIS for younger people, and for people who choose to remain in the NDIS as they age.

For older people who acquired a disability after the cut-off age for the NDIS, the Productivity Commission proposed:

“People who acquired a disability after the age pension age would enter the aged care system, with the exception of the relatively few people experiencing catastrophic injury. The latter would be covered by the National Injury Insurance Scheme (NIIS) for their full lives, and so would generally lie outside both the aged care system and the NDIS, though potentially using some services common to both.” (Ref: Productivity Commission Inquiry Report on Disability Care and Support (2011), p. C.10)

The Productivity Commission envisaged that the services available to people who acquired a disability after the age pension age would not differ from those available within the NDIS. They would be funded in accordance with the aged care system, with means-tested co-contributions and payments, reflecting the general capacity of older people to have acquired assets and savings over their working lives.

“There should be no artificial barriers to people accessing eligible services, even if those services are notionally identified as primarily serving the demands of the aged care or disability system. Rather, the critical concern is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source.” (Ref: Productivity Commission Inquiry Report on Disability Care and Support (2011), p. C.7)
Subsequent inter-governmental agreements for the implementation of the NDIS provide for:

- People who age within the NDIS to have a choice to remain in the NDIS or transfer to aged care after they turn 65 years of age
- Continuity of support for people aged 65 and over, where they were receiving specialist disability services prior to the introduction of the NDIS in their area
- The Federal Government to fund support for people who acquire a disability aged 65 years or over (or 50 years if Indigenous Australian) and ultimately, the Federal Government to be responsible for non-NDIS services for people in these age groups.

In 2013, the Federal Government gained exemption from the Age Discrimination Act 2004 for the operation of the NDIS. This automatically gave legitimacy to the exclusion of those acquiring a disability at the age of 65 or over.

Macular Disease Foundation Australia (MDFA) wrote to the Parliamentary Joint Committee on Human Rights and stated that, “the exclusion of people aged 65 or over who acquire a disability from the NDIS, clearly discriminated on the basis of age and had the potential to be in violation of the Age Discrimination Act 2004”.

The Federal Government’s actions prevented people who were denied access to the NDIS on the basis of age from lodging a legal complaint and exercising their legal rights under the Age Discrimination Act 2004. The Foundation considered these actions to be legislated would institutionalise age discrimination in the NDIS.

MDFA reiterated its objections to the NDIS age requirement at the March 2013 and May 2013 Senate Standing Committee on Community Affairs Inquiry Hearings on the NDIS Bill and the Living Longer Living

Better aged care reform bills respectively. This was on the basis that there would be substantial differences between the supports provided to individuals in the aged care system compared to those on the NDIS, resulting in the inequitable treatment of people who acquire a disability at the age of 65 years or over.

The MDFA maintained that it was discriminatory to exclude older people with a disability from the NDIS, and their inclusion in aged care should only be implemented if there are equivalent levels of assistance and support between the NDIS and the aged care system. This was critical to addressing concerns with regard to the rights to equality and non-discrimination.

Aged care programs provide only limited funding towards assistive technology, care coordination, disability-specific information, specialist disability assessment and specialist disability services. Aged care
is currently not equipped to handle the specialised low vision needs of older Australians. In addition, state and territory aids and equipment programs are inconsistent across the country, with different eligibility criteria, requiring different levels of co-payment, and providing different types of aids. In contrast, NDIS participants are entitled to receive fully funded low vision aids, equipment and assistive technologies that support their functional impairment.

The following two examples highlight the lack of provision of aids and technologies in the aged care system, despite recent reforms:

1. When the Commonwealth Home Support Programme (CHSP), was launched on 1 July 2015, the Programme included the service type ‘Goods, Equipment and Assistive Technology’ which covered low vision aids and technologies. There was no funding allocated towards this service type, yet this was where support was anticipated to be provided.

2. The Commonwealth Home Care Packages and Residential Aged Care Packages does not specify the provision of aids and technologies. Therefore, the purchase of aids and technologies may only be possible if there is residual funding left in the package and the decision to do so is at the discretion of the package provider. This makes it inconsistent, arbitrary and unlikely, as aged care providers lack knowledge and expertise in the area of low vision aids, equipment and assistive technologies.

A story of inequity
Tom and Ted

The following case study highlights the gross inequity of a system with an arbitrary cut off based on age.

Tom is independently wealthy and has age-related macular degeneration (AMD). He became legally blind at 64 and has a fully funded NDIS package for life with a simplified system for assessment and allocation of support. This package is received as an entitlement to pay for magnifiers, an electronic magnifier, a computer with a big screen and ZoomText software.

Ted, his brother, is a 66-year-old single pensioner living in a small regional town. He has managed his limited income well during his working years and has taken responsibility for health costs by paying for private health insurance all his life. Ted was diagnosed with early macular degeneration at 54. By the time he had turned 61, the progressive nature of the disease resulted in Ted requiring ongoing treatment of injections into the eye to save vision. This treatment was effective until his 66th year when he experienced a massive retinal bleed and subsequent rapid deterioration in vision. He was declared legally blind four months later.

Ted urgently needed training on mobility and some low vision technologies such as magnifiers, a text reader and an electronic magnifier to enable him to stay in his own home, maintain independence and quality of life. Ted’s private insurance, as is the case for many private health insurers, did not provide any benefit for the $8,000 he needed to spend nor was Ted able to obtain funding through the aged care system to purchase the required services or equipment.
1.2 Low vision – definitions

There are many definitions of low vision used around the world.

The definition of low vision used for the purposes of this report is ‘a best corrected visual acuity of less than 6/12 in the better eye that cannot be corrected with spectacles or surgery’.

There is good evidence that people with a visual acuity of worse than 6/12 in the better eye can benefit from low vision aids, equipment and assistive technology. If ignored, this level of vision loss can impact morbidity, mortality and quality of life.

Low vision is both a clinical condition and a lived experience, impacting quality of life. It is the absence of normal ocular function in the form of vision impairment, which involves irreversible vision loss and significantly reduced vision.¹

Low vision related impairment interferes with a person’s functioning and cannot be adequately corrected with medical or surgical therapy, or conventional eyewear such as spectacles or contact lenses. It is often a loss of sharpness to vision (visual acuity [VA]), but may present as a loss of field of vision, increased sensitivity to light, distorted vision or reduced ability to detect contrast. Low vision may be congenital, or occur as a result of injury or a complication of disease.² ³

There are a number of ways low vision is defined depending on the purpose for classification and the setting.

WHO - definition

According to the World Health Organization’s (WHO) International Classification of Diseases and Related Health Problems, version 10 (ICD-10),⁴ there are four levels of visual function.

The WHO provides two definitions of low vision: one for epidemiological purposes and a second from a service provision perspective.

For epidemiological purposes low vision can be defined as “VA worse than 6/18 and equal to or better than 3/60 in the better eye.”⁵

The service provision perspective is more holistic, defining low vision as “a person who has impairment of visual functioning even after treatment and/or standard refractive correction, and has a VA of less than 6/18 to light perception, or a visual field less than 10 degrees from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task.”⁶

<table>
<thead>
<tr>
<th>TABLE 1: Levels of visual function (WHO epidemiological definition)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NORMAL VISION</strong></td>
</tr>
<tr>
<td>ALL VISUAL IMPAIRMENT</td>
</tr>
<tr>
<td>Together, low vision and blindness represent all visual impairment (or vision loss).</td>
</tr>
</tbody>
</table>
Australia - definition

In the Australian context, a commonly accepted definition of low vision reflects that of WHO; i.e. a best corrected VA of worse than 6/18, but equal to or better than 3/60.\(^7\)

However, the definition changes in various contexts:

In qualifying for a subsidised low vision assessment in Australia, Medicare defines low vision as 6/15 or worse in the better eye, or horizontal visual field of less than 120 degrees within 10 degrees above and below the horizontal midline.\(^8\)

The Royal Australian and New Zealand College of Ophthalmologists (RANZCO) endorses the International Council of Ophthalmology (ICO), which generally uses the term ‘low vision’ to describe individuals with lesser degrees of vision loss who can be helped significantly by vision enhancement aids and devices.\(^2\)

A person with uncorrected VA in the better eye or with both eyes together of worse than 6/12 is considered unfit to hold an unconditional driving licence in Australia.\(^9\)

A conditional licence may be approved for those with vision between 6/12 and 6/24.

This level of vision loss (6/12 or worse) is also the level at which morbidity and mortality increases, and is recognised for the social and economic restrictions it places on people.\(^1, 10-12\) VA of less than 6/12 has been found to result in a greater likelihood of falls, nursing home admission, and emotional and functional difficulties.\(^1\)

From a practical and interventional viewpoint, it is logical that this definition is most appropriate to guide the implementation of measures that will improve the independence and quality of life of people with low vision and blindness.

In contrast, Australia’s NDIS specifies a very high threshold for vision related disability. The NDIS’ Operational Guideline – Access - Disability Requirements (v 3.2), states that permanent blindness meets the disability requirements for entry into NDIS.

Permanent blindness must be diagnosed by an ophthalmologist and is defined as:

a. Corrected VA (extent to which an object can be brought into focus) on the Snellen Scale must be less than or equal to 6/60 in both eyes; or

b. Constriction to within 10 degrees or less of arc of central fixation in the better eye, irrespective of corrected visual acuity (i.e. visual fields are reduced to a measured arc of 10 degrees or less); or

c. A combination of visual defects resulting in the same degree of visual impairment as that occurring in the above points.

For people who do not have permanent blindness, a diagnosis of the following disorders of the choroid and retina is required for entry into the NDIS:

- Behr’s syndrome
- Kearns-Sayre syndrome
- Optic atrophy
- Retinitis pigmentosa
- Retinoschisis (degenerative and hereditary types/juvenile retinoschisis)
- Stargardt’s disease
- Usher syndrome

The NDIS’ Operational Guideline – Access - Disability Requirements (v 3.2) does state that these lists of vision related diseases are not exhaustive and in no way suggestive that a person without these diseases is excluded from the NDIS. However, entry to the NDIS for people with conditions outside this list would be an exception rather than the rule.

In the National Eye Health Survey (NEHS) 2016, led by Vision 2020 Australia and the Centre for Eye Research Australia,\(^13\) ‘vision impairment’ was defined as a presenting visual acuity of worse than 6/12 but better than 6/60 in the better eye. Blindness was
defined as presenting visual acuity of worse than 6/60 in the better eye.

It should be noted that this survey, discussed below, placed a significant emphasis on uncorrected refractive error and cataract, which can be effectively managed by new spectacles or surgery respectively. As such, ‘vision impairment’ in the NEHS does not correspond with low vision as defined in this report, as low vision is not correctable with spectacles or surgery.\(^{13}\)

1.3 Prevalence, causes and affected populations

Blue Mountains Eye Study & Melbourne Visual Impairment Project

Population-based data has been derived from the Blue Mountains Eye Study (data collected 1992-1994)\(^{11}\) and the Melbourne Visual Impairment Project (data collected 1992-1996).\(^{14}\) A synthesis of data from these two studies was conducted in 2005 to project prevalence of low vision to the year 2024.\(^{15}\)

Findings of this synthesis estimated 114,900 Australians had low vision in 2004 (defined as VA less than 6/12 in the better eye which could not be corrected with spectacles or surgery), including 42,600 who were blind (VA worse than 6/60). These numbers were projected to approximately double by 2024.

The most common cause of uncorrectable low vision was age-related macular degeneration (AMD, 42%). Table 2 summarises the findings reported by Taylor et al (2005)\(^{15}\) on the prevalence and causes of uncorrectable low vision in Australia. The causes of low vision are similar to those identified in the more recent NEHS for 2016 in Table 3.

There is a strong association between VI and advancing age.\(^{16}\) Based on Australian population projections at the time of data extrapolation, it was estimated that the number of people with low vision would be around 30% higher today (2016).\(^{15}\) This significant rise can be explained by the fact that the primary causes of vision loss are age-related, including diabetic eye disease, age-related macular degeneration and glaucoma.\(^{17}\)

The prevalence of diabetes in Australia (5.4%)\(^{18}\) increases rapidly up to 75 years of age, with rates among those aged 65–74 years three times higher than those aged 45–54 years, and almost double the rate of those aged 55–64 years.\(^{19}\)

As a result of Australia’s ageing population and the obesity epidemic, diabetic retinopathy is a growing cause of low vision. The Global Burden of Diseases, Injuries, and Risk Factors Study 2013 examined trends in causes and prevalence of vision impairment in South-East Asia and Oceania, and suggested that in the future, a much great proportion of vision loss will be due to diabetic eye disease.\(^{20}\)

Furthermore, higher rates of diabetes among Indigenous Australians (39% in those aged >55 years)\(^{21}\) has led to diabetic retinopathy being one of the main causes of low vision in the Aboriginal and Torres Strait Islander populations.\(^{22}\) Poor overall access to health care outside Aboriginal Community Controlled Health Services is reflected in the extremely low uptake of low vision services among Indigenous Australians despite greater need. Of the 90,203 people accessing low vision services in 2014, only 2% identified as Aboriginal.\(^{23}\)

Low vision also occurs in younger people. Among children in middle to high income countries, low vision is largely due to unavoidable causes\(^{24}\) including oculocutaneous albinism, nystagmus, optic nerve hypoplasia, coloboma, retinal diseases and congenital cataract.\(^{25}\) Such diseases are quite rare; estimated to affect just 0.03% of the population at birth in high income countries.\(^{25, 26}\)
The prevalence of ocular diseases resulting in VI in Australian children is generally agreed to be low, however quality of life is a significant concern, as a lifetime of vision difficulties and/or disability can affect education, employment and social opportunities.

The National Eye Health Survey
In the 2016 Australian National Eye Health Study, the age-adjusted prevalence of vision impairment (VI) and blindness in non-Indigenous Australians aged 50+ was found to be 4.57% and 0.12% respectively. In Indigenous Australians aged 40+ both VI and blindness were found to be three times higher at 13.6% and 0.36%.

These figures included vision impairment due to uncorrected refractive error and cataract. The rates of blindness appear to be significantly less than those previously reported. Rates of vision impairment also appear to have declined.

The prevalence of vision impairment did not differ between males and females.

The rates of vision impairment increased dramatically with increasing age, with most cases occurring in people over the age of 65.

The prevalence of vision impairment in non-Indigenous people increased from 4.42% on people aged 50 to 59 to 15.21% in people aged 80+. (Note: these figures included uncorrected refractive error and cataract.)

The main cause of bilateral vision impairment in both Indigenous and non-Indigenous people was uncorrected refractive error (63.4% and 61.7% respectively) and cataract (20.2% and 13.9% respectively), however as these can normally be immediately corrected with glasses (refractive error) or surgery (cataract), these conditions are not of direct relevance to this report.

Excluding correctable causes, the main cause of vision impairment was diabetic retinopathy in Indigenous people and age-related macular degeneration in non-Indigenous people.

Diabetic retinopathy is expected to become a more significant cause of vision impairment in future years in both Indigenous and non-Indigenous populations, due to the rising rates of diabetes in Australia.

Unpublished data from the National Eye Health Survey (Ref: personal communication Dr M Dirani, 22 December 2016) provides a conservative estimate of approximately

TABLE 2: Prevalence and causes of uncorrectable low vision in Australia in 2004, projected to double by 2024. Macular degeneration, glaucoma and diabetic retinopathy all typically have onset in older ages. (adapted from Vision Loss in Australia, 2005

<table>
<thead>
<tr>
<th>Cause</th>
<th>Estimated number of people in 2004 (95% confidence interval)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macular degeneration</td>
<td>48 300 (43 200-73 900)</td>
<td>42</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>13 700 (12 600-38 800)</td>
<td>12</td>
</tr>
<tr>
<td>Diabetic retinopathy</td>
<td>7 800 (7 200-31 000)</td>
<td>7</td>
</tr>
<tr>
<td>Other retinal</td>
<td>15 900 (14 700-34 500)</td>
<td>14</td>
</tr>
<tr>
<td>Neuro-ophthalmic</td>
<td>8 700 (7 900-27 800)</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>20 500 (18 900-26 400)</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td>114 900</td>
<td>100</td>
</tr>
</tbody>
</table>

BCVA = Best corrected Visual Acuity
100,000 Australians aged over 50 in 2016 with uncorrectable vision loss and blindness. This estimate is less than the 2014 projection of approximately 206,000 cases of uncorrectable vision loss from Taylor’s analysis a decade earlier, and may be due in part to early intervention with new and improved treatments for conditions such as age-related macular degeneration, diabetic retinopathy, retinal vein occlusions and glaucoma.

### 1.4 Types of interventions for low vision

There is a broad range of interventions and eye care delivery models described in the literature aimed at improving the lives of people with low vision. Interventions may be categorised as:

- **Clinical**
- **Rehabilitative**
- **Adaptive / assistive technologies**

The scope of the review informing this report was limited to low vision aids, equipment or assistive technology aimed at enhancing visual performance and assisting in maintaining independence and quality of life. These fall within the ‘adaptive/assistive technologies’ class of interventions.

These adaptive/assistive technology interventions can address the functional needs of people with low vision through the provision of optical and non-optical aids or technology, environmental adaptations, orientation and mobility training, skills training or other occupational therapy, to maintain or enhance independence and quality of life.

Service delivery may be acquired through either a single health professional or a multi-disciplinary team (Section 5.3 details low vision services and service providers).

Low vision aids discussed in this report are categorised as optical (magnifiers, telescopes, prisms), non-optical (improved contrast and lighting) and electronic assistive (computer based, text to voice readers, bar code readers, software, hardware and mobility orientated electronic devices that may be built into smart phones).

<table>
<thead>
<tr>
<th>Causes of low vision (excluding refractive error and cataract)</th>
<th>Causes of blindness (excluding refractive error and cataract)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Indigenous</strong></td>
<td><strong>Non-Indigenous</strong></td>
</tr>
<tr>
<td>Age related macular degeneration</td>
<td>7%</td>
</tr>
<tr>
<td>Diabetic retinopathy</td>
<td>33%</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>3%</td>
</tr>
<tr>
<td>Combined</td>
<td>10%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
</tr>
<tr>
<td>Not known</td>
<td>40%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100%</td>
</tr>
<tr>
<td>Cases of low vision</td>
<td>30</td>
</tr>
</tbody>
</table>
This report also includes reading aids that maximise visual reading capacity, such as image magnification (optical and electronic magnifiers), text contrast (coloured or neutral density filters), telescopes to help see bus numbers, train boards etc. and devices such as prisms, which optimise viewing angle or gaze position.

Data is included on aids that support daily living such as liquid level indicators and talking watches. The different types of low vision aids available in Australia and the estimated retail price range for each is listed in Table 4. Wide price ranges can be explained through differing designs and quality, with better optical quality lenses required for higher levels of magnification. The effectiveness of different low vision aids is outlined in Section 3.

Some people with severe sight loss choose to learn Braille. Braille is a writing system where raised dots are used as a substitute for written letters. Braille is mostly relevant to people who have lost their sight at a young age and those with complete sight loss, rather than the comparatively larger number of people with age-related vision loss who typically retain some residual vision. This report focuses on reading aids which are commonly used when sight is lost later in life and when learning Braille is not considered appropriate.

Low vision services excluded from this report include orientation and mobility training, regular or electronic canes, guide dogs, other skills training or environmental modifications provided through occupational therapy, visual prosthesis devices or complex, multidisciplinary low-vision interventions.

**Low Vision Aids**

Low vision aids are prescribed following a low vision assessment where the level of vision loss is measured and the client’s goals determined. Low vision services are multi-disciplinary and often involve referral between specialised services.

These services are about finding solutions from simple to more high-tech options that make tasks easier or even possible. A proven approach is to make things bigger, bolder and brighter. ‘Bigger’ might be as simple as moving the TV closer or using a magnifier. ‘Bolder’ is enhancing the contrast, such as preparing light vegetables on a black chopping board. ‘Brighter’ is achieved by using better lighting. As a first step, a hand magnifier which provides two to three times magnification may be useful. The ability to be able to trial a magnifier for a few days prior to purchase can help clients work out what is best for them.

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**Rod’s story**

At 87 years of age, Rod lives with diabetes and macular degeneration. He has severe vision impairment, very poor health and is bed ridden for much of every day. Rod was prescribed a stand magnifier and new high strength reading glasses so that he could, in good light, read small print. A lap table was also beneficial so that he could use the stand magnifier to read the newspaper while in bed.
### TABLE 4: Low vision aids price guide

<table>
<thead>
<tr>
<th>Category</th>
<th>Device Type</th>
<th>Price Range</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Optical</strong></td>
<td></td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td>Magnifiers</td>
<td>Optical Magnifiers</td>
<td>$7</td>
<td>$530</td>
</tr>
<tr>
<td></td>
<td>Screen Magnifiers</td>
<td>$625</td>
<td>$830</td>
</tr>
<tr>
<td></td>
<td>Portable Handheld Magnifiers</td>
<td>$395</td>
<td>$1,995</td>
</tr>
<tr>
<td><strong>Non Optical</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Braille Displays</td>
<td></td>
<td>$3,095</td>
<td>$7,995</td>
</tr>
<tr>
<td>Braille Embossers</td>
<td></td>
<td>$1,000</td>
<td>$28,495</td>
</tr>
<tr>
<td><strong>Electronic Assistive Technologies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Magnifiers</td>
<td>Handheld Electronic Magnifiers</td>
<td>$395</td>
<td>$1,995</td>
</tr>
<tr>
<td></td>
<td>Electronic Desktop Magnifiers</td>
<td>$2,890</td>
<td>$6,690</td>
</tr>
<tr>
<td></td>
<td>Magnification With Speech</td>
<td>$3,310</td>
<td>$3,310</td>
</tr>
<tr>
<td>Reading Machines</td>
<td>Audio Reader</td>
<td>$460</td>
<td>$460</td>
</tr>
<tr>
<td></td>
<td>Book Readers</td>
<td>$475</td>
<td>$545</td>
</tr>
<tr>
<td></td>
<td>Stand Alone Reading Machines</td>
<td>$1,130</td>
<td>$7,310</td>
</tr>
<tr>
<td></td>
<td>Camera Based Readers</td>
<td>$1,195</td>
<td>$4,990</td>
</tr>
<tr>
<td></td>
<td>Talking GPS Devices</td>
<td>$395</td>
<td>$995</td>
</tr>
<tr>
<td>Devices Utilising Home Computers</td>
<td>Low Vision Keyboards</td>
<td>$60</td>
<td>$220</td>
</tr>
<tr>
<td></td>
<td>Low Vision Software</td>
<td>$490</td>
<td>$2,195</td>
</tr>
<tr>
<td></td>
<td>Computer Based Devices</td>
<td>$2,509</td>
<td>$5,078</td>
</tr>
<tr>
<td>Deaf Blind Communicators</td>
<td>Deaf Blind Communicator</td>
<td>$6,279</td>
<td>$11,795</td>
</tr>
<tr>
<td><strong>Other Devices</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialised lighting</td>
<td>Desk Lamps</td>
<td>$145</td>
<td>$350</td>
</tr>
<tr>
<td></td>
<td>Floor Lamps</td>
<td>$319</td>
<td>$319</td>
</tr>
<tr>
<td></td>
<td>Portable Lamps</td>
<td>$60</td>
<td>$319</td>
</tr>
<tr>
<td></td>
<td>Magnifying Lamps</td>
<td>$319</td>
<td>$350</td>
</tr>
<tr>
<td>Health and Medication</td>
<td>Low Vision Medication Cases</td>
<td>$82</td>
<td>$95</td>
</tr>
<tr>
<td></td>
<td>Talking Alarm Clock and Medication Reminder</td>
<td>$65</td>
<td>$72</td>
</tr>
<tr>
<td>Clocks and Watches</td>
<td>Vibrating Watches</td>
<td>$149</td>
<td>$149</td>
</tr>
<tr>
<td></td>
<td>Talking Watches and Alarms</td>
<td>$65</td>
<td>$72</td>
</tr>
<tr>
<td></td>
<td>Low Vision Clock and Calendar</td>
<td>$215</td>
<td>$215</td>
</tr>
<tr>
<td>Calculators</td>
<td>Large Display Calculators</td>
<td>$520</td>
<td>$520</td>
</tr>
<tr>
<td></td>
<td>Calculators with Speech</td>
<td>$670</td>
<td>$670</td>
</tr>
</tbody>
</table>

Note - some of the above more complex devices also require in-home consultation for setup and instructional sessions. These consultation services range from $175 - $195, depending on location.
2 Consequences of low vision

2.1 Individual

2.1.1 Quality of life

The impact of low vision on an individual’s overall quality of life (QoL) is well documented.\(^2\) The QoL consequences for each individual, as well as their families, carers and community differ depending on a variety of factors including:

- **Visual:** the level of residual vision, symptoms and condition
- **Functional:** ability to perform day to day tasks, mobility, activity level
- **Social:** social contact and interpersonal relationships
- **Psychological and emotional status**
- **Economic:** financial and non-financial

2.1.1.1 Visual consequences

Visual effects experienced depend on the cause of vision loss and often but not always, include a loss of sharpness which is measurable on a VA chart. Other effects that may be present with or without loss of VA include a loss of field of vision (central or peripheral), increased light sensitivity, distorted vision, and cloudiness or loss of contrast.

As previously stated, low vision is typically classified based on measurements that relate to VA and visual fields. Such classifications have implications on a person’s ability to obtain a driving licence, and access government support services and/or income assistance for their disability. Studies have found VA to be a helpful indicator for predicting morbidity and mortality, particularly at the acuity level of 6/12 or worse.\(^1\)

2.1.1.2 Functional

The functional effects of low vision on a person’s day to day life can be significant but highly variable depending on the person’s vision and individual lifestyle. A person with limited distance vision may have difficulty with tasks such as recognising faces or street signs, avoiding obstacles or understanding non-verbal communication. A person with poor near vision may have difficulty reading, preparing food, sewing or undertaking other near work. A person with restricted visual fields may have difficulty undertaking general activities in low light, finding objects or undertaking tasks requiring mobility.

There is no direct relationship between the degree of vision loss and how well an individual can function because vision is a complex sense influenced by factors other than just the physiology of the eye. The WHO uses the term “biopsychosocial” to describe the physical, psychological and social factors that determine how low vision

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**Joan’s story**

72-year-old Joan is on treatment for macular degeneration but has some vision loss in one eye. She uses a seven times stand magnifier for reading and a 6x hand held magnifier when she goes shopping.

Joan uses a mono mouse which she plugs into her TV to scroll over text. She also uses Zoom Text software which adjusts the size and contrast of text on her computer, together with a keyboard with enlarged text and high contrast colours. With this support she can write and read emails. Joan was prescribed 8x binoculars to see bus numbers, supporting her travel needs and maintaining her independence to shop, visit friends and other social activities.
impacts a person’s day to day functioning. In this way, environmental factors such as the nature of the terrain, weather conditions and building layouts, and personal factors such as profession, education and behaviour patterns, can play just as important a role in determining how well a person can perform tasks as does the physiological make-up of the eye or degree of disease progression.

Low vision can directly and indirectly affect mobility. The direct impacts relate to a person’s ability to move easily through their environment, especially in situations where there is low light or variable lighting conditions, uneven terrain, unfamiliar areas or in crowded environments. The indirect impacts are related to the changes more broadly associated with adapting to a life without adequate vision and the increased levels of caution and fear associated with trying to negotiate complex environments.

2.1.1.3 Social Consequences
The effects of impaired mobility may mean people no longer feel comfortable or safe travelling away from their homes or familiar environments. When low vision takes away a person’s ability to drive, it may become necessary to rely on more restrictive transport options such as trains and buses. If vision is sufficiently impacted they may not feel comfortable or be able to these forms of transport. If the person with low vision chooses to disengage from friends and family they may become socially isolated and predisposed to depression. Interpersonal relationships can also be indirectly affected by low vision. Close friends and family that feel an obligation to become overly protective can further threaten the ability of person with low vision to remain independent and increase their feelings of helplessness. A person’s ability to cope with both the emotional and social challenges of vision impairment are paramount for psychological well-being.

Many older people with poor vision are prematurely placed into permanent residential care, despite a lack of other health concerns. Here, poor awareness by aged care staff of the needs and management of people with low vision, and inadequate use of eye tests and treatment can lead to increased frustration, depression and morbidity.

Early access to appropriate low vision devices along with adequate training could assist an older person to maintain independence in their own home and prevent unnecessary age care admissions.

2.1.1.4 Morbidity and Mortality
Low vision has been linked to increased morbidity and mortality because it effects a person’s ability to properly perceive their surroundings and react to changing situations. This is especially true of older people. Visual impairments that can reduce visual perception and responsiveness can be categorised as reductions in contrast, depth perception, decreased central vision or blur, poor low light adaptation, reduced side and peripheral vision or simply not seeing an object. These visual impairments can independently or collectively contribute to slips/trips/missteps, cuts, medication errors, sporting injuries, or more serious incidents such as burns and car crashes.

Visual acuity is independently predictive of morbidity and mortality. VA of worse than 6/12 has been found to result in a greater
People with vision loss are twice as likely to fall and four times more likely to suffer from hip fractures. Vision loss also has further indirect impacts associated with increased anxiety or fear of falls or accidents, even if a person has not yet experienced them. This may result in other complications or reductions in QoL by fostering feelings of social isolation or encouraging the deterioration of personal health and fitness.

Factors found to be commonly associated with poor vision related QoL include female gender, lower educational status, declining health status, poorer visual acuity, increased severity of eye disease, greater degree of visual field loss, and difficulties with mobility. Improvements in overall quality of life and activities of daily living among people accessing low vision services have been demonstrated. However within current literature, the effects of low vision services on mood, and vision and health-related QoL, still remain unclear.

2.1.5 Psychological and emotional consequences

The impact of low vision on a person’s perception and experience of social inclusion, independence and mobility can negatively affect their psychological and emotional state.

Some of the more common negative feelings amongst people with low vision include embarrassment when trying to read in public, believing that they have lost the ability to perform simple tasks, loss of autonomy, losing the ability to drive or feelings of reduced worth. People with low vision experience up to a three times higher rate of depression than people with good vision, although depression is certainly not an inevitable consequence of vision loss.

Fran’s story

Fran lives with Stargardt’s disease, a genetically inherited juvenile form of macular degeneration, which began to affect her vision when she was in her early 20s. Despite slowly losing her central vision, Fran completed a degree in political science and took up a successful career in broadcasting.

For Fran, low vision aids and technology have been essential throughout the years and especially since she was diagnosed as legally blind in her mid-40s.

Determined to maximise her independence, she makes use of a number of low vision aids, including a telescope to read bus numbers, a small magnifier with a light, a talking watch, a coin sorter, a collapsible cane and glasses with a strong magnifier in one eye for reading at very close proximity. Simple things like a hat with a visor and sunglasses are part of her kit and essential for controlling glare outdoors.

In the early days of her career, Fran continued to work using a typewriter with large text, however once computers came into existence, her world changed.

Her smart phone has become an essential low vision aid for daily living, with the text to voice and voice to text functions highly valuable. Regular use of apps such as Tripview for public transport, Blindsquare for GPS directions, Footsteps pedometer for navigation and Ready2Go for audio books, have revolutionised her ability to continue to live independently.
People’s susceptibility to depression is influenced by a variety of factors including: age, pre-existing health conditions, levels of functional ability, levels of social support and broader cultural attitudes. Culture defines what is considered normal and reasonable and how well people with low vision are likely to be supported. QoL expectations can also largely be influenced or driven by cultural and social values.\textsuperscript{40,48}

2.1.1.6 Economic consequences
The economic consequences of low vision affect the individual, family, community and the economy in general (Section 5).

For an individual, in addition to a reduced capacity for employment, the effect of reduced capabilities and confidence due to vision loss often causes various other health and social consequences, leading to disability or dependency relationships much sooner than might otherwise occur. Decreased independence can increase the requirements for expensive medical care or social services.\textsuperscript{40,41,49}

The costs associated with these follow-on effects can be extensive but can broadly be categorised as: presentation and diagnostic costs; medical costs for treatment, monitoring and optical aids; social costs associated with increased injuries and costs of treatment for indirect associations such as depression or anxiety; and social costs for rehabilitation, accommodation or government support.

\textbf{It is therefore important that approaches to try and reduce future cost implications for low vision, especially within the framework of an ageing population, be holistic in order to address the widespread nature of the social and economic impacts of low vision.}\textsuperscript{50}

While sight loss can be devastating, in many cases the challenges of living independently with visual impairment can be met through appropriate support. The types of low vision aids used vary depending on need and the level of vision loss, which can change over time.
2.2 Carers

**Decreased independence associated with low vision eventually leads to the need for support in everyday living.** In Australia, studies have shown a link between visual impairment and admission to aged care, which can be attributed to a loss of independence. In cases where a person with low vision is not admitted to aged care, or a personal care-worker is not employed, support is often sought from family members or friends who become informal carers.

Activities associated with being a carer for a person with low vision include: accessing services, reading, and help around maintaining social activities and domestic tasks. Longitudinal research has indicated that active coping by acceptance and seeking family support is associated with improved adaptation to vision loss. However the responsibility placed upon the carer can have considerable social and economic consequences, which can impact their own quality of life.

Carers of those with vision loss have increased depressive symptoms, particularly when co-morbidities and high levels of care recipient dependence are present. A study surveying 500 carers of those living with AMD indicated that over half (56%) self-reported a negative state of mind, as well as a need to make changes to other areas of their life as result of care giving.

Caring for people with low vision can also have a considerable economic impact on the carer, as it is common for obligations such as employment to be missed as a result of conflicting care giving responsibilities. Some carers may not be entitled to government welfare benefits for carers, and are therefore inadequately financially compensated for their time in the role. This can have an impact on a carer’s financial status, presenting difficult choices or conflicts around finances, emotions, loyalties and duties. Carers who are unable to balance caring responsibilities and personal wellbeing may compromise the health of both the carer and the person with the vision impairment. Thus, the level of care to be provided by the carer should be considered carefully. The possible impact on family and social life should be assessed and discussed, with those that it may impact upon, before proceeding to offer a level of care that may not be sustainable in the longer term.

Many carers do not consider themselves to be carers; caring is simply something that is done as part of their familial duty. They may not seek any carers’ support services, while others may not even know that support is available or not know where to access support. Barriers to accessing support can include cultural issues, language and other reasons.

2.3 Family

Family members and significant others can play an important role in a person’s adaptation to living with low vision, such as providing encouragement for the initiation and access to low vision services.

Effective family support is shown to be associated with higher life satisfaction and fewer depressive symptoms among people with age related low vision. Comparatively, over-protectiveness on behalf of family members can hinder access to, and use of, low vision aids or the ability to remain independent. This can result in increased feelings of helplessness.

Family members are often also carers, and as discussed in Section 2.2, vision loss can have a considerable impact on their relationship with the person experiencing low vision, as well as overall quality of life. One study noted that vision loss as a result of diabetes was a major stressor in spousal...
relationships, showing 50% of subjects who had been involved in a committed relationship at the onset of vision impairment had later separated.

The level of family support provided to people with low vision may determine whether they require more support from outside services, or in the case of elderly people, admission to aged care. Family support is a key factor in adaptation and recovery of function in low vision and its associated psychological symptoms.

When working with people with low vision, it is important for health care providers to identify both close family and friends who provide them with support.\textsuperscript{72}

### 2.4 Community and society

Vision impairment can result in both physical and mental challenges that result in social isolation. The use of navigation aids such as white or electronic canes (not discussed in this report) and other low vision aids and technologies, such as navigation and orientation apps and training, can greatly assist a person to leave their home independently, safely and with confidence.

Depressive and anxiety disorders attributed to low vision can also affect a person’s ability and capacity to participate as a functioning and independent member of their community. Anxiety disorders such as agoraphobia (fear of open/public spaces) and social phobia, have been identified as being significantly higher among visually impaired older adults, indicating susceptibility to disorders related to places or situations, such as being on a bus or in a crowd, and social situations, such as speaking in public or eating in the company of others.\textsuperscript{34, 45} Experiencing anxiety disorders increases the risk of social isolation, which has been linked to mortality among older people.\textsuperscript{53}

From a structural or societal aspect, direct costs (Section 4.1) and indirect costs to society as a result of low vision, also have a considerable impact on the communities in which people live. People with visual impairment or their families and carers tend to work fewer hours or retire early, pay less personal income tax and consume fewer goods and services.\textsuperscript{32} Taylor and colleagues estimated that in 2004 indirect costs of visual impairment in Australia were 76% more than direct health costs, amounting to $3.2 billion.
3 Effectiveness of low vision aids

Effectiveness or success of low vision aids is determined by the degree to which affected individuals attain maximum function of any residual vision, resume or continue to perform daily living tasks, increase or maintain their independence and ultimately improve their overall quality of life.\(^{75}\)

There is a vast range of low vision aids available for people with low vision to access in order to achieve such outcomes. These range from simple optical magnifiers to high-tech, assistive electronic devices (see Table 4).

What we know:

- Optical and electronic magnifiers make a target image larger and thereby able to be ‘read’ by someone who has impaired vision. Without magnifiers, it is extremely difficult for a person with low vision to live independently as they would have to rely on others to read essential information for daily living. This is illustrated in case studies in this report.

- Most research studies examine the relative performance of different magnifiers and use reading speed as the main outcome measure.

- As low vision aids are individually prescribed, it is difficult to evaluate their relative benefit in heterogeneous populations of people with different types of vision loss.

- Although randomised controlled trials are generally considered the gold standard to demonstrate the value of an intervention, they are not always practical or suitable in the area of low vision. This is because aids and technologies typically need to be individually prescribed according to personal need and withholding low vision aids is not ethical.

3.1 Summary of literature findings on effectiveness of aids or devices

While there is a large range of optical and non-optical devices that have been developed to assist people with low vision, there is a lack of high quality studies, including randomised controlled trials (RCTs) that would allow for a more comprehensive assessment of the effectiveness of these devices. This is particularly true in reference to studies undertaken for children. There is generally more evidence relating to electronic technologies than optical and very little on non-optical devices.

The available evidence suggests that reading performance is generally better with electronic devices than optical devices and there is scope for the electronic devices to continue to provide greater assistance as IT hardware and software evolves.

Close collaboration between computer scientists, clinicians and the end users is crucial to fully exploit the potential offered by mobile assistive technologies and the near ubiquitous uptake of powerful mobile devices such as smartphones and tablets. This field, as well as the development of autonomous vehicles, appear to have the most significant potential for improving the QoL and independence of people with low vision in the near future. However, there are several obstacles that will first need to be addressed to allow the full potential of autonomous vehicles for those with vision loss, to be realised.

In relation to the measured outcomes, most of the evidence from the studies reported relates to improved reading capacity. Formal evidence related to the use of low vision aids and their effects on independence, activities of daily living, injury prevention or QoL, is limited at this stage.
As noted previously, the scope of this review did not include orientation and mobility training, occupational therapy or other multidisciplinary programs where low vision aids may be incorporated and other outcomes assessed.

Research challenges
Summarising the evidence to guide decision-making in provision of low vision aids can be a challenging task for practitioners and policy makers due to the abundance of sources. Even literature on clinical studies published in peer-reviewed journals can provide conflicting evidence; hence practitioners need to be cognisant of the hierarchy of study designs and potential design flaws.

Randomised controlled trials (RCTs) are generally considered to be the most robust study design but even these designs can be subject to weaknesses such as inadequate masking or sample size. The National Health and Medical Research Council of Australia (NHMRC) provides guidelines for evaluating the quality of research evidence. The Cochrane Library (www.cochranelibrary.com) is an open access collection of high quality independent evidence to inform health decision making. A Cochrane review provides a systematic appraisal of the literature and considers only the highest quality evidence available (typically Randomised Controlled Trials (RCT) or quasi RCTs).

Cochrane Reviews
Four relevant Cochrane review articles have explored the effectiveness of low vision aids, equipment or assistive technologies in the past ten years.

Graham’s story
Graham is an acclaimed fine artist, a published writer and a former creative director who worked in some of the world’s biggest advertising agencies. Now in his late 80s, he has lost most of his sight to dry macular degeneration. Graham refers to this condition as “a wicked joke” played out against someone who has always relied on sharp vision to pursue his passions and his career.

Graham finished up in advertising long before computers were introduced to the profession, yet that hasn’t stopped him from embracing a vast array of technologies, including the DAISY player.

“The DAISY is easy to use and I have enjoyed many, many hours listening as it reads wonderful books to me. Recently I came across some sketches I’d done of Bilbo Baggins from Tolkien’s book, The Hobbit. That inspired me to listen to The Hobbit on my DAISY.

“I love classical music, I’ve always got Classic FM playing. I also love politics, so I often use the DAISY to listen to biographies about composers and international politicians. It is a great friend to me.”

Graham recently purchased an iPad and an iPhone, both of which he is getting to know with help from Vision Australia. “I love technology; it helps me and keeps me in touch with the outside world. I’ve recently learnt to touch type and using Bluetooth, I can connect a large font keyboard to my iPad to type up my notes.”

“At this age you’ve just got to keep on being interested. I rely on community transport and often I meet elderly people on the bus who complain that they can’t enjoy music or read or get around anymore because they can’t see well enough. That really annoys me so I tell them about the technology that’s available to help them, and I send them in the right direction. I’m still out there changing people’s lives, one day at a time.”
A review of low vision reading aids for adults was published in 2006, and updated in 2013. This is the most recent Cochrane review evaluating optical, non-optical and electronic assistive technologies.

The other two Cochrane reviews were limited to children and young people with low vision and reviewed optical reading aids (Section 3.2) and assistive technologies (Section 3.4).

All three reviews limited their search to RCTs or quasi RCTs. One of the major findings from these reviews was that there was a very low number of either in the literature, and hence inadequate high quality evidence, investigating effectiveness of low vision aids. There were no trials comparing low vision aids to standard refraction.

It is proposed that a major reason for the lack of RCTs in this area is that interventions typically need to be individualised and hence the use of randomisation is neither practical nor meaningful. This report summarises other study designs which have assessed the effectiveness of optical, non-optical and electronic assistive aids.

The articles identified as relevant from a search of peer-reviewed literature are summarised in Table 5. The final summary of evidence, reported in Section 4, relates to findings from 16 unique systematic literature review papers identified as specifically relevant to investigations on effectiveness of optical, non-optical and electronic assistive devices or technologies. (Appendix A outlines the search strategy. Appendix B summarises three Cochrane review articles.)

### TABLE 5: Low vision review publications investigating effectiveness of aids or devices from 2006-2016

<table>
<thead>
<tr>
<th>Type of low vision aids reviewed</th>
<th>Number of related articles</th>
<th>Year(s) published</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optical</td>
<td>8</td>
<td>2006-2015</td>
<td>75, 77-79, 81-84</td>
</tr>
<tr>
<td>Non-optical</td>
<td>4</td>
<td>2009, 2011, 2013</td>
<td>75, 81, 84, 85</td>
</tr>
<tr>
<td>Electronic assistive</td>
<td>10</td>
<td>2006-2015</td>
<td>75, 78, 80, 84, 86-91</td>
</tr>
<tr>
<td><strong>Total unique articles</strong>*</td>
<td><strong>16</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Three of the articles reviewed all types of devices

In addition to the above, the recent developments reported through other media on the potential and place of autonomous car technology in assisting people with low vision, have been discussed.

77, 78, 79, 81-84, 85, 86-91
3.2 Optical aids

Optical aids serve to make print bigger so it can be read even when VA is reduced. While magnifiers work, their design and features can impact their useability. Most research studies serve to compare two different optical aids for their relative effectiveness.

Magnification

High powered plus lenses used for magnification for near tasks were the first type of intervention prescribed for low vision patients in Australia in the 1950’s. While technology has evolved rapidly in the decades since, optical aids including handheld, stand-based, telescopic and prism (or field enhancement) lenses continue to play a major role in support for the visually impaired. These conventional devices have been a popular choice for individuals with low vision due to their portability and relatively low cost.

A Cochrane review published in 2013 evaluated the effects of reading aids for adults, aged 16 or over, with low vision and reported measurably faster reading speeds with optical and electronic magnifying devices. The review only included RCTs and quasi RCTs in which any low vision aid used for reading was compared to another low vision aid in people aged 16 or over with low vision. These devices included hand-held or stand-based microscopic magnifiers, telescopic optical devices or electronic devices such as stand-based, closed-circuit television and hand-held electronic magnifiers.

The main outcome variable was reading performance. Ten studies with 424 participants were reviewed to compare reading performance (mainly reading speed) in adults with low vision. The identified studies were conducted between 1991 and 2005. Results suggested faster reading speed with stand-based or hand-held electronic devices compared to stand-mounted or hand-held optical magnifiers. They also suggested that head-mounted electronic devices performed less well than optical magnifiers. One study found prism spectacles, sometimes prescribed to help people with central visual loss see objects outside their blind spot areas, were no more effective than conventional spectacles for people with AMD. The authors suggested further investigation on patient characteristics that predict performance with different devices, particularly in regards to costly electronic devices. Better quality research evidence is also needed to assess sustained long-term use of each device.
A Cochrane review assessing the effect of optical aids on reading in children and young people, aged 5-16 years, with low vision was published in 2015. Again, only RCTs and quasi-RCTs were included in the review where any optical low vision aid was compared to standard refractive correction (regular spectacles or glasses). No studies were found to meet the inclusion criteria for this review. Hence the authors concluded that there is a lack of good quality evidence regarding the use of optical low vision aids in children and young people and no implications for practice could currently be drawn.

The 2015 Cochrane Review authors recommended future research include functional outcome measures such as reading speed, accuracy and comprehension, as well as the effect of low vision aids on quality of life, in order to truly assess and compare the effect of these devices on a child’s life and development.

Jutai et al (2009) conducted a systematic review of evidence for the effectiveness of assistive technologies for low vision services. The review included all types of study designs, methods and outcomes including RCTs, non RCTs, systematic reviews and meta-analysis. Studies were graded in terms of methodological quality. Interventions included all types of low vision aids including optical, non-optical and electronic assistive (Further detail is provided in Sections 3.3 and 3.4).

While the reviewers found high quality evidence comparing effectiveness of electronic versus conventional optical devices was limited, they identified one good-quality case series that suggested participants’ reading speed and duration were greater with closed-circuit televisions (CCTVs) than with prescribed optical devices. Participants also had a higher preference for the CCTVs.

Another good-quality RCT, comparing two telescoping systems for spotting distance vision tasks, found the Ocutech Vision Enhancing System spectacle-mounted telescope has advantages over conventional Keplerian telescopes in terms of participants’ preferences and clinical measures. The system was reported to be preferred for weight, appearance, and image magnification.
Prisms

The reviewers also described evidence relating to prisms and other field enhancement devices designed for people with visual field loss. Some limited evidence supported the use of prisms (Fresnel and Gottlieb’s Field Awareness System) for people with peripheral field loss. There was increase in visual perception scores, and improvement in skills relating to recognition, mobility, peripheral detection, scanning, tracking and driving. However, for those with central vision loss due to AMD, the evidence from one high quality study suggests that prism relocation is no more effective than conventional eye glasses in improving VA.

Markowitz et al (2013) also reports on the use of prisms after macular function loss. They conducted a meta-analysis of all available data, irrespective of methodological quality, from published studies, including the study discussed in the previous paragraph, to determine the efficacy of prisms used for redirection of incoming images towards the peripheral retina in cases with macular function loss. The primary outcome measure used in the analysis was distance VA. In this meta-analysis, VA was found to be better after using prisms than for a control group in a sample of 449 cases where prisms were prescribed for wearing in distance glasses. Most patients (76%) reported compliance with the therapy and also reported other benefits directly derived from the VA improvement. The authors noted this finding comes from data from previous studies which have been less conclusive or reached different conclusions. They argue the pooling of data from a number of small studies for the meta-analysis method gives a more powerful and credible estimate of the true effect size than the effect size from any single study. The authors concede that while published studies collectively offer positive evidence in support of the use of prisms for low vision rehabilitation after macular function loss, further research evidence is required.

Justiss (2013) systematically reviewed evidence relating to a number of interventions including the effectiveness of bioptics or prisms to improve or maintain the driving performance and community mobility of older adults with low vision. The available evidence was found to be insufficient due to a number of study limitations including heterogeneity of sample (age, type of vision impairment), lack of standardisation of interventions (device type, time, intensity duration), and lack of standardised assessments to measure driving and community mobility.

Smallfield et al (2013) provides a systematic review of a number of low vision aids to improve the reading ability of older adults with low vision. From 32 studies reviewed, there was found to be very limited evidence supporting the effectiveness of optical magnification. They concluded that more evidence is needed to validate the effectiveness of optical magnifiers and other interventions such as text eccentric viewing, characteristic preferences, and line guides within optical magnification.

Lovie-Kitchin (2011) provides a general summary in relation to reading and low vision over the past 40 years. The review aims to provide practitioners with a step-by-step practical guide on prescribing magnification for low-vision reading based on evidence, including optical and electronic. With reference to various literature sources, Lovie-Kitchin argues that the research evidence showing the effectiveness of low vision care for reading is stronger and easier to conduct than that which is available to prove that multidisciplinary vision rehabilitation is effective.

Lovie-Kitchin (2011) also provides a summary of the evidence of the effects of impaired contrast sensitivity (reduced ability to distinguish an object from its background) in relation to reading for people with low vision. The author notes that while there are numerous studies indicating that contrast sensitivity is significantly related to reading rate and
clinical texts commonly recommend its assessment, its assessment does not seem to have affected the clinical management of most low vision patients. The evidence suggests that reading rate is only minimally affected by contrast sensitivity, accounting for no more than 38 per cent of the variance in reading rate. In a study with a large cohort of patients with AMD, when near VA and scotoma size were taken into account, contrast sensitivity did not appear to improve the prediction of reading rate.

Similar studies of low-vision patients with other causes of low vision are needed. Lovie-Kitchin discussed the limited options to improve reading for patients who are found to have reduced contrast sensitivity which includes optimising illumination, environmental modifications to minimise glare and reversing or increasing print contrast by the use of electronic devices such as closed circuit television.

3.3 Non-optical aids or devices

Non-optical aids are generally aimed at improving the visibility of objects by increasing contrast or reducing glare. This is typically achieved by optimising lighting, altering density of written text or background, or with the use of specially designed filters. Other non-optical aids can assist with activities of daily living or reduce the risk of injuries or falls.

Illumination

The evidence on the role of illumination, reviewed by Smallfield et al (2013),^4 Jutai et al (2009)^75 and Lovie-Kitchin (2011),^81 has been referred to previously in Section 3.2. Smallfield et al found moderate evidence supporting the effectiveness of illumination on reading ability. Jutai et al also found evidence that reading performance for people with AMD was affected by illumination and that the optimal illumination should be determined on an individual basis using objective measures of performance such as reading and subjective assessments of visual comfort. Lovie-Kitchin also discusses the evidence supporting the need to tailor lighting conditions to individual needs based on their condition, as well as the position and size of scotoma, which is the defective retinal area causing a blind spot.

The evidence around the use of coloured filters was determined to be weak by Jutai et al.^75 They report that results from one fair-quality case-series revealed no specific colour or type of filter enables better reading performance.

Graphic displays

Vidal-Verdu and Hafez (2007)^85 explore the use of graphical tactile displays that work as output devices for a computer or other informational source to allow visually impaired people to interpret information types such as graphs and images. While people with blindness can use devices that convert text to audio with relative ease, the goal of communicating and interpreting graphs for the vision impaired is far more challenging. Graphical tactile displays are generally refreshable tactile screens that instead of displaying information using pixels, use taxels, which are touch stimulation units.

The two main approaches for presenting graphical information are static refreshable and dynamic devices. Static refreshable displays can be explored by the fingers and have large tactile screens. Although the technology to produce these devices has existed for some time, the main obstacle to their development is cost. The primary cost is in the production of the actuators that drive the individual taxels because a device the size of a standard tablet computer may have more than 70,000 taxels. One solution would be to use virtual screens or dynamic displays with a screen that is closer in size to a standard computer mouse. However, these devices require a longer training period for successful use and recognition rates are lower than those possible with static displays. Another solution is to use electrical
rather than mechanical stimulation, although
the authors note that it would be difficult to
achieve a device that produces comfortable,
recognisable and consistent sensations
for people due to user variables including
contact force, skin location and hydration. It is
important to note that this study, although very
comprehensive in assessing the available
technologies at the time, was undertaken
in 2007. There have been significant
technological developments since that time.

3.4 Electronic assistive
technologies

Modern society is extremely knowledge
intensive and access to information is
increasingly important for performing
activities of daily living as well as engaging in
education and employment.

Electronic assistive technology refers to
Information Technology (IT) based mobile
assistive technologies or devices that can
be used to assist the visually impaired gain
access to this knowledge, and in doing
so, improve their quality of life, safety and
independence. These low vision aids are
increasing due to ongoing technological
advances and cost reductions in IT.

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Reading devices

Existing electronic technologies, such as
CCTV, are already well established as low
vision aids and newer devices, such as
off the shelf electronic readers or tablets,
may offer similar or superior functionality
with greater portability. Other technologies
available include portable Electronic Vision
Enhancement Systems (EVES) and adaptive
technologies such as screen readers,
screen magnification and optical character
recognition (OCR).

Results from a Cochrane review evaluating
the effects of reading aids for adults with low
vision\textsuperscript{78} including optical and electronic aids
are described in Section 3.2. With regard
to electronic devices, the authors note that
the last study they identified was published
in 2005, hence technology and versatility of
electronic devices may have developed and
improved since these trials were conducted.

A Cochrane review article was also
undertaken on electronic assistive
technologies for children and young
people aged 5 – 16 with low vision.\textsuperscript{80}
This aimed to determine the effects that
assistive technologies could have on reading,
educational outcomes and quality of life.
Noting that RCTs have not yet been conducted for this age range, the authors stated that high quality research in this area was needed and that a key focus for the research protocols should be on the effects and benefits that these technologies may have on the families and teachers of the children affected, rather than solely on standard outcomes. It was recommended that both functional outcomes such as reading speed, accuracy and comprehension be assessed as well as the effect that that assistive technologies may have on quality of life or independent learning capabilities.

The systematic review conducted by Smallfield et al (2013) mentioned previously in Sections 3.2 and 3.3 also evaluated the evidence on the effectiveness of electronic magnification on reading ability and found moderately strong evidence supporting their usefulness.

The Jutai et al (2009) review (Section 3.2) identified evidence that people with low vision had higher reading duration, speed and overall preference for CCTVs compared with conventional optical devices. It also found that participants expressed a preference for stand-mounted versus handheld CCTV systems. The authors identified that people with visual impairment face significant challenges when attempting to perform common computing tasks or using the internet. A summary of the existing literature to identify the impact of changing the size of icons or the background colour of the screen found that VA and contrast sensitivity are strongly linked to people’s performance in undertaking computing tasks. Increasing the sizes of icons improved the accuracy and time taken to perform computer tasks however, there was little correlation or improvement gained from changing to the background colour of the screen.

Smart phones and tablets

Smart phones are now ubiquitous in Australia, with more than 15 million devices in use nationally. The wide uptake of smart phones and tablets in particular, offers broad scope for advancement because the present generation of these devices is highly portable, has a high degree of computational power and is relatively inexpensive.

Advancements in this area provide a key opportunity to address not only the loss of ability to easily perform everyday tasks but also the key aspect of losing access to information.

Hakobyan et al (2013) investigated the possibility of making mobile phones and other handheld devices accessible by non-visual means, including haptic (touch) and audio sensory channels. These mobile assistive technologies allow people with disabilities to benefit from discrete and portable aids that are delivered by devices that are already commonly used and popular amongst the general population. This has the distinct advantage of removing some of the stigma that may be associated with using more traditional low vision aids. They also allow people with low vision to travel outside their normal environment and increase their degree of social engagement thereby assisting to reduce feelings of social isolation.
3.5 The future

Innovation in this field has expanded to allow a range of sensory modalities not limited to visual display resources. Recent advancements include speech recognition, non-speech auditory feedback, haptic feedback, text to speech and gestural recognition systems. Each of these systems can work in isolation or be integrated into the mobile device to create a range of possibilities to assist the visually impaired.

Software and interfaces developed as part of mobile assistive technologies also show promise in assisting tasks such as navigation, spatial perception, robotics, object and obstacle detection and the issue of independent shopping, which the visually impaired often rank as one of the most difficult activities to undertake.

Although still in early stages of development these technologies could be embedded in the greater environment such as on public transport or within homes to provide assistance to those with vision loss. Close collaboration between computer scientists and clinicians as well as the end users is important to fully realise the potential of this field.

Martinez-Perez et al. (2013) provide a summary of existing applications for mobile devices dedicated to the eight most prevalent health conditions as identified by WHO 2004 update of the Global Burden of Disease, including low vision and other conditions such as diabetes, asthma and depression. The study identified that the majority of applications are designed for informing and monitoring the conditions rather than providing patients with tangible assistance. The authors also identified a discrepancy between the prevalence of the various health conditions and the number of applications designed for them, with fewer applications addressing low vision in comparison with other conditions such as diabetes or depression.

Ongoing advances in digital image processing provide promise for maximising the functionality of residual vision of people with low vision. Moshtael et al (2015) discussed the technology currently available for this purpose and reviewed studies that have measured the value of image enhancement. The authors noted that electronic magnifiers had developed to the point where their capabilities far exceed those of traditional optical magnifiers. This is primarily due to the expanded functionality possible that includes brightness and contrast control, zoom function and colour inversion as well as more specific features such as spatial frequency content, scene simplification, edge and contour enhancement and jitter control. Further evidence for clinical validity is necessary, as are larger and better defined patient groups in these studies.

Disease specific applications
Moshtael et al specifically point out that these technologies would be best applied to specific diseases and be made available on a variety of displays including mobile devices such as tablets as well as screens and head mounted displays. Despite the noted limitations of the research, some significant improvements were reported by participants, although improvements varied depending on the individual, the condition they were affected by and the display technology used. Contrast improvements were found to provide significant enhancement of images as well as improving recognition of facial expressions. Remapping techniques also provided modest improvements in reading rates and overcoming blind spots by remapping or moving text falling on a scotoma to another location on the screen and hence retina. For patients with macular degeneration, the implementation of jitter effects, which would normally be considered to degrade image quality, showed significant improvements in word recognition speed and identification of facial emotion. Ultimately,
the area of digital image processing is still in its infancy but shows much promise when partnered with the continued evolution of mobile and display devices and technologies.

**Sensory substitution**
Reich et al (2012) provide an interesting synopsis of the promise of Sensory Substitution Devices (SSDs)\(^{91}\) in the management of people who are blind or visually impaired. SSDs are an innovative, non-invasive human machine technology which transforms visual information into auditory or tactile representations using transformation algorithms. While the concept of SSDs is not new, uptake and use has not been viable until recently due to expense, efficiency, portability and ease of operation of old electronic software. New technologies have enabled SSDs to shrink from closet-size devices into miniaturised components suitable for use in devices such as smartphones. Together with wireless capabilities, this has allowed for devices to be more mobile and less obtrusive. Interface advances also make these devices more accessible to users with vision loss and enable them to operate the devices independently.

Reich summarises these technological improvements together with a discussion on our improved understanding of brain processing pathways. The authors provide evidence that the visual cortex of those with blindness still retains its functional properties using other sensory modalities. For example, listening to sound echoes has been observed to activate the visual rather than the auditory cortex in blind echo-location experts. It is argued that the brain is a highly flexible sensory-independent task-specific operator, and given adequate training, it is capable of changing the type of sensory input used to retrieve task-relevant information.

Novel SSD prototypes are showing great promise. Those with blindness were able to perform tasks relevant to understanding the traits of objects placed before them: point at targets, recognise patterns; perform motion discrimination and tracking tasks and even recognise objects. User blogs are also providing anecdotal evidence of performance. However, full implementation of new advanced technologies lies in the future.

Hamilton-Fletcher and Ward (2013)\(^{87}\) provide additional insight on the potential of SSDs in encoding colour information in tactile or auditory modalities and He et al (2010)\(^{88}\) review the specific challenges and potentials of auditory guidance in sensory substitution devices.

**When the pace of product development is fast and the benefits are proven in their uptake and use, products gain market share ahead of systematic research evaluations of their effectiveness. Though the future looks exciting and also promises accessible, affordable and versatile electronic assistive devices, great benefits can be found from products which are currently widely available.**

### 3.6 Autonomous Car Technology
A lack of independent transport and the difficulties of using public transport are often cited by people with low vision as one of the main challenges they face, as a lack of adequate independent transport can exclude people from employment, education, social contact and access to medical care. These exclusions clearly have significant negative social, health and economic impacts.

Bradshaw-Martin and Easton (2014)\(^{92}\) assessed the potential for autonomous cars to assist the blind or others with disability in leading an independent life. This technology has advanced rapidly and there are a number of states within the United States that have already passed laws to regulate
their use. The European Union is also supporting experiments to potentially enable their use on public roads as early as 2017.

The authors state that the component technologies to allow for autonomous cars have likely existed since the late 1990s and that the main challenges facing broad implementation of this technology are at present primarily legal ones. The legal and liability implications are mainly related to whether the cars can operate completely autonomously or will still require a capable human driver to be present in the vehicle at all times. This has major implications for the usefulness of autonomous cars for people with low vision and there may be a scenario, at least in some countries or states, where the use of autonomous cars becomes widespread although the blind may still not be able to utilise them as a personal transportation device.

Rapaczynski (2016) states that the world is rapidly moving towards the uptake of autonomous vehicles with research forecasting that by 2035, global sales of autonomous vehicles may comprise 75% of the total light vehicle market. The question will remain however, as to how quickly society will become comfortable with vehicles driven only by computers with blind or disabled passengers travelling in them who are unable to take over control of the vehicle in any emergency situation where human intervention may be required.

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Alicia’s story

Alicia has Stargardt’s disease, a hereditary eye condition that causes the cells in the centre of the retina to die, leaving a person with only their peripheral vision. Diagnosed at the age of 19 in 1990, Alicia’s vision progressively deteriorated and she has now lost 95% of her sight. Alicia works fulltime, is married and has raised a son who is now a young adult. Alicia says with the help of technology she is able to manage just like everyone else.

“One of my favourite things in the world is my iPhone, which has given me back a lot of the independence I thought I had lost forever. I can look up train timetables and plan trips using public transport, with my iPhone and iPad I can message people, read books, search the internet and look up recipes. Magnification too, has changed everything. Using my portable magnifier, I can pretty much see anything I want to. I use it to learn new settings on appliances, to read the mail and to crochet and knit, which I really love to do.

At work I use a camera with magnification to zoom in on notes presented on the white board although often I arrange to have presentations sent to me prior to meetings so that I can upload them to my laptop. Then when I’m in the meeting I will detach the keyboard so that I can lift the screen to my face to view magnified files. I’m not a naturally organised person but I do find that planning ahead helps. When reading long emails or documents, I use a text to speech application.”
4 Cost and cost-effectiveness of interventions

4.1 Cost of vision loss to society

The total cost of vision loss to the Australian community was estimated to exceed $16 billion in 2009. People with low vision incur significantly higher direct health care costs than normally sighted people. In addition, the loss of wellbeing is the greatest single contributor to the overall cost of vision loss. These costs are associated with the increased morbidity and mortality from vision loss and include the risk of depression, falls and hip fractures and increased admission to nursing homes or health services.

More research is needed relating to the cost-effectiveness of low vision aids and services.

Measurement of the costs associated with health care provides a foundation for understanding cost-effectiveness of prevention and intervention. Efforts to quantify the economic impact of vision loss and its cost to government, industry and the community have been made globally and in Australia.

In Australia, vision loss due to all causes, including uncorrected refractive error, has been estimated to cost the community close to $10 billion in 2004, and $16.6 billion in 2009. The costs included direct health costs, indirect costs and loss of wellbeing (or quality of life).

Direct costs amounted to $2.58 billion in 2009 and included hospital (inpatient and outpatient), out-of-hospital medical, pharmaceutical, optometry, and other health professional time.

Indirect costs amounted to $4.2 billion in 2009 and included productivity losses of those with vision loss and their carers, costs of aids, equipment and home modifications and taxation revenue forgone due to lost earnings and welfare payments.

The loss of wellbeing was found to be the greatest single contributor to the overall cost of vision loss in 2004 (49%) and in 2009 (57%). These costs are associated with disease morbidity and mortality and include costs associated with the increased risk of depression, falls and hip fractures, increased admission to nursing homes or health services. These costs were quantified using the Disability Adjusted Life Year (DALY) approach.

Research in Australia showing the high direct and indirect costs associated with vision loss is supported by other international studies. In the US, those with vision loss were found to incur significantly higher health care costs than those with normal vision. Non-eye related costs were found to be almost double for people who are legally blind compared to those with normal sight, and 90% of these costs were attributable to non-eye related medical care. A study in the United Kingdom found total annual healthcare utilisation costs to be more than sevenfold higher for patients with wet AMD compared to those without the condition.

In a study conducted by the AMD Alliance International and Access Economics, the direct costs globally of vision loss in 2010 were estimated at US$2.3 trillion with an expectation that this will rise to US$2.8 trillion by 2020. For perspective, this amount is greater than the Gross Domestic Product of all but six countries around the world including United States of America, China, Japan, Germany, United Kingdom and France.
4.2 Cost-effectiveness of low vision interventions

Despite the large body of evidence surrounding low vision in relation to its growing prevalence, impact on individuals, families, carers and communities, low vision aids, low vision services and costs, there is relatively little research quantifying the cost-effectiveness or cost/benefit of interventions for low vision. Such information is critical for evidence informed policy. Cost-effectiveness evaluations assist governments and other decision-makers who are responsible for health resource allocation to make more objective health spending decisions.

In Australia, as in many other developed nations, the government sets out recommendations for methods to conduct cost-effectiveness evaluations for health interventions so that outcomes between various fields of medicine can be compared. Such economic evaluations are gaining increasing importance as there is concern that the ageing population will put unsustainable pressure on public health spending.

When evaluating the cost-effectiveness of an intervention, intervention costs, such as those described above, are weighed against the benefits. There are many ways to quantify the benefits of interventions, with the most common being based on outcomes from QoL questionnaires (Appendix C).

For outcomes from QoL questionnaires to be comparable across health disciplines, they need to be general health rather than vision specific. For the purpose of health economic analysis, outcomes are quantified using the metric termed a “utility.” Utility can be considered a value quantifying QoL in the range one to zero, where zero represents death and one represents perfect health.

Numerous QoL studies have aimed to establish utility values for various conditions. For example, complete blindness has been found to be associated with a utility of 0.26. Losing sight is one of the most feared health states.

Utility is multiplied by the number of years lived in a particular state in order to calculate the Quality Adjusted Life Year (QALY). Hence, one QALY is defined as one year lived in perfect health which would be roughly equivalent to living two years in a state where health is only considered to be 50% of “perfect” (i.e. utility of 0.5). A QALY can be considered a “unit” of QoL that governments or decision makers are seeking to purchase at the most competitive price. In Australia, an intervention may be considered cost-effective if it costs less than $64,000 per QALY gained.

The QALY measure is similar to the DALY measure although it has an inverse relationship in that QALY is a measure of healthy years gained whereas DALY is a measure of years of healthy life lost due to disability or premature death. DALY is calculated in a similar way to QALY although instead of using utility, the disability weight is used. The DALY approach is typically used when analysis is conducted on a global scale where as QALY is generally the favoured approach when focussed on a specific region as utility is more context specific.

In relation to the economic evaluation of low vision aids, whilst there are some limited reports in the literature evaluating costs, very little evidence was found where effectiveness was measured in a way that could be used for economic analysis e.g. there were no reports measuring change in utility using generic health related QoL questionnaires. One reason may be that existing generic questionnaires may not show sensitivity or responsiveness to VI or low vision aids. Indeed, the EQ-5D has been reported to have poor responsiveness for measuring the impact of low vision interventions and poor agreement has also been cited as a problem between other methods e.g. VisQoL and Time-Trade-Off methods. As a consequence, there is very little evidence on cost-effectiveness of low vision aids.
4.3 Emerging results from ongoing research

One paper was identified which reported a cost-consequences study of an inpatient versus outpatient service model for low vision services to veterans with macular disease.\textsuperscript{107} This research was designed to compare higher cost specialist low vision clinic assessment to services provided at home or at a more convenient location for the patient. The outcomes for each group were assessed using the Veterans Affairs LV VFQ-48 and changes in performing everyday tasks. At the three to four month follow-up, both groups showed significant improvements in overall visual abilities, mobility and visual motor skills. While greater improvements were found for management within the low vision clinic, the incremental cost-effectiveness ratios were not calculated in this study and some methodological problems were identified.\textsuperscript{29} The follow-up study (LOVIT II)\textsuperscript{108} addresses some of these issues and aims to evaluate cost-effectiveness. Outcomes from this study are yet to be published.

Taylor et al (2014)\textsuperscript{109} also plan to report on the cost-effectiveness of low vision aids, equipment and assistive technologies. They describe a comprehensive RCT study methodology comparing a portable electronic vision enhancement system (p-EVES) to optical magnifiers for near vision activities in the visually impaired. Although the results of the study are yet to be published, they are anticipated to provide a highly valuable insight on a broad scope.
of measurement tools and their outcomes including the comparison of four types of utility measures (EQ-5D, ICE-CAP-A, VisQoL and WHO-5).

The authors note the use of all instruments is indicated since there is inadequate knowledge on which type of utility measure is the most appropriate for assessing QALY change in respect to low vision aids for people with visual impairment. In addition to using the utility index to quantify benefits, the authors plan to use the reported minutes or hours of carer time freed up through the use of the p-EVES compared to optical aids. These benefits will be weighed against the cost of the two interventions (including devices and professional time to prescribe them) in order to quantify their cost-effectiveness.

Peter and Pearl’s story

An Optilec magnifier, among other devices, has made a dramatic difference to the lives of Peter and Pearl.

Pearl, who was born with a retinal condition, and Peter, who had a workplace accident aged 19, are both legally blind but have always lived independently in a major Australian capital city, since they married in 1966.

Now in their 70s and retired, the couple founded and established CBM Australia, now part of an international not-for-profit organisation, which supports people, predominantly in developing nations, who are blind or have another disability.

“We both have a small amount of navigational vision, so we have always been able to get around and travel with our guide dogs and Trekker, a portable GPS system,” said Peter.

An Optilec magnifier enables them to do almost everything a fully sighted person uses their vision to accomplish including reading books, newspapers and labels, paying bills and attending to correspondence.

Being able to do all this independently is very important, says Peter. “We have a son and a daughter who live in the same city, but they are both very busy with their families. With all the love in the world, they can only be here occasionally, and while there are some things we can save up for them to help with, other things need to be attended to straight away,” he said.

In the kitchen, Pearl has talking scales and a wand that reads labels to help her navigate the pantry. Both Peter and Pearl use computers with speaking and sight enhancing software.

“Low vision technology can be expensive to access and that can be particularly difficult for people who are unable to work or are on a pension,” said Peter.

“Our life-experience would be incredibly more difficult, much bleaker and far less fulfilling without the aids and technologies we have. We feel very privileged and very thankful to have the equipment we use every day.

“I hope Government can facilitate greater access to technology for people with vision disability so that they can enjoy the independence and quality of life Pearl and I have enjoyed.”
The provision of low vision services in Australia is variable and fragmented, often with poorly defined referral pathways.

The majority of services are provided by not-for-profit organisations, some of which offer broad-ranging, multi-disciplinary support, although a small number of optometrists working in private practice also provide services specifically related to low vision. Optometrists could have greater involvement, however a combination of factors including expertise and minimal Medicare reimbursement limit the ability to provide the service. Some for-profit suppliers of equipment also provide a limited service relating to aids and technologies.

Funding of services is currently in a state of significant confusion due to the introduction of disability and aged care reforms. Legally blind people aged under 65 should now be appropriately supported through the NDIS, although concerns remain for younger people with less serious vision loss who do not qualify for access to the NDIS, especially as state disability programs are generally being wound back.

People who acquire a disability after the age of 65 are excluded from the NDIS and expected to obtain all their supports through the aged care system. However, the system remains complex and many gaps remain, including funding of low vision aids.

While state based programs are intended to provide some support, many of these are being rolled into the NDIS leaving people over 65 and those with lesser levels of vision loss with no mechanism to access subsidised aids and technologies. Regardless, each state has a different system, leading to vastly different levels of support between jurisdictions.

Considering low uptake and differential performance of low vision aids in different people, it is important to consider factors such as accessibility and modes of delivery of low vision interventions in the Australian context.

5.1 Historical perspective

Diagnosis of low vision in patients and access to low vision services in Australia have improved dramatically, however there is still much to achieve.

Fifty years ago there were no low vision clinics in Australia, health care providers were not well trained or involved in providing care or support for patients with permanent vision loss, and there were few devices specially designed to aid low vision. In 1954, Australian low vision pioneer Professor Josef Lederer published the development of a series of single high plus lenses for reading with sub-normal vision. These lenses were the first simple (as opposed to compound) reading lenses to reduce aberrations sufficiently to be used as spectacle magnifiers for people with low vision.

In 1972, the Kooyong low vision clinic in Melbourne was established by the Association for the Blind (now Vision Australia), in cooperation with the Australian College of Optometry and the Department of Ophthalmology at the University of Melbourne. This served as a model for multi-disciplinary low vision service delivery for many years. Furthermore, to assess the visual capacity for reading among people with low vision, as well as provide a measure of near VA that could be compared with distance VA measures, the Bailey-Lovie
The introduction of undergraduate optometric education in low-vision care and a post graduate diploma in low vision rehabilitation was a major step towards addressing the low vision knowledge gap in Australia and engaging clinicians in multidisciplinary care.

While all optometrists are now trained in low vision practice, to optimise use of residual vision for people with low-vision, some acquire specialist post-graduate training which is typically consolidated by experience in the field at specialist low vision clinics. Some private suppliers of low vision aids also perform low vision assessments and make recommendations on the purchase of low vision aids. This can include in-home assessments, training and free trials.

Despite these achievements, low vision pathways in Australia remain highly fragmented, with little to no co-management or cooperation between primary and tertiary level medical and ophthalmic care, and low vision services.

5.2 Low vision service providers

Eye care practitioners, including ophthalmologists, optometrists and orthoptists, provide core services in diagnosis and treatment of eye disease in Australia. Optometrists work primarily within private practices, and ophthalmologists and orthoptists within public or private hospitals and private clinics.

Allied health practitioners, including occupational therapists, orientation and mobility instructors, physiotherapists and psychologists, provide an array of different services to optimise patients’ residual vision with the use of aids, and enhance quality of life through achieving ongoing independence and confidence in everyday activities. While general practitioners (GPs) do not provide low vision services, they can play a role within the referral pathway at the primary care level.

Best practice models of low vision care are multi-disciplinary, extend beyond the involvement of just eye health practitioners and attempt to address the fragmentation of services by bringing together different components. In the UK, in 2009, Dickenson and colleagues documented multi-disciplinary care in low vision services operating in hospitals, multi-agency clinics and social service providers, involving optometrists, orthoptists and nurses.

Such comprehensive services are not currently available in Australia though some specialist low vision clinics do offer a number of these components.

Many Australians with low vision navigate a number of service providers to meet their needs, as illustrated in Marie’s story on page 42, where services were prompted by a low vision assessment at a low vision clinic and a later home visit by another agency.
Marie’s story

A small investment in low vision aids helped 85-year-old Marie remain engaged with the world and socially connected, despite being legally blind and living alone in her family home.

Marie is an elderly woman and a widow who is determined to continue living independently in her own home. An avid reader, she loves nothing more than to settle down with the Sydney Morning Herald, her cat on her knee, and while away the hours, catching up on local and international news.

Marie has age-related macular degeneration, and although she has managed with deteriorating vision for many years, one year ago she began to lose the ability to read printed pages using only her spectacles.

A low vision consultation by Macular Disease Foundation Australia and Guide Dogs NSW/ACT alerted Marie to the need to increase her magnification and the lighting in her home. However, a few months later, she found herself back in the same situation. “As a result of my deteriorating vision, there wasn’t a lot I could do. I couldn’t get out easily, I couldn’t read and I couldn’t even watch television because the remote control became too difficult to use,” she said.

A home visit by Vision Australia provided the solution. “Vision Australia advised me on small changes I can make to my home that will help me, including a large button remote control so that I can get back to watching television. They also gave me a new DAISY player which automatically downloads the Sydney Morning Herald each morning and enables me to access books. I was given a full demonstration of the DAISY and a large print out of the controls, which makes it very easy to use. There is also a Helpline available if I have difficulty or want to access more books. “On the first day I had my DAISY, I read the Herald and then I started to read a book. I didn’t move all day and the only complaint came from my cat who wasn’t getting the usual attention.

“My DAISY has helped me get back in touch with what is happening in the world. I’m not feeling bored anymore and I have plenty to talk to my friends and family about. Now that I’m reading novels again, I’m even considering joining the book club at my local library.”

Marie paid just $160 for her new electronic magnifier and pays $9 each month for her DAISY Wi-Fi online player. It is a very small investment in low vision aids, which is giving a massive return to Marie’s quality of life, keeping her engaged, independent and able to continue living in her own home. These low vision aids help reduce Marie’s financial burden from low vision as she does not require additional personal assistance services, and helps save the government money, as these low vision aids delay her entry into costly residential aged care.
5.3 Types of low vision services in Australia

Living with low vision impacts the physical, psychological and social spheres of a person’s life. In order to enhance quality of life in each of these spheres, there are different types of low vision services available in Australia to assist patients at different stages of the pathway. The need for increased co-operation and referral between different service providers has been identified, yet many ophthalmologists and optometrists lack awareness of the services available. Current models of low vision service delivery have not been adequate in addressing issues of increased prevalence and low uptake among patients, suggesting the need to invest in this sector and develop new models of care.

5.3.1 Clinical services

Although clinical low vision services are offered by eye health practitioners, these comprise just a small part of low vision services. The involvement of eye health practitioners is important to be able to act on any change in vision status and initiate treatment as required.

At the primary care level, clinical services can include vision screening, assessment of functional vision, diagnosis, simple advice on environmental modification and non-optical interventions, simple low vision aids (low power magnifiers), and referral to specialist low vision services. At the secondary and tertiary levels, clinical services can include diagnosis and treatment, assessment of low vision, refraction, and prescription and use of complex optical and non-optical low vision aids.

Optometrists are well placed to provide clinical low vision services within the primary and secondary levels of care in Australia, however currently this rarely happens. Recent studies have shown that the majority of low vision patients with AMD, diabetic retinopathy or glaucoma seen by optometrists, are referred directly to ophthalmologists.

Bill’s story

85-year-old Bill lives with age-related macular degeneration and is legally blind in both eyes. Using the phone is just one important part of maintaining his independence and communication with family and friends. He was prescribed a 6 x illuminated stand magnifier which enabled him to read telephone numbers and when writing them down he simply used a black felt tipped pen. Two years later his vision had measurably deteriorated and after a low vision assessment he obtained a stronger magnifier which enabled him to read essential print again. This review also prompted medical review and treatment of a central retinal vein occlusion.
5.3.2 Low vision services

Low vision services include, but are not limited to: provision and training of aids and devices, supported living, employment and education support, counselling, advocacy, and orientation and mobility training. In the Australian context, low vision assessment and training are provided free of charge as specialist services by non-government organisations (NGOs), as well as by a small number of private optometrists and some suppliers of low vision equipment. The provision of low vision aids occurs at a cost to the consumer. Few primary or secondary level low vision services are available and low vision services are not integrated into the public or private health care system.\textsuperscript{121} Ideally low vision services should be offered at the primary care level as there is well established evidence for early intervention.\textsuperscript{17, 114, 121, 122} The current tertiary-led model mainly directs patients from hospital eye care to low vision services at low vision clinics operated entirely by NGOs.\textsuperscript{121} Table 6 outlines key NGOs providing multi-state low vision services.

5.3.2 Use of low vision aids, equipment & assistive technology

Both eye care practitioners and allied health professionals trained in low vision care can provide assistance and training in the use of low vision aids, equipment and assistive technology described in Section 3 of this report. Despite this, these services are largely provided by allied health professionals working within NGOs at specialist low vision clinics or in outreach programs, as well as directly from low vision aid suppliers. Individual prescription of an appropriate low vision aid and training in the use of magnification and other low vision aids is an essential part of low vision management, particularly for reading. Provided sufficient magnification is prescribed, reading performance and perhaps manipulation skills can develop quickly within two to four weeks of prescription.\textsuperscript{112} Low vision aids can be used in conjunction with orientation and mobility training. Orientation and mobility trainers will recommend the use of a variety of aids from simple white canes to more technical devices.\textsuperscript{123}

"The information revolution makes access to information easy and fast, but for me, it makes it possible. First you need the training... then just persist and practice". Fran

5.4 Australian government funding

As described in Section 5.1 the origins of low vision services in Australia are grounded in the NGO sector. Little has changed in the present day, with the majority of low vision services still positioned within the NGO or private sectors.\textsuperscript{121} Though some limited

### TABLE 6: Key NGOs providing multi-state low vision services

(*denotes outreach services only)

<table>
<thead>
<tr>
<th>NGO</th>
<th>QLD</th>
<th>NSW</th>
<th>VIC</th>
<th>ACT</th>
<th>SA</th>
<th>WA</th>
<th>NT</th>
<th>TAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision Australia\textsuperscript{1}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guide Dogs\textsuperscript{2}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Royal Society for the Blind\textsuperscript{3}</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\textsuperscript{1} [https://www.visionaustralia.org/](https://www.visionaustralia.org/)
\textsuperscript{3} [http://www.rsb.org.au/](http://www.rsb.org.au/)
block funding is available to these NGOs, the government’s role in the provision of low vision services remains limited, perhaps due to the origins of the sector and lack of investment, and continues to rely on an NGO based model of care that is fragmented in nature. The following section highlights the scope of Australian state and national level government support for the provision of low vision services.

5.4.1 Medicare coverage
In May 2005, Medicare item 10942 was introduced, subsidising the cost of a low vision assessment performed by an eye care practitioner. The fee in 2016 is $34.55 of which 85% ($28.45) is subsidised by Medicare. Patients claiming a low vision assessment under item 10942 are only eligible if they have been established, during a comprehensive consultation, as having low vision as specifically defined in the item. The item is not intended for patients expected to undergo cataract surgery in the near future who may only temporarily meet the criteria for having low vision. The Medicare item definition includes: “testing of residual vision to provide optimum visual performance involving one or more of spectacle correction, determination of contrast sensitivity, determination of glare sensitivity and prescription of magnification aids in a patient who has best corrected visual acuity of 6/15 or N.12 or worse in the better eye, or horizontal visual field of less than 120 degrees within 10 degrees above and below the horizontal midline.”

Unfortunately, the introduction of item 10942 did not create a sustained interest among optometrists as initially expected. The number of claims for Medicare item 10942 has been steadily declining since its introduction in 2005 from 5033 to 3938 in 2012, despite the increased need and low uptake of low vision services among an ageing Australian population. The numerous barriers contributing to this decline in claims are detailed in Section 6. Two barriers worth highlighting include optometrists’ lack of confidence to provide low vision services, and inadequate remuneration for the time needed for low vision assessment and prescription of low vision aids.

5.4.2 National policies
People with vision loss may seek to access subsidised services and aids through one of two systems, the National Disability Insurance Scheme (NDIS) or the aged care system, depending on whether they are diagnosed before or after the age of 65, as discussed in Section 1.2.

Trials of the NDIS started in 2013 in NSW, Victoria, Tasmania and South Australia. The full roll-out across Australia commenced in July 2016 and is expected to reach completion by June 2019. Access to the NDIS depends on whether a person meets the disability requirements (Section 24, NDIS Act 2013) as defined by legislation (outlined in section 5.4) and the Becoming a Participant Rules, and as guided by NDIS operational guidelines. Once entering the NDIS, participants will be covered by the scheme for life or until they choose to move to aged care services. However people who have pre-existing vision loss and are aged 65 years or over when the NDIS is fully implemented in their region, will not have the option to enter the NDIS.

Currently, people with low vision aged 65 or over and living at home can access subsidised services through the current Australian government aged care programmes: Commonwealth Home Support Programme (CHSP) and Home Care Packages.

The CHSP only enables consumers to purchase subsidised services from government funded organisations. Home Care Packages require consumers to make co-payments for packages and, due to Consumer Directed Care principles, consumers have limited power to choose the services they wish to purchase. Additionally,
only a fixed number of aged care packages are available at any one time, which has resulted in waiting lists. This is contrast to the NDIS, where there are no co-payments required, no waiting lists, and no limits to the size of individualised budgets.

The Commonwealth is responsible for ageing-related aids and equipment within the aged care programs. These services are limited to support provided via a Home Care Package, where an eligible consumer may choose how to fund such measures, or via the Commonwealth Home Support Programme (CHSP) which is rationed and has a $500 limit (or $1,000 at the discretion of the provider). There is anecdotal evidence that this service is not being adequately provided.

Because support services covered by the aged care system attract a co-payment based on an individual’s capacity to pay, people who acquire vision loss at the age of 65 or over are disadvantaged when compared to younger individuals with a vision impairment.125

These reduced services for those at the age of 65 or over are especially concerning as the majority (60%) of blindness and low vision clients fall above this age.23

It is important to note that the Department of Veteran Affairs (DVA) funds a range of magnifiers and other low vision aids, as well as everyday living and high cost equipment, such as video magnifiers, talking bar code scanner, reading machines. Gold card holders and eligible white card holders with a specific condition that affects their vision can access this equipment.

5.4.3 State based subsidies

Accessibility of low vision services differs across Australian states and territories. In addition to service providers outlined in Table 7, a number of subsidised state based programs are available. Accessing certain Commonwealth Government programs, such as the Home Care Packages and residential care, will render consumers ineligible for many of the programs in Table 7.

State and Territory aids and equipment and assistive technology schemes have different budgets, scope, eligibility requirements and levels of subsidy. Due to capped budgets, people may face considerable waiting periods for all but life-saving equipment, such as oxygen tanks. 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 is excluded from schemes in Victoria, 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. Some funded agencies may provide equipment loans or refurbished items.

All State and Territory schemes rule people ineligible for support if they are receiving Australian Government aged care Home Care Packages levels three and four or residential care. Some programs deem ineligible any recipient of other Government funded programs, which includes level one and two Home Care Packages. There is concern that with the merging of Home Care and CHSP programmes in 2018, further restrictions on eligibility of these State and Territory schemes will occur. A key issue for older people who have been assessed as eligible for a package but who, for whatever reason, are not yet receiving services is that they are deemed ineligible for State and Territory-based aids and equipment programs. As a result, older people with low vision may be in an unsupported and vulnerable situation for a time.
## TABLE 7: State based subsidies – low vision services & aids

<table>
<thead>
<tr>
<th>State</th>
<th>Organisation/Scheme</th>
<th>Subsidised low vision services</th>
<th>Subsidised LV aids</th>
<th>Consumer co-payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>Vision Australia NSW Spectacle Scheme</td>
<td>Low vision aids supplied once every two years. Centrelink income statement must be provided.</td>
<td>✓</td>
<td>No co-payment</td>
</tr>
<tr>
<td></td>
<td>EnableNSW</td>
<td>Prescription of low vision aids as determined by appropriate clinician.</td>
<td>✓</td>
<td>Yes, based on age or income</td>
</tr>
<tr>
<td>ACT</td>
<td>Canberra Blind Society</td>
<td>Occupational therapy, independent living training, support/counselling, adaptive technology training, community education.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ACT Equipment Scheme (ACTES)</td>
<td>Prescription of low vision aids via clinician referral.</td>
<td>✓</td>
<td>No co-payment</td>
</tr>
<tr>
<td></td>
<td>ACT Low Vision Scheme</td>
<td>Up to $100 (per two years) for low vision aids.</td>
<td>✓</td>
<td>No co-payment</td>
</tr>
<tr>
<td>VIC</td>
<td>East Melbourne Optometry &amp; Low Vision Centre</td>
<td>Low vision assessment, prescription of low vision aids</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>State-wide Equipment Program (SWEP)</td>
<td>N/A</td>
<td>×</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Aids &amp; Equipment Program (A&amp;EP)</td>
<td>N/A</td>
<td>×</td>
<td>N/A</td>
</tr>
<tr>
<td>QLD</td>
<td>Queensland Blind Association</td>
<td>Advocacy, referral to community services</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Medical Aids Subsidy Scheme (MASS)</td>
<td>Although not listed in guidelines, the scheme is able to fund simple low vision assistive technology like handheld magnifiers for daily personal use. Case by case basis</td>
<td>Yes, if the cost of the equipment is above the maximum subsidy.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Aids Equipment &amp; Assistive Technology Initiative (CAEATI) - Specialised Services Area, Communication Aids</td>
<td>Although not listed in guidelines, the scheme is able to fund more complex low vision assistive technology like electronic magnifiers for participating in community activities (e.g. library or support group use) Clients must prove the assistive technology is for the purpose of accessing the community. Case by case basis</td>
<td>Yes, if the cost of the equipment is above the maximum subsidy.</td>
<td></td>
</tr>
<tr>
<td>SA</td>
<td>The Royal Society for the Blind (RSB) SA</td>
<td>Low vision centre, occupational therapy, employment services, orientation &amp; mobility, advocacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Department for Communities and Social Inclusion (DCSI) state-wide Equipment Program</td>
<td>N/A</td>
<td>×</td>
<td>N/A</td>
</tr>
<tr>
<td>WA</td>
<td>VisAbility</td>
<td>Low vision centre, occupational therapy, employment services, orientation &amp; mobility, advocacy</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Aids &amp; Equipment Program (CAEP)</td>
<td>N/A</td>
<td>×</td>
<td>N/A</td>
</tr>
<tr>
<td>NT</td>
<td>Disability Equipment Program (DEP)</td>
<td>Case by case basis</td>
<td>Yes, if the cost of the equipment is above the maximum subsidy.</td>
<td></td>
</tr>
<tr>
<td>TAS</td>
<td>Community Equipment Scheme (CES)</td>
<td>N/A</td>
<td>✓</td>
<td>N/A</td>
</tr>
</tbody>
</table>
5.5 Private funding (health insurance)

Funding of low vision aids and technologies by private health insurers in ‘Extras’ policies is variable and mostly very limited in scale. This is despite near universal coverage of hearing aids and spectacles in these policies.

Macular Disease Foundation Australia conducted an audit on the six largest Australian private health funds, which make up 86% of the Australian private health insurance market. Funds included Bupa, NIB, HCF, Australian Unity, HBF and Medibank Private. The latter two did not provide any ‘Extras’ benefits for low vision aids. A snapshot of access to low vision aids through private funding is presented in Table 8.

Private health insurance is positioned as an essential part of the Australian health system, with financial incentives and penalties used to encourage its purchase. As a result, many Australians (46.2% of the population) have private health insurance. While some ‘Extras’ coverage is available, the provision of fair and adequate subsidies is still limited.

Not all private health insurers offer rebates for low vision aids, equipment and assistive technologies, and most of those that do only provide it at the higher and more expensive levels of cover.

This is contrasted by the near universal coverage in ‘Extras’ policies by providers for hearing aids and optical aids that correct refractive error (spectacles and contact lenses). Many providers also offer rebates for health promotion interventions with weak evidence of effectiveness and efficacy, such as gym memberships and natural therapies. As presented in Table 7, there are very few government programs that offer subsidies for low vision aids, equipment and technologies.

It is especially inequitable and unjustified that aids, which have been demonstrated to significantly increase independence and improve quality of life for those with functional vision loss, are not more established in private health insurance policies.

<table>
<thead>
<tr>
<th>Private Health Fund</th>
<th>Benefit ($AUD)</th>
<th>Limit ($AUD)</th>
<th>Waiting Period</th>
<th>Claim requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bupa</td>
<td>$45-$90</td>
<td>$150-$300 pp/pa</td>
<td>2 months</td>
<td>Letter from eye care practitioner</td>
</tr>
<tr>
<td>NIB</td>
<td>60%-75% of LV aid cost</td>
<td>$250-$500 (every 3 years)</td>
<td>12 months</td>
<td>Letter from eye care practitioner or occupational therapist</td>
</tr>
<tr>
<td>HCF</td>
<td>$75-$500 limited magnifying devices only</td>
<td>$500-$575 (every 3 years)</td>
<td>12 months</td>
<td>Letter from eye care practitioner or occupational therapist</td>
</tr>
<tr>
<td>Australian Unity</td>
<td>60%-80% of LV aid cost</td>
<td>$150-$300 pp/pa</td>
<td>6 months</td>
<td>Letter from eye care practitioner</td>
</tr>
<tr>
<td>HBF</td>
<td>nil</td>
<td>nil</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Medibank Private</td>
<td>nil</td>
<td>nil</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>
5.6 Accessibility of low vision services and low vision aids

Available reports suggest only 10-15% of visually impaired people access low vision services.\textsuperscript{119, 120} Structural factors, such as government policy, service provision, and models of care;\textsuperscript{130} as well as individual factors such as patient self-perception of low vision, and poor awareness or understanding of available services, all affect accessibility of low vision care in Australia.\textsuperscript{131} Identified barriers to accessibility are discussed in Section 6.

5.6.1 Qualification and eligibility

Qualification for low vision services and aids differ depending on age and the grading and documentation of low vision, which is generally provided by an eye care practitioner.

Under the NDIS, people with low vision will be deemed eligible if they are aged less than 65 when they access the scheme; their vision impairment is, or is likely to be permanent; is likely to result in substantially reduced functional capacity to undertake communication, social interaction, learning, mobility, self-care, or self-management; in addition to affecting their ability to engage in social and economic participation (Section 1.2).\textsuperscript{132}

For older people who are not covered under the NDIS, there are no specific requirements to access low vision services. Eligibility requirements differ among NGOs providing low vision services. Typically if someone has a functional deficit, a low vision assessment can be arranged at no cost to the consumer, from which subsequent options can then be determined. People over 65 years may be able to access NGO services through the aged care system.

People who may \textit{not} qualify for, or only have limited access to, low vision services include: a person with a perceptual disability (such as Irlen syndrome or dyslexia), or a person who has monocular vision impairment (as they have good vision in the other eye). Requests for NGO services are typically reviewed on a case by case basis.\textsuperscript{4}

5.6.2 Access to services

Ideally, low vision services should be provided at primary, secondary and tertiary levels of care. Early intervention might prevent the many negative consequences of low vision summarised in Section 2. However, the current model of low vision care in Australia sees many patients referred to tertiary level medical care, creating congestion among resource constrained services such as ophthalmology, particularly public hospital clinics.\textsuperscript{121} A study conducted in South Australia showed that the majority of referrals made to low vision services were done by private ophthalmology clinic for people over 65 years (mean age 78 years).\textsuperscript{117} This suggests issues of accessibility, particularly for pensioners and elderly Australians on a low income.

An analysis of optometric and ophthalmic referral pathways for low vision care in Australia\textsuperscript{114} revealed that referrals to low vision services were often based on certain criteria for the extent of vision loss. Such criteria may create issues of accessibility for low vision patients with glaucoma, as they may encounter difficulties with mobility even though their visual acuities are relatively intact. Furthermore, people with diabetes experiencing low vision due to the effects of diabetic retinopathy, must frequently navigate multiple and complex routes to care on their own, due to the fragmented nature of the current model of care for diabetes.\textsuperscript{114}

Physical access to subsidised low vision services, especially for those living in rural and remote areas is also problematic. Larger NGOs such as Vision Australia and Guide Dogs Australia offer limited outreach services to remote areas (Table 6), however these services may be infrequent and many areas are not covered. Low vision pathways are discussed in detail in Section 5.7.

\textsuperscript{4} Information obtained from Vision Australia, April 2016.
5.6.3 Access to low vision aids

Low vision aids are not covered under Medicare, therefore people who cannot afford to purchase devices privately, rely on either national (Section 5.4.2) or state based subsidies (Section 5.4.3) to cover the cost. As shown in Table 7, subsidised programs supporting access to low vision services and aids vary from state to state. Four states (Victoria, SA, WA and Tasmania) currently have no provisions around access to low vision aids through current disability equipment schemes. Even those states that do provide aids impose barriers to access such as low subsidies, co-payments and eligibility criteria. These barriers exclude the most vulnerable people such as aged care consumers who receive home care or residential care packages. Subsidised coverage of low vision aids through private health funds is limited (Table 8).

The National Aids and Equipment Reform Alliance (NAERA) made a submission in September 2010 to the Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme. This submission highlighted that delivery of appropriate and timely aids and equipment can improve quality of life for those with functional impairments and their families and carers but also reduce residential care admissions, family and carer burden and increase participation in employment and education. In the area of low vision there is evidence for benefits of aids such as electronic hand held and desktop magnifiers (Section 3).

In the UK, optical low vision aids are available through the National Health Service. Optical magnifiers have been available since 2004 and electronic

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**Helen’s story**

When Helen lost her sight almost overnight to age-related macular degeneration, her role changed dramatically from medical professional to a person living with disability.

Helen, a retired medical practitioner has continued to contribute to the medical profession by adapting to her low vision with the use of low vision aids, equipment and assistive technologies.

“My computer is my main aid - it is practical and lets me continue reading and reviewing articles for medical journals with the use of ZoomText, as well as communicating with family, friends and medical colleagues,” said Helen. “I also use a CCTV reading aid, a handheld magnifier and listen to books on my hand held Navigator and a Daisy player. It is with the assistance of these aids that I am able to take up new hobbies. I am currently revising my knowledge of Latin, something that would be impossible without this technology.”

Helen expressed her concern about the cost of purchasing aids and technologies, and limited access to training.

“I believe the government needs to start improving services for those living with low vision – it currently falls to the private and not for profit sector to do this. If you have a mobility impairment then there are many options available to you like physiotherapy and counselling, but there is nothing like that for vision impairment.

“The Government needs to take some responsibility and I’m concerned that the current NDIS and Aged Care reforms are still not addressing this important issue. More needs to be done.”
magnifiers since 2009. These are typically supplied through hospital low vision services which might be staffed by optometrists, dispensing opticians or orthoptists. These departments often provide optical low vision aids on an extended loan. The relative cost effectiveness of various electronic low vision aids is currently being considered in these jurisdictions.\textsuperscript{133} The UK example highlights both provision of basic low vision aids across the health sector and also integration of low vision services into hospital eye clinics.

WHO published a Priority Assistive Products List in 2016\textsuperscript{134} which included a number of low vision aids among the 50 identified priority assistive products. These included audio-players with DAISY (Digital Accessible Information System) capability, digital handheld magnifiers and optical magnifiers. Inclusion in this list meant these were considered after scoping review, Delphi exercise, global survey and a consensus meeting to be “highly needed and an absolute necessity to maintain or improve an individual’s functioning”. The list was motivated by the fact that few countries have national assistive technology policies or programs. The report went further to state that when products are not available in the public sector, high out of pocket costs can result and people from poorer sections of society can be forced to rely on donations or charitable services.

5.7 Low vision pathways

Optometry and ophthalmology are the two key providers of eye health services involving prevention, early detection, diagnosis, treatment and low vision services.

Low vision services primarily involve low vision assessment, orientation and mobility training and the provision of low vision aids, equipment and assistive technologies to maintain independence and quality of life.

The continuum of care involves guiding and providing low vision services for those who have lost vision and those for whom early intervention is beneficial as they have some functional vision remaining. However, this is often lost in this model of care.\textsuperscript{135, 136}

The end result is a missed opportunity for early access to low vision services and the benefits of learning how to use low vision aids before vision has deteriorated too much.

The current tertiary-led model of low vision care in Australia is not meeting the growing demands for services among a steadily ageing population that is predisposed to conditions that cause low vision.\textsuperscript{121}

Despite ophthalmologists and optometrists being well equipped to diagnose and manage people with low vision conditions such as AMD, diabetic retinopathy and glaucoma, pathways are typically unidirectional, often bypassing optometry and other allied health services.\textsuperscript{115}

Optometrists refer people with low vision directly to ophthalmology 97% of the time, regardless of the underlying condition\textsuperscript{114} and despite the fact that ophthalmologists typically do not provide low vision services. This may be due to a lack in confidence among optometrists around diagnosis or
providing low vision services, despite having the training to do so. Similar referral patterns exist among general practitioners, with 97% referring people with low vision to ophthalmology, despite the availability of optometrists, low vision services, or support services.

Patients with low vision are directed through a traditional medical treatment pathway despite benefits of multidisciplinary care. Often people who are referred to tertiary level low vision services do not require the full range of services provided.

Furthermore, ophthalmologists are generally focused on medical treatment, and do not refer their low-vision patients for low-vision services as early or as often as they should. Some NGOs offering low vision services require referral from an eye care practitioner whereas others do not. However rarely do primary care physicians or optometrists refer directly to low vision services, especially at lower levels of vision loss.

The end result is a missed opportunity for early access to low vision services and the benefits of learning how to use low vision aids before vision has deteriorated too much.

Key stakeholders in the low vision sector are advocating for the uptake of the American Academy of Ophthalmology’s (AAO) SmartSight model of care in an attempt to redirect unnecessary ophthalmic referrals to secondary optometric care, and increase access at the primary care level through community based services.

AAO SmartSight initiative follows a three-level model and functions to ensure that all people with low vision are offered low vision services. The first level seeks to identify low vision and provide patients with information. The second provides simple assessment and interventions for visual loss, while encouraging cross disciplinary communication. The third focuses on comprehensive low vision services involving a multidisciplinary team of allied health practitioners. It is suggested that the percentage of need met at each level of care should be as follows: primary (30%), secondary (50%), tertiary (20%), which stands in contrast to the current tertiary-led model of care.

The International Agency for the Prevention of Blindness (IAPB) low vision working group will seek to work with the WHO Collaborating Centre for the Rehabilitation of the Visually Impaired as they begin to develop universal standards for low vision care. These will be used by WHO to provide guidance to WHO member states on vision rehabilitation.

Importantly, a shift in current pathways and models of care will require improved co-management and collaboration between different eye care, and allied health practitioners.

Bridge the gaps – a pilot

In response to the complexities of navigating the fragmented low vision services sector, a pilot program is helping to bridge these gaps.

The Care Coordination Programme, a partnership of the Save Sight Institute and the Walter and Eliza Hall Trusts, offers guidance for people in the community adjusting to life with low vision.

The programme is available to those in NSW and ACT with a diagnosed eye condition, and focuses on helping people understand their condition and the potential implications of not complying with treatment regimes, as well as linking people to relevant support services including low vision aids, equipment and assistive technologies, orientation and mobility, and counselling.
6 Barriers to the access of low vision services in Australia

Appropriate and timely delivery of low vision services reduces both visual loss and health care costs, as preventive eye care is significantly less costly than subsequent disability.\textsuperscript{114} Currently, it is estimated that only 5-10\% of people with low vision globally, and 10-15\% of people with low vision in Australia\textsuperscript{119, 129} use low vision services.

For those with mobility problems, distance from services, and use of public transport or taxis can be a barrier.\textsuperscript{138}

Poor uptake of services in Australia is attributed to various barriers related to models of care, services and providers, as well as individual issues related to patient perceptions, knowledge and behaviour.

Often people believe low vision aids are only for people who are disabled to the level of legal blindness. They remain unaware of the devices, counselling and/or training available to help them optimise residual vision.\textsuperscript{117}

6.1 Systemic barriers

6.1.1 The current model of care

The historical evolution of Australia’s primarily NGO-based low vision sector has seen limited public (Section 5.4) and private (Section 5.5) support of low vision services and low vision aids. As a consequence, low vision services often run in isolation to clinical services. The current model of low vision care is fragmented, and neither uses or promotes the potential of primary and secondary optometry to relieve under resourced ophthalmic services\textsuperscript{139} where possible.\textsuperscript{121}

Studies showing a mismatch between the range of low vision services available at tertiary rehabilitation centres and the uptake of those services demonstrate the needs of many could be met at a secondary level.\textsuperscript{121} However this would require further development of low vision expertise and capacity in the optometric and allied health sector. The Centre for Eye Research Australia (CERA) has developed an online module to support this skills development.\textsuperscript{140}

The current model of care is supported by practitioner perspectives that perceive low vision pathways as tertiary-led and unidirectional, rather than integrative and circular.\textsuperscript{114, 115} As a result, allied health services are used at the end of the pathway as opposed to being integrated during diagnosis. This can result in patients missing the full benefits of these services in the early stages of vision loss.\textsuperscript{114}

6.1.2 Barriers related to services

Poor distribution and coordination of low vision services remains an issue.

Currently, low vision service delivery varies by state and individual organisation (Tables 6 and 7) with some jurisdictions such as the NT and many rural or remote communities experiencing an overall shortage of services. In addition, few private optometrists provide low vision services and the number of patients seen by these optometrists is small.\textsuperscript{119} Possible reasons behind this are outlined in Section 6.1.3.

Fragmented and differentiated service types and modes of delivery is also suggested to have created barriers to access.\textsuperscript{141}

For example, some organisations providing low vision services rely on the patient to make first contact, thus failure of patients to act on a referral may also contribute to low uptake.\textsuperscript{117}

One study\textsuperscript{115} identified that GPs lacked awareness of the services provided by low vision organisations and the value of those services for patients specifically with AMD, diabetic retinopathy and glaucoma.
Factors such as this may be attributed to the tendency of low vision NGOs to focus attention on their blind clientele rather than generate a broader awareness of the services they provide for those with mild or moderate vision impairment. Nonetheless such perceptions have the capacity to contribute to low numbers of referrals at the primary care level, ultimately creating barriers to accessing low vision services.

6.1.3 Barriers related to eye care practitioners

Poor collaboration and co-management between different low vision service providers, particular among eye care practitioners, has been identified among previous studies as a major barrier. Eye care practitioners typically restrict themselves to clinical services and advice, and non-medical pathways where low vision patients are not included.

A voluntary audit of Australian optometrists conducted in 2009 found that, of 359 responding optometrists, over 50% referred all people with low vision to non-government low vision service providers. One in five optometrists cited lack of confidence in the management of a person with low vision, as the reason for immediate referral.

A Victorian study surveying optometrists about low vision services generated a very low response rate of 97/1050. Optometrists who were not providing low vision services felt they lacked access to aids, and confidence in providing low-vision care, despite having low vision training. Those optometrists who were providing low vision care felt they were not being adequately remunerated for their skills and time.

Previous studies have shown that eye care practitioners tend to defer low vision referrals until their patients’ eye conditions have deteriorated. Optometrists tend to refer patients to specialist low vision services a little earlier than ophthalmologists, who typically do not refer patients to low vision services until visual acuity or visual field loss are close to the legally blind levels.

Late referrals deter patients from accessing low vision services, therefore preventing the opportunity to optimise their remaining vision and maximise independence and quality of life.

Good collaboration and co-management between optometrists, ophthalmologists and allied health practitioners providing low vision services will help alleviate barriers to access. Benefits to the patient include early intervention, avoiding duplication of services, instituting cost-effective care, building confidence of practitioners in the referral process and minimising costs in the health care system such as expensive hospital or ophthalmology time.

6.2 Individual barriers

6.2.1 Patient self-perception of low vision

Patients with low vision may not necessarily perceive themselves as having low vision, even in cases where moderate or severe VI is present. Patients may experience self-denial regarding vision loss, resulting in avoidant coping behaviour. Avoidant coping is linked to a patient’s belief that their vision problems are out of their control or unsolvable. It has been identified as a significant determinant of decline in vision-related functioning and poor quality of life.

Such perceptions have been identified as a major barrier to low vision service uptake. A study looking at low vision patient pathways found that 37% of patients who had declined referral to a low vision service had done so because they either felt the service was not needed, or it would not help. Similarly, results from a different study presented a high percentage of patients who reported receiving little or no information from their referring professional, and subsequently did not feel the need to access low vision services.

These studies highlight the importance of patient communication for eye care
practitioners and other allied health professionals who are in a position to refer patients to low vision services, and the provision of necessary information about the scope and benefits of low vision services.

6.2.2 Awareness & understanding of services

Poor awareness and understanding among patients of the role low vision services play in maximising QoL and independence has been identified as a major barrier to uptake of services. This has been attributed to poor understanding of the term and definition of “low vision”, as patients may perceive themselves as being either visually impaired or blind\textsuperscript{138} and not somewhere in between. Those who are not classified as blind have reported feeling fraudulent or inappropriate in accessing low vision services,\textsuperscript{138} perhaps due to a perception that people who are legally blind take priority.

Lack of awareness and low perception of need among patients may be linked to the way low vision NGOs advertise and market their services, which primarily targets those who are blind.\textsuperscript{24}

One study\textsuperscript{130} reported that 34% of failed referrals spoke a language other than English, suggesting that language and cultural appropriateness may also present a barrier to access.

6.2.3 Mobility & co-morbidities

People with low vision are typically older\textsuperscript{23} and therefore less mobile. They may be living with co-morbidities, especially in the case of low vision due to diabetic retinopathy, and may need help to physically access a low vision service.

A reduction in vision often leads older people to lose their driver’s licence, increasing dependence on family members or public transport, which is limited in rural areas.\textsuperscript{125}

One study showed that 74% of patients referred to low vision services had co-morbidities (n=98).\textsuperscript{130}

Patients who had been referred to a low vision service and had either refused referral or not attended their appointment stated either transport issues (44%) or co-morbidities such as diabetes (22%) as the reason for not attending.\textsuperscript{130}
7 References


47. Holloway EE, Sturrock BA, Lamoureux EL, Keeffe JE, Rees G. Help seeking among vision-impaired adults referred to their GP for depressive symptoms: patient characteristics and outcomes associated with referral uptake. 2015.


72. Reinhardt JP. Effects of positive and negative support received and provided on adaptation to chronic visual impairment. Applied Developmental Science 2001; 5(2): 76-85.


129. Lovie-Kitchin J. Where do all the low vision patients go? . Australian Optometry 2010; 9(October).


144. Keeffe JE, Lovie-Kitchin JE, Taylor HR. Referral to low vision services by ophthalmologists. 1996.


Definitions

Glossary and Abbreviated Terms

• **AAO**
  American Academy of Ophthalmology

• **AMD**
  Age-related Macular Degeneration

• **Bioptics**
  A type of low vision aid which has a telescope or telescopes attached to one or both lenses of an individual’s eyeglasses to enlarge the image size of distant objects

• **BCVA**
  Best Correct Visual Acuity

• **CERA**
  Centre for Eye Research Australia

• **CCTV**
  Closed Circuit Television

• **CHSP**
  Commonwealth Home Support Programme: An entry level home help programme funded by the Australian Government to support older persons to continue living at home by providing low level services such as domestic assistance and home maintenance

• **DR**
  Diabetic Retinopathy (DR) is a complication of diabetes characterised by damage to retina associated with change to the blood vessels

• **DALY**
  Disability Adjusted Life Year: The number of years lost due to morbidity, disability or premature death

• **DAISY**
  Digital Accessible Information System: An interactive technological innovation which converts written information to Braille or text to speech.

• **DVA**
  Department of Veterans Affairs: A Government department which provides financial and other support to those affected by war including veterans, widowers, dependants and carers

• **EQ-5D**
  Euro-Qol Five Dimensions Questionnaire: A standardised questionnaire which measures health status by providing a numerical value and descriptive profile

• **GP**
  General Practitioner

• **IAPB**
  International Agency for the Prevention of Blindness

• **ICE-CAP-A**
  ICEpop CAPability measure for Adults: an economic evaluation tool which measures the capability of adults by testing their ability to attain attachment, stability, achievement, enjoyment and autonomy.

• **ICO**
  International Council of Ophthalmology

• **IT**
  Information Technology

• **Low vision aids, equipment and essential technologies**
  This term encompasses all low vision aids, equipment and assistive technology. These are task-specific devices designed to aid individuals with vision impairment to complete activities of daily living. Examples include magnifiers, loupes, high magnification reading glasses, illuminated hand magnifiers, stand magnifiers, distance telescopic devices, non-optical low vision aids and electronic assistive technologies.

• **LV VFQ-48**
  Veterans Affairs Low Vision Visual Functioning Questionnaire: a standardised questionnaire which measures how an individual’s vision affects activities of daily living.

• **MD (also AMD)**
  Macular Degeneration: A term used to describe degenerative diseases which affect the retina in the eye leading to the gradual loss of central vision.
• **MDFA**
  Macular Disease Foundation Australia: A National non-profit organisation based in Sydney, promoting awareness of the leading cause of blindness in Australia, with programs for education, awareness, early detection, treatment and rehabilitation

• **Medicare**
  The federal public health insurance program which provides free or subsidised medical services such as doctor appointments and treatment in public hospitals for Australian residents

• **NAERA**
  National Aids and Equipment Reform Alliance

• **NDIS**
  National Disability Insurance Scheme: A national government program designed to provide financial and other support to all persons with a significant disability under the age of 65

• **NEHS**
  National Eye Health Survey, population based survey of Indigenous and Non-Indigenous Australians in 2016 by CERA and Vision 2020 Australia

• **NHMRC**
  National Health and Medical Research Council

• **NGO**
  Non-Government Organisation

• **OCR**
  Optical Character Recognition: Software which allows an individual to convert one type of file to another such as converting written text to speech

• **p-EVES**
  portable Electronic Vision Enhancement Systems

• **Pixel**
  A small individual part of a digital image

• **Prism**
  A lens type which can be used to correct double vision, positional or convergence dysfunction

• **QALY**
  Quality Adjusted Life Year: Generic measure of disease burden, representing the quality and quantity of life lived. In economic evaluations, one QALY equals to one year of perfect health.

• **QoL**
  Quality of life

• **RANZCO**
  Royal Australian and New Zealand College of Ophthalmologists

• **RCT**
  Randomised Control Trial

• **SSD**
  Sensory Substitution Device: Non-invasive method for replacing or supplementing one of the human senses, for example Braille.

• **Taxel**
  A touch stimulation unit which is the tactile equivalent of a pixel

• **Time-Trade-Off method**
  A method used primarily in health economics to define quality of life within certain impaired health states by requiring the participant to determine the trade-off point between years lived at full health and years lived with impaired health

• **Veterans Affairs Low Vision Visual Functioning Questionnaire**
  Standardised questionnaire which measures how an individual’s vision affects activities of daily living

• **VA**
  Visual Acuity

• **VI**
  Vision Impairment

• **VisQoL**
  A six item questionnaire used to determine vision-related quality of life

• **WHO**
  World Health Organization

• **WHO-5**
  World Health Organization-Five: a standardised questionnaire which measures current wellbeing levels
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Search strategy for the literature review

We used a systematic approach to collate data from published and grey literature on the effectiveness and cost-effectiveness of low vision aids globally.

Both the peer-reviewed and grey literature were searched to obtain related data and research evidence using academic datasets from sites such as PubMed literature database (National Library of Medicine) and public search engines (including GOOGLE and YAHOO). Evidence from reviews in the past 10 years were synthesised and search strategies developed to capture more recent studies which were not included in the published reviews.

Search terms were developed based on vision science and low vision rehabilitation theory. Appropriate adjustments were made to search terms according to the classification of specific datasets. All study types were deemed eligible, excluding clinical case studies.

The search terms and restrictions used to identify peer-reviewed studies using the PubMed literature database included;

- Low vision OR visually impaired persons
- AND (impact OR outcome OR intervention OR rehabilitation OR technology OR aids OR device OR cost OR cost-effective OR magnifier OR software)
- Limited to the previous 10 years (the search was conducted on 8th April, 2016).

This search originally resulted in a total of 4065 hits. While reviewing the titles and abstracts of these results, a high number of literature review papers which covered specific or general aspects of low vision rehabilitation were found. Hence the search was subsequently limited to review papers only. This resulted in a total of 447 hits of which 74 were deemed relevant to low vision after a title and abstract review. We further excluded reviews relating to low vision which went beyond the scope of this report: orientation and mobility skills training for identification cane use\textsuperscript{145} and driving,\textsuperscript{146, 147} more broad reviews of occupational therapy and skills training\textsuperscript{148-152} and specific skills training for reading such as eccentric viewing and steady eye strategies for people with central vision loss.\textsuperscript{153, 154}

We also searched websites of major conferences, organisations, network websites, and contacted specific individuals and units by email or phone seeking relevant research in this area.

The reporting for this literature review followed the PRISMA statement (http://www.prisma-statement.org). Abstracts of identified studies or reports were examined and if considered relevant, the full text was retrieved. Study type, methods and key elements of the work were extracted and summarised.
<table>
<thead>
<tr>
<th>Study designs accepted for review</th>
<th>Randomised and quasi-randomised trials in which any device or aid used for reading had been compared to another device or aid.</th>
<th>Randomised controlled trials (RCTs) and quasi-RCTs where any optical low vision aid was compared to standard refractive correction.</th>
<th>RCTs and quasi-RCTs that compare the use of Assistive technology (AT) with standard optical aids, which include distance refractive correction or compare different types of ATs with each other, without or in addition to conventional optical aids, and those that compare ATs given with or without instructions for use.</th>
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<tr>
<td>Study participants</td>
<td>Adults aged 16 or over with low vision as defined by the study investigators.</td>
<td>Children and young people aged between 5 and 16 years of age with low vision as defined by the WHO.</td>
<td>Children and young people between the ages of 5 and 16 years with low vision as defined by the WHO.</td>
</tr>
<tr>
<td>Primary outcome measure</td>
<td>Maximum reading speed and reading acuity under ideal conditions of text magnification and contrast.</td>
<td>Maximum reading speed in words per minute.</td>
<td>Maximum reading speed in words per minute.</td>
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<td>Number of studies accepted for review</td>
<td>10</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Years of data collection or period included in the review</td>
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<td>1946 - 2015</td>
<td>1946 - 2014</td>
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<td>Total sample size</td>
<td>424</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Results</td>
<td>There was moderate-low quality evidence suggesting that reading speed is higher with electronic devices than with optical magnifiers and reading using head-mounted electronic devices is slower than with stand-based electronic devices. One study suggested no difference between a diffractive spectacle-mounted magnifier and either refractive or aplanatic magnifiers. One study found overlay coloured filters were no better and possibly worse than a clear filter.</td>
<td>No studies met the inclusion criteria for this review.</td>
<td>No studies met the inclusion criteria for this review.</td>
</tr>
<tr>
<td>Comments</td>
<td>There is inadequate evidence on the effect of different types of low-vision aids on reading performance. It would be necessary to investigate which patient characteristics predict performance with different devices, including costly electronic devices. The technology of electronic devices may have changed and improved since these studies were conducted.</td>
<td>There is inadequate quality evidence from which implications for practice can be drawn.</td>
<td>High-quality evidence about the usefulness of electronic AT for children and young people with visual impairment is needed to inform the choices healthcare and education providers and family have to make when selecting a technology.</td>
</tr>
</tbody>
</table>
Appendix C

Tools for measuring the consequences of low vision and the effectiveness of interventions

There are numerous ways in which the effectiveness of low vision aids can be measured. Throughout the literature, a wide variety of methods has been reported with little consensus on the best approach. This can be problematic as the lack of consensus in using a standardised set of tools hinders the potential for cross-study comparisons. Early studies primarily measured the outcomes by measuring the frequency and duration of use of a particular aid or by evaluation of objective clinical measures of visual function, such as reading speed.

Difficulty with reading has been reported as one of the most common reasons for the referral of a person with low vision and its assessment has long been used as the primary outcome measure for the effectiveness of low vision trials. Measured reading performance is still among the best predictors of patient reported visual ability and vision related quality of life (QoL). While recognising its continued importance, there are concerns surrounding the use of reading ability as a clinical outcome measure. Two of the main concerns include the difficulty in determining whether standardised test-based visual performance matches real world performance, and what the relationship is between self-reported reading ability and measured reading performance. Due to these and other challenges, there have been dozens of standardised reading tests developed in an attempt to create a test that is a strong indicator of real world reading performance. Some of these are listed in Table A2, which also includes a summary of other measurement methods.

QoL definitions are generally broad, and the parameters context dependent, however such evaluations are increasingly being valued as these outcome measures that have a broader applicability and can be compared between various health conditions. In addition, indices that are obtained from some QoL assessments can be used in cost-effectiveness evaluations. More recently, there has been a preference for assessing outcomes based on subjective measures such as patient-reported QoL questionnaires or measures of a person’s ability to carry out activities of daily living (ADL) such as self-care and eating. Vision specific questionnaires such as the Low Vision QoL (LVQOL) and the National Eye Institute Visual Function Questionnaire (NEI-VFQ) combine general QoL measures with vision related functional ability. There is much evidence to support the link between vision impairment and poor functional status, deeming ADL an important measure when assessing low vision. Tasks related to ADL such as reading, outdoor mobility, participation in leisure activities and shopping, have been outlined as most limiting among visually impaired patients who had not undergone visual rehabilitation. However, there is evidence that functional measures show the greatest sensitivity to low vision interventions, highlighting the need to use tools that combine functional measures, with less specific measures such as QoL and ADL.
Table A2: Low vision outcome measurement tools.29, 79, 155, 157

<table>
<thead>
<tr>
<th>Type of assessment</th>
<th>Examples of types of measures</th>
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<tbody>
<tr>
<td><strong>Objective/Clinical</strong></td>
<td></td>
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<tr>
<td>Visual Acuity</td>
<td>Distance or near [High or low contrast] [Chart types include, Snellen, Bailey-Lovie, Jaegar]</td>
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<tr>
<td>Reading speed/accuracy</td>
<td>The Pepper Visual Skill for Reading Test (VSRT) [Minnesota Low-Vision Reading Test (MNREAD)]</td>
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<td>Reading Comprehension</td>
<td>Neale Analysis of Reading Ability version 2 (NARA II) [Rapid Serial Visual Presentation (RSVP)]</td>
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<td>Functional</td>
<td>Activities of Daily Living (ADL) [The Functional Visual Performance Test (FVPT)]</td>
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<td>Vision-specific</td>
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<td></td>
<td>Impact of Vision Impairment (IVI) [Low Vision Quality of Life Core-Measure (LVQOL)]</td>
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<td>National Eye Institute Visual Function Questionnaire (NEI-VFQ) [Vision Core Measure (VCM1)]</td>
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<td>LV Prasad-Functional Vision Questionnaire (LVP-FVQ) [Children's Visual Function Questionnaire (CVFQ)]</td>
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<td>Cardiff Visual Ability Questionnaire for Children (CVAQC) [Impact of Vision Impairment on Children (IVI_C)]</td>
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<td>Psychological Status</td>
<td>Adaptation to Age-Related Visual Loss (AVL) scale [Centre for Epidemiological Studies Depression Scale (CES-D)]</td>
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<td>Coopersmith Self-Esteem Inventory [Elderly Care Research Center (ECRC) Coping Scale]</td>
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<td>Generalised Self-Efficacy Scale (GSES) [Geriatric Depression Scale (GDS)]</td>
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<td>Minnesota Multiphasic Personality Inventory (MMPI) [Zung Self-Rating Depression Scale]</td>
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<td>Hospital Anxiety and Depression Scale (HADS) [Profile of Mood States (POMS)]</td>
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<td>Life Satisfaction Index – Wellbeing [Psychological General Well-being Index]</td>
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<td>Wellbeing Questionnaire 12 item (W-BQ12)</td>
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<td>Type of assessment</td>
<td>Examples of types of measures</td>
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<td>Subjective (cont.)</td>
<td>Quality of Life (cont.) Vision-specific (cont.)</td>
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<td><strong>General health</strong></td>
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<td>EuroQol Thermometer</td>
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<td>Medical Outcomes Short Form (SF-36/SF-12)</td>
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<td>Single Item QOL Measure</td>
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<td><strong>ADL</strong> Vision-specific</td>
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<td>Activities of Daily Vision Scale (ADVS)</td>
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<td>Daily Living Tasks Dependent on Vision (DLTV)</td>
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<td><strong>General</strong> Instrument Activities of Daily Living scale (IADL)</td>
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<td><strong>Other</strong> Quality of Well-Being Scale (QWB)</td>
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<td>Diagnostic and Statistical Manual (DSMIV)</td>
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<td>Community Disability Scale (CDS)</td>
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<td>General Health Questionnaire</td>
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<td>Positive and Negative Affect Scale</td>
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<td>Multilevel Assessment Instrument (MAI)</td>
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<td>Freiburg Inventory on Coping with Illness</td>
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<td>Health Utility Index 3 (HUI-3)</td>
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<td>ICE-CAP-A</td>
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“Early access to appropriate low vision devices along with adequate training could assist an older person to maintain independence in their own home and prevent unnecessary age care admissions.”
Macular Disease Foundation Australia

Macular Disease Foundation Australia’s vision is to reduce the incidence and impact of macular disease in Australia.

The Foundation is the national body and voice for the macular disease community.

Our work involves providing education and awareness, funding and supporting research, representing and advocating on behalf of the community, and providing vital client services.

www.mdfoundation.com.au

Helpline: 1800 111 709
OUR VISION

To reduce the incidence and impact of macular disease in Australia

Celebrating 15 years

Macular Disease Foundation Australia
Suite 902, Level 9, 447 Kent Street
Sydney NSW 2000
Helpline: 1800 111 709
www.mdfoundation.com.au
ABN 52 096 255 177