



Community and Disability Services' Ministers' Conference

**Low Vision and Rehabilitation
Submission**

May 2006

Contents

Executive Summary	2
Purpose	4
Recommendations to CDSMC	4
Background	5
<i>National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss</i>	7
The need for low vision and rehabilitation services	8
<i>Economics of vision loss</i>	9
<i>Vision loss prevalence and projections</i>	9
Australian policy priorities and context	10
<i>Council of Australian Governments (COAG) National Reform Agenda</i>	10
<i>The National Chronic Disease Strategy</i>	10

Executive Summary

This submission is provided by Vision 2020 Australia to the Community and Disability Services' Ministers' Conference (CDSMC) and has been developed with the support of member organisations. This approach follows a decision made by the Australian Health Ministers' Conference (AHMC) to refer low vision and rehabilitation issues to the CDSMC; these issues were initially raised by the sector during the development of the National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss (National Framework).

The Vision 2020 Australia Low Vision and Rehabilitation Working Group was formed during the inaugural Vision 2020 Australia Member Forum with a view to providing the CDSMC with a submission following the AHMC referral. In developing this submission the Working Group met by teleconference and provided feedback on document development. The Working Group consisted of representatives from the following organisations: Association for the Blind, Western Australia, Blind Citizens Australia, CanDo4Kids – Townsend House, Centre for Eye Research Australia, Centre for Health Research - Queensland University of Technology, Christian Blind Mission International (Australia), Guide Dogs (Qld), Guide Dogs (Vic), Guide Dogs Association (SA&NT), Guide Dogs NSW / ACT, Retina Australia (Vic), Royal Guide Dogs Association of Tasmania, Royal Society for the Blind of SA, Royal Blind Foundation of Queensland, Seeing Eye Dogs Australia, Victorian College of Optometry and Vision Australia.

Vision 2020 Australia is seeking to establish a formal dialogue with the CDSMC membership to address essential aspects of vision loss which are not recognised within the 'health' specific focus of the National Framework. Not all vision loss is preventable or treatable and current trends suggest that Australia will have to manage more blindness and vision loss in the coming years. This document seeks the cooperation of government to assist the sector to improve service delivery and prepare for increase demand.

It is proposed that the CDSMC endorse two recommendations:

1. Establishment of a CDSMC working group or other forum to:
 - a. Map the current provision and funding of low vision and rehabilitation services across all states and territories, and
 - b. consult with the low vision and rehabilitation sector, toward the development of a complementary strategy to the National Framework.
2. The inclusion of low vision and rehabilitation initiatives in the 2007-2012 Commonwealth State Territory Disability Agreement to support the implementation of a complementary strategy.

Low vision and rehabilitation services are dealing with what is essentially an 'invisible' disability, the impact of which is seldom considered by the sighted community. The services offered across the sector enable community and economic participation for people with a vision impairment, while reducing dependence on other services (including hospitals and nursing homes). The provision of effective low vision and rehabilitation services will assist the government to achieve policy priorities such as those included in the Council of Australian Governments National Reform Agenda

and the National Chronic Disease Strategy – both seek to reduce the impact of disability on community, economy and services. People who receive low vision and rehabilitation services are better able to contribute to their community.

Unfortunately the current situation in low vision and rehabilitation service provision is inequitable and fragmented. Vision 2020 Australia is seeking the support of the CDSMC to establish a national strategic approach to inform the future development of low vision and rehabilitation services in Australia.

Purpose

This submission is provided by Vision 2020 Australia in consultation with its member organisations. It is intended to instigate a process of discussion across government and the low vision and rehabilitation sector (the sector) with a view to the eventual development of a complementary strategy to the National Framework.

It is envisaged that this complementary strategy will incorporate initiatives under the 2007-2012 CSTDA. This approach will contribute to a policy environment that enables the growth of an integrated, efficient and comprehensive system of eye health and vision management. Currently, the provision of low vision and rehabilitation services across Australia is disparate, fragmented and inequitable with a number of essential programs provided by charitable organisations.

The following have been identified by the sector as priority issues which should be addressed throughout the CSTDA and complementary low vision and rehabilitation strategy:

- Increasing research activity to develop an evidence base
- Enhancing service delivery models including the exploration of innovative approaches and the introduction of national service benchmarking
- Improving access to adaptive technologies
- Consumer and professional awareness of the role of low vision and rehabilitation strategies
- Service integration and continuum of care initiatives
- Developmental and transitional support, particularly in education and employment.
- Recognition of advocacy and generic service access issues.

Recommendations

Vision 2020 Australia recommends that the CDSMC endorse the following :

1. Establishment of a CDSMC working group or other forum to:
 - a. Map the current provision and funding of low vision and rehabilitation services across all states and territories, and
 - b. consult with the low vision and rehabilitation sector, toward the development of a complementary strategy to the National Framework.
2. The inclusion of low vision and rehabilitation initiatives in the 2007-2012 Commonwealth State Territory Disability Agreement to support the implementation of a complementary strategy.

The development of a complementary strategy to the National Framework will enable a whole of government approach to eye health and vision management and enhanced continuum of care activities across the Australian vision care sector. The reach of disease prevention strategies as set out in the National Framework is limited to conditions which can be prevented or treated. Prevention and early intervention

strategies require a number of years to impact on prevalence; current projections suggest that vision loss will increase in the near future and regardless of the cause, the economic and human impact must be addressed, including social isolation and discrimination.

Such an approach demonstrates a willingness to consider disability trends and preparedness to action, in accordance with CSTDA Policy Priority 4 which states:

Improve long-term strategies to respond to and manage demand for specialist disability services through:

- *A strategic approach to broad national and local/jurisdictional planning to underpin the determination and allocation of equitable funding to respond to unmet demand, growth in demand and cost increase.*
- *Approaches which enhance prevention and early intervention outcomes, the effective co-ordination across services systems and clear and transparent decision making.*

Necessary improvements to low vision and rehabilitation services can in part be achieved under the five strategic priorities of the current CSTDA:

1. Strengthen access to generic services for people with disabilities
2. Strengthen across government linkages
3. Strengthen individuals, families and carers
4. Improve long-term strategies to respond to and manage demand for specialist disability services
5. Improve accountability, performance reporting and quality

Vision loss has previously received inadequate attention under specific CSTDA initiatives including research initiatives.

Background

Vision 2020 Australia is a national body representing organisations working together to eliminate avoidable blindness and reduce the impact of vision loss. This collaboration brings together 46 member organisations involved in local and global eye care service delivery, health promotion, vision management, low vision and rehabilitation, aetiology and public eye health research, professional representative organisations and community support.

Vision 2020 Australia initiates and facilitates opportunities for member collaboration, undertakes awareness raising activities and leads advocacy efforts aimed at the prevention of avoidable blindness, vision loss and improved vision.

Vision 2020 Australia took a lead role in the development of what is now the National Framework, endorsed by the Australian Health Ministers' Conference (AHMC) November 2005.

It is Vision 2020 Australia's position that low vision and rehabilitation are integral components of a comprehensive vision care system. Low vision services play a vital role in reducing the impact of vision loss and blindness and assisting with healthy ageing. They are recognised as an integral component of the global VISION 2020: The Right to Sight program which focuses on five main priorities; one of them being low vision. Along with several member organisations, Vision 2020 Australia advocated throughout the development of the National Framework for the inclusion of low vision and rehabilitation. While the National Framework now acknowledges the importance of low vision services and rehabilitation, a comprehensive inclusion was not achieved. AHMC, recognising the cross-jurisdictional difficulties inherent in the request, referred the low vision and rehabilitation aspects through to CDSMC.

Vision 2020 Australia is now in the process of meeting members of CDSMC to establish a dialogue on the development of a low vision and rehabilitation response to the National Framework.

During the Vision 2020 Australia Member Forum held on 9 March 2006 and opened by Health Minister, The Hon Tony Abbott, all members were engaged in a facilitated session which identified a number of priorities for the sector. The Vision 2020 Australia Low Vision and Rehabilitation Working Group was formed with a view to providing the CDSMC with a submission following the AHMC referral.

In developing this submission the Working Group met by teleconference, provided feedback on draft documents and provided individual responses directly to Vision 2020 Australia.

Vision 2020 Australia Low Vision and Rehabilitation Working Group membership:

- Association for the Blind, Western Australia
- Blind Citizens Australia
- CanDo4Kids – Townsend House Incorporated
- Centre for Eye Research Australia
- Centre for Health Research, Queensland University of Technology
- Christian Blind Mission International (Australia)
- Guide Dogs (Qld)
- Guide Dogs (Vic)
- Guide Dogs Association (SA&NT)
- Guide Dogs NSW / ACT
- Retina Australia (Vic)
- Royal Guide Dogs Association of Tasmania
- Royal Society for the Blind of SA
- Royal Blind Foundation of Queensland
- Seeing Eye Dogs Australia
- Victorian College of Optometry
- Vision Australia

National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss

The National Framework *sets out a strategic National Framework for Action for the Promotion of Eye Health and Prevention of Avoidable Blindness. It aims to provide a blueprint for nationally coordinated action by governments, health professionals, non-government organisations, industry and individuals to work in partnership.*¹

While low vision and rehabilitation was not addressed in the National Framework, the importance of linking with low vision and rehabilitation services was recognised. A number of examples of this recognition are provided below:

Increasing early detection: Primary Health Initiatives

Action - *establish appropriate referral pathways for those detected with low vision or eye disease (pg 17)*

Barriers to accessing low vision services are often due to the fact that low vision and vision management services are treated as an add on, rather than part of the continuum of eye care programs. Barriers to accessing available low vision services may also be emotional, such as shock, fear, denial and embarrassment. There is a reported low uptake rate for assisted technology. Many people do not know what is available or what their options are regarding appropriate eye care and therefore may be needlessly dependent on others for care. (p22)

Improving access to eye health care services: Rural and Remote Communities

Action - *explore mechanisms by which low vision and rehabilitation services can be provided to remote and regional areas (p24)*

Improving access to eye health care services: Public Awareness

Action - *raise awareness of low vision management strategies and the availability of special interest, self-help and support groups (pg29)*

Improving access to eye health care services: Public Awareness

Action - *improve public awareness of the range of low vision services, rehabilitation, support, counselling and devices available (p25)*

Improving the systems and quality of care: Service Integration

Action - *develop referral pathways that include referrals to vision rehabilitation or low vision services that are available in the community (p29)*

Improving access to eye health care services: Consumer focus

Action - *involve people with, or at risk of developing, low vision and blindness in significant service design and delivery decisions, for example through formal consultations and membership of advisory and management committees within the health system (pg31)*

Action - *trial and evaluate self-management interventions for people with vision loss (pg31)*

¹ National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss, endorsed by the Australian health Ministers' Conference, November 2005

The need for low vision and rehabilitation services

Organisations represented in the Vision 2020 Australia Low Vision and Rehabilitation Working Group offer a range of services aimed at addressing the variety of needs of people who are blind or vision impaired. Whether or not a person is blind (no functional vision) or has low vision (limited useful sight), these services improve an individual's capacity to lead a full life and participate in their community.

The stage of life that vision loss is experienced will impact on the nature of an individual's needs and the services required. If someone is born with a severe vision impairment their developmental needs will differ significantly compared with an individual who has lost vision in the early adult years or later in life. Developmental programs include ongoing assessments by paediatric orthoptists and ophthalmologists to maximise the development of vision, intensive paediatric physiotherapy toward the development of gross and eventually fine motor skills, evaluation of language and cognitive function, introduction of Braille as a precursor to literacy and numeracy skills and counselling for families. The variable nature of vision loss will mean that clients' needs are different; a number of conditions are degenerative and vision will become progressively worse, whilst others will experience good and bad vision days.

Navigating the environment and coping with day to day activities that sighted people take for granted can be assisted through the use of optical devices, usually prescribed by an orthoptist or optometrist who can assess remaining vision and maximise its use. Home assessments by orthoptists help families and elderly clients to arrange their living environment to be more accessible, to maximise the best use of lighting and to prescribe appropriate assistive devices.

For the sighted population, the experience of a person with vision loss is seldom considered, particularly given that vision impairment is essentially an 'invisible' disability. It is an unfortunate fact that discrimination and isolation creates barriers for people who are blind or vision impaired to fully participate in the community. For this reason, blind and low vision consumer based advocacy services are essential to generate equality and community support.

Simple activities such as gardening, shopping, preparation of meals, crossing a road and using public transport are all activities that are dangerous without the adaptive skills offered through orientation and mobility training. The physical and psychological rehabilitation of people who have acquired brain injury through trauma or stroke is often delayed when vision damage has occurred. In these circumstances, vision rehabilitation is a priority and precedes physical mobility rehabilitation.

Accessing information and generic services can be a significant challenge for people with low vision. Adaptive technologies are critical tools, particularly for people who want to participate in education and employment. Essential activities such as banking, paying bills and booking tickets now demand interaction with technology and this has significant implications for the person who has a vision impairment.

Economics of vision loss

Clear Insight: The Economic Impact and Cost of Vision Loss in Australia is an Access Economics report developed for the Centre for Eye Research Australia. The report provides an insight into the costs of vision loss in Australia. In 2004 the annual indirect costs associated with vision impairment were estimated at \$3.2 billion. Indirect annual costs include:

- Lost earnings for people who are blind or have a vision impairment - estimated to cost the economy nearly \$1.8 billion.
- The cost of carers, including their lost productivity (earnings) - estimated at \$845 million.
- Aids, equipment, home modifications and other indirect costs - estimated at \$371 million.
- Deadweight losses associated with transfer payments (taxation revenue foregone and welfare payments) - estimated at \$208 million.²

Further, the suffering and premature death associated with vision impairment is estimated to impose a further \$4.8 billion – the value of the loss of healthy life, after netting out other costs borne by people with vision impairment.³

It has also been shown that vision impairment *"...prevents healthy and independent ageing. It is associated with the following:*

- *Risk of falls increased two times*
- *Risk of depression increased three times*
- *Risk of hip fractures increased four to eight times*
- *Admission to nursing homes three years early*
- *Social dependence increased two times*⁴

Vision 2020 Australia supports initiatives which will maximise the opportunities for people who are blind or have a vision impairment to actively contribute to the community and economy. Reducing the impact of disability on the Australian economy has now been recognised by the Council of Australian Governments as a priority.

Vision loss prevalence and projections

The World Health Organisation has acknowledged that conditions such as age related macular degeneration, diabetic retinopathy and glaucoma are increasing globally. With these increases, rising demand for low vision programs is expected.

Clear Insight indicates that over 480,000 Australians are vision impaired in both eyes and over 50,000 of these people are blind. Projections indicate that blindness is set to

² Eye Research Australia 2004 *Clear Insight: The Economic Impact and Cost of Vision Loss in Australia* a Report prepared by Access Economics Pty Ltd. The Centre for Eye Research Australia, Melbourne 2004

³ Refer 1

⁴ Eye Research Australia 2004 *Clear Insight: The Economic Impact and Cost of Vision Loss in Australia. An Overview of the Report* prepared by Access Economics Pty Ltd, 2004.

increase by 73% over the next two decades to more than 87,000 people (aged over 40).⁵

Australian policy priorities and context

Governments recognise that chronic disease, ageing and associated disability will impact significantly on the Australian economy through increasing demand for services and productivity implications. There is also recognition that supporting workforce participation for those with a disability is highly desirable.

For individuals who are born with a severe vision impairment, early intervention is imperative to maximise developmental opportunities and enable education and employment. For people who develop vision impairment beyond childhood, transitional support is vital to ensure education and employment opportunities are maximised. As the Australian population ages, vision impairment will also increase. If delayed retirement is widely adopted in an ageing Australia, these projections must be considered; keeping people in the workforce will mean providing improved access to adaptive technologies, transitional support, generic accessibility and independent living skills.

Council of Australian Governments (COAG) National Reform Agenda

Vision 2020 Australia applauds the COAG National Reform Agenda, particularly in regard to addressing the issue of disability and its impact on health and productivity. Encouraging workforce and community participation of people with vision impairment should be done through the delivery of innovative and enabling services. This approach will contribute to the achievement of the COAG Human Capital and Health Reform Agenda outcomes:

- A reduction in the proportion of the working-age population not participating in the workforce due to illness, injury or disability;
- An increase in the proportion of young people meeting basic literacy and numeracy standards, and improved overall levels of achievement;
- An increase in the proportion of young people making a smooth transition from school or work or further study;
- An increase in the proportion of adult workers who have the skills and qualifications needed to enjoy active and productive working lives; and
- Encourage and support increased workforce participation among key groups.⁶

The National Chronic Disease Strategy

Chronic disease is emerging as a significant health challenge in Australia and globally. By the year 2020 chronic disease will account for almost three quarters of all deaths. Nationally it is recognised as the leading cause of disability in the community and for high support service usage.⁷ In preparing to better tackle chronic disease, Australian governments have developed the National Chronic Disease Strategy and disease

⁵ Eye Research Australia 2004 *Clear Insight: The Economic Impact and Cost of Vision Loss in Australia* a Report prepared by Access Economics Pty Ltd. The Centre for Eye Research Australia, Melbourne 2004

⁶ Council of Australian Governments meeting, 10 February 2006, communiqué

⁷ National Health Priority Action Council (NHPAC) (2006), *National Chronic Disease Strategy*, Australian Government Department of Health and Ageing, Canberra. Pg 1-3

specific National Service Improvement Frameworks – asthma; cancer; diabetes; heart, stroke and vascular disease; osteoarthritis, rheumatoid arthritis and osteoporosis.

The National Chronic Disease Strategy (NCDS) utilises the Australian Institute of Health and Welfare’s definition of chronic disease. The following elements are applicable to the character of several diseases and conditions which cause vision loss:

- Have complex and multiple causes;
- Usually have a gradual onset, although they can have sudden onset and acute stages;
- Occur across the life cycle, although they become more prevalent with older age;
- Can compromise quality of life through physical limitations and disability;
- Are long term and persistent, leading to a gradual deterioration of health;
- While usually not immediately life threatening, they are the most common and leading cause of premature mortality.

Of particular interest and relevance to Vision 2020 Australia is the inclusion of self-management strategies within the NCDS.

Key direction 40 states:

...includes coping with changes to life roles and aspirations, and accommodating long term engagement with the health system...Of particular importance are the peer, disability, carer and aged care support sectors. These sectors often take the lead role in developing self-management resources, yet they tend to be poorly resourced and not well integrated with other parts of the health system.

These sectors are also essential in providing psychosocial support and rehabilitation services for people with chronic disease, as well as providing support and respite for their families and carers, and these are essential elements of self management.⁸

Critical data on the efficacy of self-management strategies is now available from within the low vision and rehabilitation sector and further investigation is underway. A national low vision and rehabilitation strategy will enable this to occur nationally and in accordance with best practice.

The importance of cross-jurisdictional and cross-sector collaboration is emphasised here. The development of a complementary low vision and rehabilitation strategy to the National Framework will enable linkages between health and disability organisations and jurisdictions to assist the development of effective self-management approaches.

⁸ National Health Priority Action Council (NHPAC) (2006), *National Chronic Disease Strategy*, Australian Government Department of Health and Ageing, Canberra. Pg 40