



Productivity Commission Inquiry into Long Term Disability Care and Support Scheme

Macular Degeneration Foundation

Submission

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Contact: Julie Heraghty
Chief Executive
Macular Degeneration Foundation
Suite 302, 447 Kent Street, Sydney
Phone: (02) 8268 8406
Toll Free: 1800 111 709
Fax: (02) 9261 8912
Email: ceo@mdfoundation.com.au

Contact: Jayne Gan
Client Project Officer
Macular Degeneration Foundation
Suite 302, 447 Kent Street, Sydney
Phone: (02) 8268 8411
Toll Free: 1800 111 709
Fax: (02) 9261 8912
Email: jayne@mdfoundation.com.au

Introduction

The Macular Degeneration Foundation is the peak body in Australia offering information and support for people with Macular Degeneration (MD). The MD Foundation is committed to working on behalf of the entire MD community, specifically those with the disease, their families and carers.

The Foundation's vision is to reduce the incidence and impact of MD through education, awareness, research, support services and representation. The MD Foundation supports the development of an essential and accessible disability care and support framework that addresses the immediate and long term needs of people with MD and their carers.

The Foundation endorses a framework with the key criteria being prevention, early intervention, equity of access and a continuum of short and long term care. Furthermore, the framework should promote independence and quality of life.

MD is the leading cause of blindness and severe vision loss in Australia¹ and any Disability Care and Support Framework (DCSF) should incorporate the needs of people who have a disability due to MD.

The Productivity Commission should consider the following as a part of the inquiry into disability care and support needs in relation to the MD community:

1. The total economic cost of vision loss in Australia is estimated to be \$16.6 billion in 2009 (with a total health system cost of \$2.98 billion)²
2. The direct and indirect costs of vision impairment for people with MD (\$2.6 billion in a year, this will grow to \$6.5 billion in 2025)³
3. Visual impairment prevents healthy and independent ageing. It is associated with the following:
 - a. Risk of falls increased two times
 - b. Risk of depression increased three times
 - c. Risk of hip fractures increased four to eight times
 - d. Admission to nursing homes three years early
 - e. Social dependence increased two times
 - f. Social independence decreased two times⁴
4. The Socio-Economic impacts of visual impairment include:
 - a. Lower employment rates
 - b. Higher use of services (including two times as likely to use health services)
 - c. Social isolation
 - d. Emotional distress⁵
5. Early detection and intervention can help slow the progression of MD
6. Access to rehabilitation services can lessen the daily impacts or burden of the disease and improve the quality of life of people with low vision⁶
7. Early detection is critical to saving sight and is vital for the best possible treatment outcomes for people with Wet MD⁷

Key Principles of a Disability Care and Support Framework

The following principles should be considered as part of decision making when developing a Disability Care and Support Framework (DCSF) in relation to the MD community:

1. People with MD can be severely or profoundly affected by their vision impairment resulting in disability;
2. Those who are severely affected with MD of any age require support and care from a range of services and professionals;
3. Access to early intervention strategies, rehabilitation services and treatment for those who are eligible should be aligned to individual needs, emphasising self determination, choice, and flexibility;
4. The Macular Degeneration Foundation has a strong role to play in any design of a DCSF;
5. Effective participatory community consultation is undertaken for the development of the framework;
6. Effective representation is ensured and a process for participatory monitoring and evaluation and continuous improvement be implemented;
7. Empowerment and capacity building should be promoted to support and enhance social inclusion principles throughout the new framework;
8. The provision of services to cover medical, social and emotional requirements during the period of need should be a key consideration;
9. The development of a transparent and accountable system through guidelines, minimum service standards, or an accreditation process for rehabilitation services be implemented to guarantee the delivery of quality services;
10. A 'level playing field' be created for the fair allocation of resources across the disability sectors, including the recognition of the impact and burden of disease for people with MD;
11. Any framework include consideration of equity and access to:
 - a. Low vision aids and technology
 - b. Transport
 - c. Carer Services
12. Any scheme provide for a national framework which is economically sustainable, comprehensive, seamless, accessible, efficient and fair;
13. Any scheme should promote and increase access to education, vocational training and employment; and
14. The *Convention on the Rights of Persons with a Disability* be acknowledged and included.

1. Eligibility for the Disability Care and Support Framework

(i) Macular Degeneration

Macular Degeneration is the name given to a group of degenerative retinal diseases that cause progressive loss of central vision. Impairment of central vision results in a loss of detailed vision which includes the ability to read, recognise faces, drive a car, and see colours clearly and any other activity that requires fine vision⁸.

MD is the leading cause of blindness and severe vision loss in Australia⁹, affecting one in seven people over the age of fifty¹⁰. It is hereditary with a fifty per cent chance of developing MD if a family history is present¹¹. MD is caused by genetic and environmental factors. Risk factors include age, family history, smoking and diet and lifestyle factors¹².

It is often called AMD or Age-related Macular Degeneration (defined as from age 50 years) but this disease is **NOT** a natural part of ageing, it is a health condition - a disease which can result in severe or profound disability at any age. It sits as a category of disability which “falls between the gaps” for anyone over 50 because many live at home, in retirement villages or with family carer support and are not covered by any aged care system. Those under 50 years of age are a smaller but highly significant group and require obvious and unquestionable inclusion in the framework. For the most part studies have been undertaken on AMD, meaning most of the statistical figures in this submission will be AMD statistics as they forms the largest and highly relevant component of the MD population.

The MD Foundation’s vision is to reduce the incidence and impact of MD in Australia and it works on behalf of the entire MD community which includes people with the disease, their family and carers. The Foundation promotes early intervention and prevention of MD through its information, education, and communication programs. Furthermore, the Foundation encourages independence and quality of life for people with MD through its support services and referral to low vision rehabilitation services.

(ii) Classifications of Vision Impairment

For this report the stages of disease for AMD is appropriate to use as the classification for any one deemed to require disability care and support.

Those with a ‘severe or profound’ vision disability are classified as people who have a vision impairment which is moderate (intermediate stage MD) to severe (late stage MD).

The identification of severe or profound vision impairment experienced by a person with MD should be defined according to:

1. The level of visual acuity; and
2. Burden of Disease

Table 1: Mapping Severe and Profound Disability to Classifications of AMD and Vision Impairment

ABS Disability Classification	Stage of Disease	Stage of Vision Impairment	Clinical Description	VA	Burden of Disease
	No AMD	Early Diagnostic Stage	No sign of MD	VA >6/12	0%
	Early AMD	Mild Severity	Intermediate Drusen	6/18 < VA ≤ 6/12	6%
Severe and Profound (depending on the individual rate of Burden of Disease)	Intermediate AMD	Moderate Severity	Geographic Atrophy or Neovascular MD	6/60 ≤ VA ≤ 6/18	36%
Severe and Profound	Advanced AMD	Blindness (Severe)	Geographic Atrophy or Neovascular MD	VA < 6/60	58%

Table 1: Indicates the group identified as having a severe or profound disability due to MD (in red) and should therefore be considered as eligible for inclusion in the DCSF. The second category (in blue) represents the group of people with MD who may be identified as having a severe and profound disability according to the burden of disease they experience when assessed.

(iii) Visual Acuity

The World Health Organisation defines vision impairment as broadly covering a limitation in one or more functions of the eye, which includes impairment of visual acuity (sharpness or clarity of vision) experienced by people with MD.

Moderate vision impairment is defined in terms of Visual Acuity (VA) as $6/60 \leq VA \leq 6/18$ and (legal) blindness $VA < 6/60$ ¹³.

AMD is responsible for 48% of severe vision loss in Australia¹⁴, with over 98,070 Australians having moderate to severe vision impairment due to AMD in 2010 (40,394 Geographic Atrophy and 57, 676 Neovascular)¹⁵.

All people who are classified as 'blind' in terms of vision impairment are identified as having a severe or profound disability. However, a person may have a moderate vision impairment can experience a severe and profound disability due to the level of burden of disease.

(iv) Burden of Disease

When assessing severe or profound disability it is important to assess the burden of disease for vision impairment for an individual with MD since their quality of life will be impacted by low vision.

The burden of disease is measured in Disability Adjusted Life Years (DALYs) being healthy Years of Life lost due to Disability (YLD). For example, a disability weight of 0.02 for mild

sight loss is interpreted as losing 2% of a person's quality of life relative to perfect health outcomes¹⁶.

The DALY burden for YLD for vision impairment due to AMD in Australia is:

- 35.7% or moderate vision impairment ($6/60 \leq VA \leq 6/18$)
- 62.1% for blindness ($VA < 6/60$)

The burden of disease for AMD in Australia is calculated at approximately \$62,000 per individual in 2010¹⁷.

The global DALY burden for YLD for vision impairment is:

- 36% for moderate vision impairment ($6/60 \leq VA \leq 6/18$)
- 58% for blindness ($VA < 6/60$)¹⁸

DALY weights are fairly consistent across countries; however the Australian DALY is calculated as slightly higher than the global DALY.

The global cost of VI due to AMD is US\$343 billion including US\$255 billion direct health care costs. The Global Burden of Disease (GBD) for people with vision impairment will be deprived of the equivalent of 118 million years of healthy life (DALYs) due to disability and premature death in 2010, with AMD the cause of 6 million of these DALYs. If current trends continue this health burden will rise to 150 million DALYs in 2020¹⁹.

Moderate to severe vision impairment has a significant impact on a person's quality of life due to their disability²⁰. In any framework it is important that the relative level of disability should be judged on an individual basis using both measures of VA and burden of disease (DALYs) for people with moderate vision impairment.

Given that the definition, used by this inquiry, of a disability is the "limitation, restriction or impairment that is likely to last for at least six months and restricts everyday activities", the following evidence supports that MD can be classified as a severe and profound disability and should be recognised as such in this inquiry.

Vision impairment prevents healthy and independent ageing. It is associated with an increased risk of depression, loss of independence, increased social dependence, inability to participate in valued and daily activities and early admission into nursing homes²¹. Research has identified that a consequence of visual impairment for people with MD is that quality of life is significantly worse than the general population. The quality of life of people with MD has been found to be comparable to other chronic illnesses such as cancer and heart disease²².

Central vision loss due to MD also greatly affects a person's ability to perform valued daily activities such as reading, leisure activities, watching TV, driving and recognising faces²³. A multi-country cross sectional study in Canada, France, Germany, Spain and the UK found that people with MD have a third of the ability to perform everyday activities²⁴. A person's inability to maintain participation in activities due to vision loss has been associated with an increased risk of depression²⁵, loss of independence²⁶ and a lower level of life satisfaction²⁷. The short and long term effect of these outcomes is that people with vision

impairment are at a greater risk of social isolation, social dependence and the need of earlier nursing home care²⁸.

It is evident that people with moderate vision impairment and blindness due to MD can experience a severe or profound disability: “a profound core activity limitation, where the individual is unable to do, or always needs help with a core activity or task”. Severe or profound disability due to MD should be judged on an individual basis as the burden of disease can affect people differently having a direct impact on independence and quality of life²⁹.

The following times are identified as the highest need for people diagnosed with MD are:

- a) When first diagnosed with MD;
- b) When experiencing sudden or severe vision loss;
- c) When vision loss affects independence and quality of life as measured by the burden of disease;
- d) When the person with MD faces unpredictable circumstance related to emotional, social and economic impacts, such as loss of a job, the loss of a partner or social isolation;
- e) When the effect of vision loss is compounded due to co-morbidity; and
- f) Other incidents that affect a person’s vision or healthcare.

The burden of vision impairment highlighted in “The Global Economic Cost of Visual Impairment” report can be reduced through early implementation of national disability plans including vision health, which address effective prevention, treatment and low vision rehabilitation strategies³⁰.

2. Criteria

Selection criteria should be based on both an individual’s visual acuity and an assessment of the level of burden of disease (including the emotional, social and economic impacts of low vision).

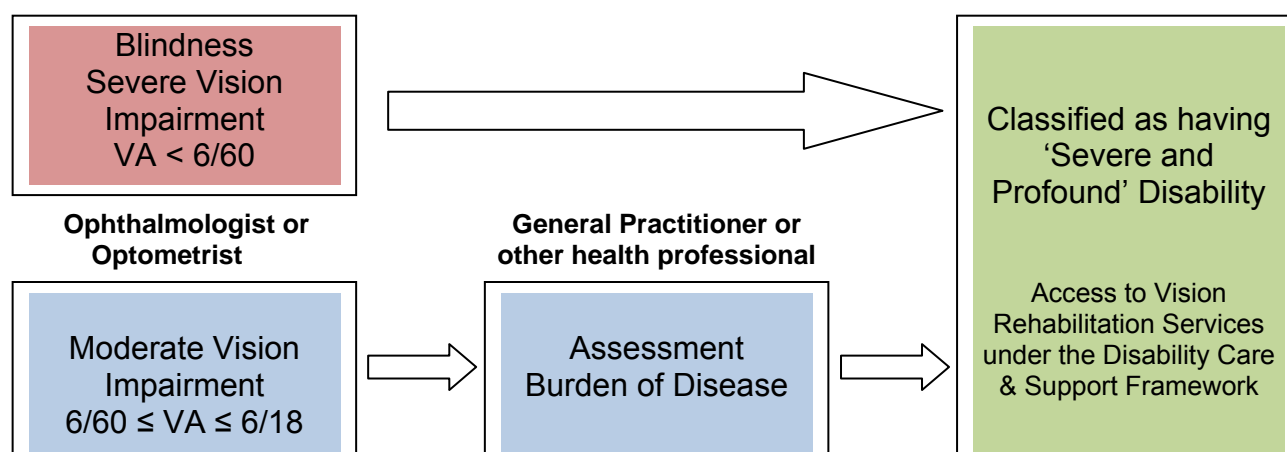
(i) Visual Acuity

The selection criteria for people who fit the ‘severe and profound disability’ category should include people who have a VA ($6/60 \leq VA \leq 6/18$ or $VA < 6/60$) as diagnosed by an ophthalmologist or optometrist.

People who are categorised as (legally) blind ($VA < 6/60$) should automatically have access to vision rehabilitation services as identified as having a severe or profound disability.

People with a moderate vision impairment ($6/60 \leq VA \leq 6/18$) should have the level of burden of disease assessed by a General Practitioner (GP) or other appropriate health professional.

Flow Chart 1: Mapping the Selection Criteria for Severe and Profound Disability



(ii) Burden of Disease Assessment

The Burden of Disease should be established (DALYs), as well as the emotional, social and economic impacts of MD using the well established and internationally used assessment tools utilised to independently assess individuals with moderate vision impairment due to MD.

The assessment tool should be comprehensive, structured, consistent and easy to use. The use of the assessment tool can be modeled on the current process for the Australian GP Mental Health Plan Assessment Tool³¹ or the Type 2 Diabetes Risk Assessment Tool³².

This will provide information which will enable early intervention and management of patients, as well as clearly defined referral pathways to health and allied service providers for medical treatment and vision rehabilitation.

3. The Role of the General Practitioner

Those identified as eligible for inclusion in the DCSF should have their case managed by a General Practitioner. As the case manager, the GP would develop an individual case plan, and should conduct referrals to relevant agencies and service providers as required.

GPs need to receive professional reports from all those involved in the treatment and rehabilitation programs, with a complete picture of the progress of the patient's treatment and rehabilitation program therefore enabling comprehensive management and follow up.

One of the key aspects of this plan is to ensure that patient's receive both components of any rehabilitation plan - both medical and rehabilitation. This is too often **not** the case with a person's needs not being adequately met as they "fall between the gaps" of the medical and rehabilitation areas. The seamless flow of referral requires the GP as case manager; an important communication linkage for the patient's ongoing well being.

Treatment for MD is undertaken by an ophthalmologist and/or retinal specialist and visual acuity is measured. The burden of disease, including the emotional, social and economic

consequences of vision impairment, is assessed by a range of professionals and various rehabilitation pathways can be recommended.

The GP is pivotal in developing and managing a comprehensive case plan in order to create more efficient and equitable access to vision rehabilitation services. As the central point of contact, the GP can ensure that a rehabilitation treatment plan is being implemented and the best possible care and support is being provided.

4. Types of Services

The two types of services that are required by people who have a moderate to severe vision impairment are:

- a) Medical Treatment Services
- b) Vision Rehabilitation Services

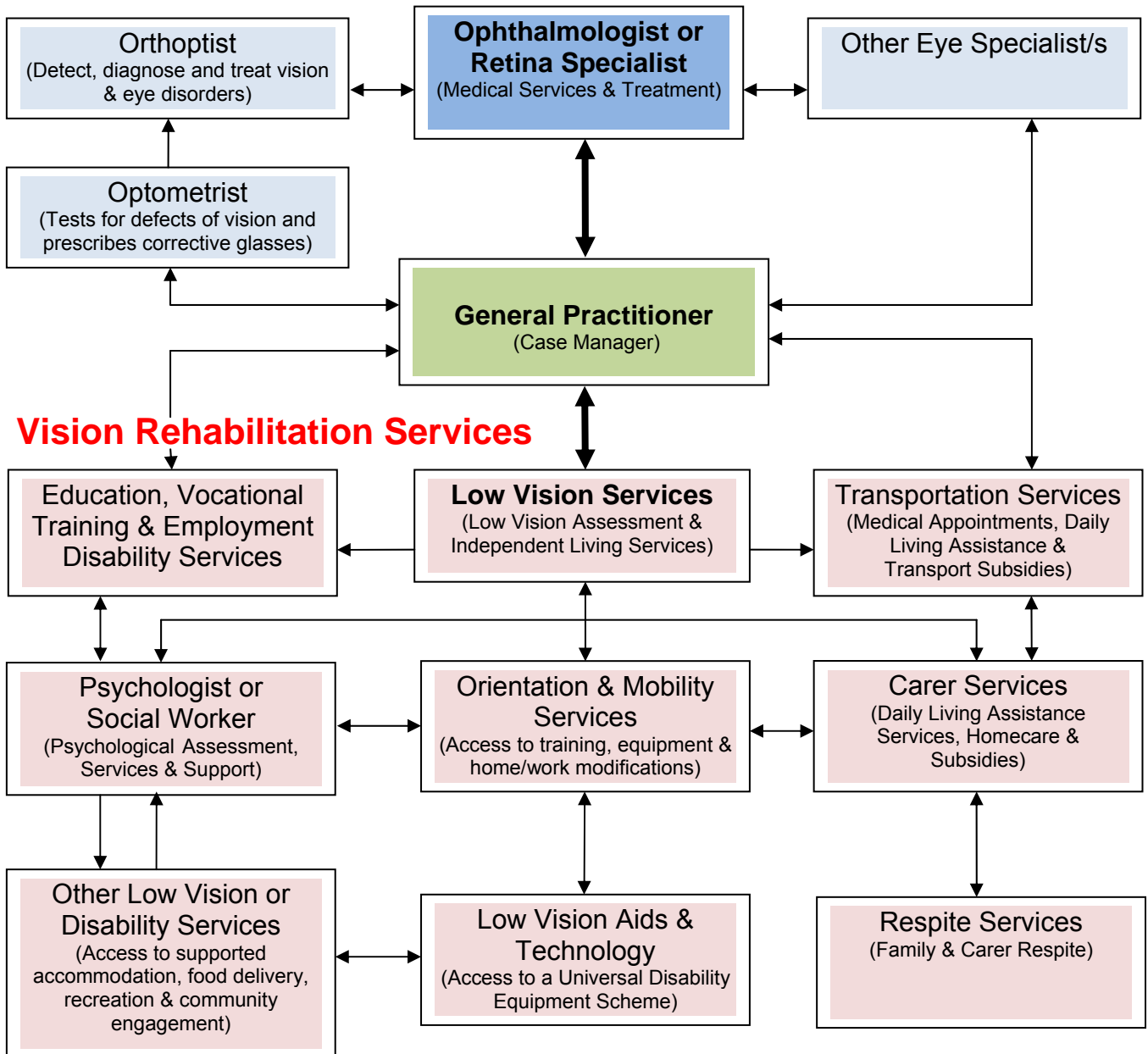
Both types of services should be considered for financial support under the new DSCF. The GP (or other health professional) would undertake primary responsibility to conduct a needs assessment and develop an individual Vision Rehabilitation Plan. GP's would also create referral pathways to other required health professionals or agencies on an "as required" basis (including psychologist, occupational therapist, mobility or low vision therapist etc).

Social and other services and subsidies required by an individual with severe vision impairment or blindness are covered within the vision rehabilitation services category. All services should be equitable and available to those who meet the selection criteria for 'severe and profound disability' due to vision impairment.

Any scheme should allow for choice, whereby those with a 'disability' and/or their carer/s are able to choose and access services that best meet their needs.

Flow Chart 2: Mapping a Seamless Referral Pathway

Medical Treatment Services



5. Medical Assessment and Treatment

Medical services should be aim to be affordable, accessible and operate on the premise of prevention, early intervention and effective treatment to address the individual needs of people with MD.

Those with MD have to attend regular appointments with an optometrist, orthoptist, ophthalmologist, and other eye specialist/s. The medical treatment services should be coordinated by the treating ophthalmologist and feedback from medical assessments and treatment discussed by the GP with the patient.

Currently, medical assessments, tests and treatment are covered under Medicare. Appointments with eye health professionals to monitor and treat MD can be costly and cumulatively expensive. The expenses from these services should continue to be available with appropriate Medicare rebates. Where ongoing frequent medical fees are not currently covered by Medicare (ie: Optical Coherence Tomography), costs should be investigated to determine the viability of them to be covered by Medicare.

The more severe form of MD is characterised by a bleed or hemorrhage of a weak blood vessel in the macula and is called Wet MD. For most people with Wet MD, they require immediate and frequent treatment to give the best possible chance of preserving sight³³.

The treating physician should explain the medical diagnosis and discuss treatment options with the patient. The patient will then be referred to their GP who is the case manager and can coordinate referrals to relevant rehabilitation professionals or agencies.

There has been for some patients a disconnect between the visit to the ophthalmologist and rehabilitation with the medical model failing to engage and connect with the rehabilitation side of vision loss. The GP as case manager will be able to ensure that this gap which can result in serious consequences is rectified by the GP Vision Rehabilitation Plan.

MD is related to modifiable risk factors such as smoking, maintaining a healthy weight, protecting eyes from sunlight, fitness, blood pressure, cholesterol and diet (limiting intake of fats)³⁴. It is crucial to create awareness of MD risk factors so individuals can change their behavior to reduce the risk of developing MD or slow the progression of the disease. There are diet and lifestyle changes people can make to help slow the progression of MD³⁵.

Evidence suggests the earlier a person is diagnosed with MD, the greater the opportunity of saving sight. Information, education and communication campaigns directed at behavior modification for prevention, early intervention and treatment for MD (such as the MD Foundation's activities and programs) should be supported under the new DCSF.

6. Vision Rehabilitation Services

Vision rehabilitation services aim to help people minimise the health, social, emotional and economic impacts of vision impairment, so people can lead as close to normal life as possible with their remaining vision, use of other senses or with aids and technology. The goal is to maintain independent living and quality of life for people with low vision.

(i) Services Required

There is a fundamental need to ensure services cover most of the individual care and support needs of a person with a severe vision disability throughout their lifetime according to need. There are a number of vision rehabilitation services that can be identified as required by a person with severe vision disability including:

- a) Low vision services (including information, assessment and training in independent daily living);
- b) Orientation and mobility services (including mobility at home, work or within the local community);

- c) Low vision aids and technology (including low vision equipment and any training required in the use of aids and assistive technology);
- d) Carer and respite services (including assistance with daily living activities and respite services available for family or carers);
- e) Education, vocational training and disability employment services (to increase skills and provide support to find and maintain worthwhile education, training and employment);
- f) Transport services (including to medical or rehabilitation appointments and daily living transportation needs to support independence and allow people to stay within their homes longer);
- g) Emotional support (including psychological and social services, information and education);
- h) Community participation (including leisure and recreation); and
- i) Other disability services (supporting independent living and community participation).

The vision rehabilitation services should be accessible via funding provided through the DCSF. Individuals and/or their carers should be given the power to decide which services they require and when and how they would like to access them; through consultation and guidance from the GP Vision Rehabilitation Plan.

(ii) Barriers

Rehabilitation services can reduce the impact of vision loss, however only 20% of Australians that could benefit from these services use them. Current barriers to accessing low vision rehabilitation include:

- a) A lack of awareness in services offered among people with vision impairment and referring professionals;
- b) A misconception that rehabilitation services are only for people who are blind;
- c) Confusion with the referral process;
- d) Problems with using transport to access rehabilitation services; and
- e) Personal factors such as co-morbidities³⁶.

It is crucial that medical professionals refer people with a severe vision disability to seek assessment and rehabilitation services. A key role of the GP will be the development of an individual Vision Rehabilitation Plan. It is vital that GPs act as a case manager, providing information and referral to other relevant health professionals or organisations to meet individual needs.

Greater capacity for people to manage their vision loss can promote confidence, reduce stress and improve overall quality of life. The DCSF should focus on improving the uptake of rehabilitation services by people with a severe vision disability. It should remove barriers to services to promote independent living for people with a severe disability due to MD.

It is evident that a variety of services are required to assist people with severe low vision including; medical, low vision, aids and technology, care and respite, psychological and emotional support, education, vocational training or employment, transportation, and community participation.

The GP, as the case manager, should be aware of vision and disability rehabilitation options available to be able to offer effective referral within the multi-disciplinary health team (similar to the functioning of the Australian GP Mental Health Plan or the Type 2 Diabetes Plan).

Referral pathways should be strengthened through improving the knowledge of MD and of vision rehabilitation amongst health professionals.

(iii) Low Vision Services Standards

Like most major service providers service standards through guidelines and/or accreditation are essential and should be considered through any new scheme. A seamless referral network is critical to an efficient and effective service.

People who have a severe vision disability due to MD require support and help from a range of health professionals and services. The Centre for Eye Research Australia (CERA) found that up to 85% of people with low vision and visual acuity of < 6/12 in Australia could benefit from accessing low vision rehabilitation³⁷.

Low vision services and access to rehabilitation programs can assist people with vision impairment by lessening emotional distress³⁸ and increasing the ability to participate in daily activities unassisted thereby increasing independence³⁹.

Low vision organisations such as Vision Australia, Royal Society for the Blind South Australia, Queensland Blind Association, and Guide Dogs (to name a few), are crucial in providing a variety of low vision services aimed at assisting the person with low vision in their home, work or local community. It is important for people with a severe vision disability to access vision rehabilitation services to promote independence and maintain quality of life.

Access to low vision service providers is crucial for people severely affected with MD to demonstrate skills to best use their remaining vision and other senses to continue daily living activities, as well as to introduce low vision aids or technology that will further support independence. These service organisations meet a need for the low vision community, and as such should be an integral part of any seamless referral system.

There are some key areas that could be improved and addressed in the development of the new disability care and support framework:

- a) Service organisations are required to fulfill a minimum level of expectations with service delivery standards introduced or an accreditation process which is linked to Government funding. This would allow for equity to access in the provision of a standard level of service, thereby addressing the current trend that individuals can receive different services and service standards across organisations and states;
- b) A requirement of service standards, or an accreditation process, is to review and improve the existing referral process between low vision service organisations and other service providers. This will minimise the current risk of people getting 'lost in the system' or 'falling through the gaps'. This is particularly relevant in creating

greater coordination between agencies to ensure the individual needs of the client are met satisfactorily and to avoid duplication of services; and

- c) The level and quality of low vision services should ensure people who have severe vision impairment living in rural or remote areas, receive equitable service delivery.

7. Low Vision Aids and Technology

A recent audit of low vision aids and equipment carried out by the Foundation in May 2010 found that there is no standard subsidy across the states and territories that provide equitable access to subsidies for low vision aids and technology⁴⁰. The Department of Health in several states (QLD, SA and VIC) have no subsidy scheme available for purchasing low vision aids or assistive technology. Where subsidies do exist, the criterion to access the schemes are severely limiting requiring means testing, DVA membership or pensioner or senior card holder status. Furthermore, existing subsidies are insufficient to address the low vision aids and technology needs for people with a severe vision disability.

Access to low vision aids and technology is valued by users and increases independence and quality of life for people who are vision impaired⁴¹. The DCSF should focus on ensuring the provision aids and technology to people who are identified as having a severe and profound vision disability.

Costs associated with aids and technology can limit the availability of assistive equipment for many people with severe low vision. A national program should be developed creating equitable access criteria to support the costs of low vision aids and technology, making them affordable and accessible.

Subsidies to assist covering the cost of a specific aid or technology should be applied for with the endorsement of a GP or low vision professional. Subsidies should be made available according to the category of low vision equipment. An appropriate sustainable subsidy program for the cost of low vision aids or technology should be designed and implemented under the new DCSF. Training in the use of the low vision aids and/or technology is essential for maximum use⁴².

Mechanisms for remote, rural or socially isolated people with a severe vision disability should be addressed. A communication platform must be available and accessible to convey the types and choices of low vision aids and technology, as well as the method and means to obtain them under the DCSF. Where cost remains a barrier for the purchase of low vision aids and technology, long-term loan and recycled equipment schemes should be supported under the DCSF.

Aids and technology must be a major component of the DCSF as they provide the central pathway for independence and quality of life for people with a severe vision disability.

8. Care and Respite

People with a severe vision disability due to MD may require the support of family, friends and carers. When independent living is no longer possible it is the role of the carer to undertake activities that can no longer be performed by the person who has low vision. Where possible, the MDF supports carer programs that allow the person with severe low vision to maintain living as independently as possible within their own home.

Care should support independent and daily living needs, and participatory independent care plans should be developed and implemented by carers and relevant service providers covering objectives, care activities, roles and responsibilities. Any carer scheme should allow for equity of access and regular monitoring and evaluation of services to ensure the delivery of quality services accountable to the client⁴³.

Where the carer is a family member or friend, access to appropriate local respite services should be available.

9. Emotional Support

Studies have shown that people with MD experience depression at the same rate as people with cancer or heart disease⁴⁴. Depression is a serious illness and can have effects on physical and mental health, affecting independence and quality of living⁴⁵. It is vital that people with severe MD have access to appropriate psychological services that are easily accessible and affordable.

Depression must be recognised in order to be treated effectively by a health care professional. Having a GP act in the role of case manager will ensure regular assessments are completed to identify depression (and/or other mental illness) experienced by a person with a severe vision disability, thereby promoting early intervention for psychological support. Emotional support must be included as a necessary service option for people with a severe vision disability and included within the DCSF.

The GP acting as the case manager should identify and provide referral to appropriate local psychological services. Clients should be supported according to their individual needs, and fees should be covered by Medicare as allocated under the GP Mental Health Care Plan as part of the *National Action Plan on Mental Health 2006-2011*⁴⁶. Any additional ongoing fees to provide emotional support for people with a vision disability should be reviewed under Medicare or provided under the DCSF.

10. Community Participation

Wherever possible the new scheme should encourage and support community participation. Healthy living should be promoted, especially to reduce the impact of co-morbidity. Regular exercise and leisure activities can help people with low vision remain active and engaged in the community. It is important to reduce social isolation and maintain confidence to continue to participate in activities⁴⁷.

Low vision doubles the risk of falls⁴⁸, and central vision loss associated with MD can result in impaired balance and increased risk of falls. Most falls are preventable, with about 50 per cent of falls occurring within homes or immediate surroundings⁴⁹.

Physical activity keeps us healthy and reduces the risk of falls. When considering community participation the information and education of falls prevention, and the participation in orientation and mobility training, is important and should be included within the DCSF.

11. Education, Vocational Training and Employment

There are high productivity losses from reduced labour market participation through lower employment, greater absenteeism, and premature mortality associated with low vision and blindness⁵⁰. Labour force participation for people with disabilities is 53 per cent, with Vision Australia reporting that 63 per cent of people who are blind or vision impaired are underemployed or unemployed⁵¹. Lost earnings for visually impaired are estimated to cost the Australian economy \$1.8 billion in 2004⁵².

Participation in education, vocational training, and/or employment by people who have a severe vision disability boosts their level of productivity and positively impacts quality of life. It is important when developing the DCSF that access to appropriate education, vocational training and Disability Employment Services is supported. The individual Vision Rehabilitation Plan should give information about education, training and employment options and services, including subsidy or support schemes such as the Employment Assistance Fund⁵³. Full participation by people with a disability should be encouraged and promoted through the DCSF.

12. Transportation Services

A national transport scheme should be made available under the DCSF to enable access to appropriate local medical and rehabilitation services for people with a severe disability due to MD. Local transport services or carer transport services should be made available to provide access to regular transport and patient travel. Where possible, local transport services should be made available through local government or outsourced to an organisation supported by the DCSF.

Moreover, subsidised travel, such as taxi vouchers, should be made available for people who meet the criteria as having a severe vision disability. The scheme should also address the physical accessibility and affordability of transport services for rural and remote clients, especially when requiring treatment services.

13. Consumer Input

People who are blind or have severe low vision that meet the 'severe or profound disability' selection criteria need to be consulted and empowered in the development of an accessible DCSF that meets their needs and rights. People with vision disability should be involved in decision making with ongoing input to the growth and maturity of any ultimate framework.

14. Costs

The DCSF must be equitable and appropriate, covering costs associated with the disability and the care required which includes rehabilitation services. Access to the service should not be hindered due to cost and the financial system for 'severe and profound' disability must be simple and easy.

A fee structure should enable low income earners to have the best opportunity to access quality services. The amount of financial support should reflect service costs and be regularly reviewed.

15. The e-health system

The implementation of the proposed e-health system, involves records being shared across health professionals via an Individual Electronic Health Record (IEHR), allowing healthcare providers to make better decisions about health and treatment advice, and greater transparency and sharing of information⁵⁴. This will be of great value to the GP, as the case manager, for co-ordination and efficiency in the management of patients with a severe vision disability.

16. The Macular Degeneration Foundation

Those with MD need clear, accurate and appropriate information about their disease. The ready availability of this information for people with MD and their families and/or carer is essential for effective care. This includes information about the risk factors for MD, treatment, the low vision rehabilitation pathway, and safe and independent everyday living.

The MD Foundation supports the MD community and health professionals providing information through publications, website and helpline.

The Foundation has an ongoing, critical and necessary role in any scheme; especially in supporting the proposed case manager (the General Practitioner) in his or her role.

A pilot project with General Practitioners in NSW conducted by the MD Foundation through a grant funded by the Federal Department of Health and Ageing (in 2009 and 2010); highlighted the need for ongoing professional development and support for GPs in diagnosis, treatment and rehabilitation of MD.

The not-for-profit sector has an extremely important role in providing advice, information, education, support, advocacy and education for individuals, families and carers affected by MD, and as such should be recognised and included in the DCSF and ultimately in any Disability Care and Support Scheme.

17. Conclusion

The objective of the reform directions under the *National Disability Agreement* is for people with a disability to have enhanced quality of life and participation as valued members of the community⁵⁵.

The MD Foundation's submission highlights:

1. The critical importance of including those with MD in a Disability Care and Support Scheme;
2. The criterion of those with MD include those who meet the 'severe or profound disability' selection criteria;
3. The criteria used should be an internationally accepted and recognised criteria as outlined;
4. Those identified as eligible for inclusion in any Scheme should be case managed by a General Practitioner;
5. A well structured, seamless, equitable and accessible referral process be implemented to ensure both medical and rehabilitation services are included in disability care and support;
6. The importance of equity of access to a range of appropriate services acknowledging both medical and rehabilitation needs;
7. Services should have standards and guidelines and consideration be given to an accreditation processes for vision rehabilitation;
8. The importance of meeting the medical, emotional, social and economic needs of people with a severe or profound disability due to MD;
9. The importance of having a simple, easy and accessible scheme with input in design and evaluation from the very people who will use the services; and
10. The need to include prevention, early intervention, treatment and rehabilitation needs for people with a severe vision disability due to MD in any national Disability Care and Support Framework.

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