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Macular Disease Foundation AUSTRALIA™

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Submission to the Productivity Commission

Human Services - Identifying sectors for reform

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OUR VISION

To reduce the incidence and impact of macular disease in Australia

Macular Disease Foundation Australia thanks the Productivity Commission for the opportunity to respond to the Issues Paper: Human Services - Identifying sectors for reform.

1.0 Centrelink

Recommendation: Centrelink's customer service delivery be reviewed to ensure an accountable consumer-centric organisation, incorporating best practice operations relating to accurate, effective and accessible communications with clients. Service delivery must be supported by an adequate investment in innovation and technology to facilitate informed consumer choice.

Informed User Choice
At its most basic level, fostering informed user choice requires the provision of accurate, up-to-date, easily understood information including all appropriate options, in a variety of formats to suit the needs of different users. It has been the Foundation's experience that Centrelink's operations, policies and procedures do not consistently meet these requirements.

The first contact that many people have with the Human Services sector is at a Centrelink office or the Centrelink phone line.

Feedback to the Foundation about contact with Centrelink has highlighted issues relating to efficient and effective servicing of clients, which has a direct impact on the ability of consumers to make appropriate, informed choices regarding their ongoing needs.

This includes feedback that the consumer interface with Centrelink can be an extremely difficult and frustrating experience, requiring great patience, persistence, excessive time and significant pre-existing knowledge of the system. Information provided can be frequently incorrect, incomplete, inappropriate or overly complex, which does not help the consumer to make an informed decision about their future.

A consumer-centred information service must be the driver of the business model for Centrelink with procedures and practices that help the consumer to make the right choices. It must also be underpinned by a system of accountability.

Examples of customer delivery issues with Centrelink, specifically in relation to Aged Care services, include:

- **Waiting times**: waiting excessively on the phone or in Centrelink offices
- **Initial contact**: In terms of phone contact - when answered, the initial contact is frequently unable to help, with the call being transferred and being placed in another queue, resulting in a further lengthy wait
- **Dropping out:** 'dropping out' calls result in frustration with additional calls required, with the call then going to the back of the queue, and the issue needing to be explained again to a different person
- **Case management:** different people managing a case, with varying detail in the recording of case notes, invariably means the client must explain an issue in detail each time they call
- **Call back system:** Centrelink call back system by staff - if the client does not answer the phone on the first attempt, Centrelink staff are apparently unable to leave phone

messages, so there is no way a client can even tell if Centrelink has called. Technology could provide an answer here, for example with text messaging (as now used by GPs) to advise of the failure to connect by telephone

- **Information:** incorrect, inadequate or confusing information provided, which has the potential to result in poor choices being made by the customer.
- **Call centre process**: recognising the volume of calls, it is acknowledged that a central call centre is appropriate. However, the continuity of service is interrupted due to inadequate records of the last call and a new case manager beginning the process again. Technology could provide answers in the form of comprehensive templates that record all required information to progress the enquiry. If this is in fact currently available, it has not been apparent in calls to Centrelink
- **Processing:** failure to process applications in a reasonable timeframe results in frustration and poor client outcomes
- **Accessibility:** Communications from Centrelink (eg the website) are not necessarily easily accessible for people with significant vision loss or blindness.

There is no doubt that very sensitive issues are managed by Centrelink along with high volumes of client interaction, leading to challenges within the service to cope with the workload. However, it is a reasonable proposition that the people who access Centrelink are entitled to information, support and services in an efficient and effective system, especially as many of them are elderly, have health challenges and are experiencing financially difficult circumstances.

In the provision of quality service the following key elements should be considered:

- Consumer-centred service delivery
- Adequate supply of staff for the service demands
- Adequate training programs for staff
- Innovative technology which caters for various modes of communication and service delivery for effectiveness, efficiency and to suit the varying needs of consumers. For example, it must not be assumed that everyone is able to access online help.
- Flexibility in service delivery to accommodate differing consumer needs and reflecting a modern working economy. For example, since the needs of many elderly people are managed by their working-aged children, the limiting of phone support for Aged Care from 8am to 5pm, Monday to Friday only, can mean that people may have to take time off work to call Centrelink, or interrupt their work program at the expense of the employer, especially given the frequently long waits for a call to be answered.

2.0 The Aged Care/Disability divide in low vision – improving consumer choice

Recommendation: Implement a nationally funded aids and equipment program (including low vision aids and technologies) to overcome the gross inequity and lack of consumer choice resulting from the exclusion of people aged 65+ from the NDIS.

While both sides of government are to be congratulated for their bipartisan support of the disability sector with the introduction of the NDIS, there remains a major gap in the accessibility and affordability of disability services for people who acquire a disability at the age of 65 years or over (such as vision loss in those with late-stage macular degeneration or diabetic retinopathy). As such, their choice is seriously limited.

These people have been excluded from the NDIS by virtue of their age, and are now expected to access supports and services within the aged care system.

Unfortunately, the Aged Care system has neither the capacity, capabilities nor resources required to enable people to exercise choice in the supports and services they obtain to maintain a reasonable quality of life and independence.

The supports and services available through the aged care system are primarily geared towards frail ageing where people require regular and ongoing personal support.

In contrast, people with vision impairment are not necessarily frail, and may not need personal support, providing they can, on an episodic basis, access suitable, individualised low vision aids and technologies and mobility training.

While such supports are easily accessible and fully funded in the NDIS, it has been the Foundation's experience that it is extremely difficult, if not impossible, for people to receive adequate assistance to obtain sophisticated assistive technology unless they have a high level Commonwealth Home Care package.

The new Commonwealth Home Support Programme (CHSP) can allow the purchase of inexpensive aids (up to $500 per year or $1000 at the discretion of the provider), however this is inadequate as it does not allow the one-off purchase of more costly but appropriate equipment such as a CCTV or voice-to-text reader, which can enable the person with vision loss to maintain independence and avoid the need for additional, even more expensive, ongoing higher level support.

It is currently easier to obtain major funding for costly long-term personal assistance supports than it is for comparatively inexpensive cost-effective aids and technologies that can maintain peoples' independence and greatly enhance quality of life.

It has also been the Foundation's experience that:

a) many current aged care providers (who are not necessarily skilled in issues relating to vision loss) are unaware of the value of low vision aids and technologies and are not offering them, or
b) providers may be reluctant to reduce the amount of funding available for their services and hence may not suggest the purchase of low vision aids, as these services come from the same overall funding pool, or
c) people in rural and regional locations commonly will not have access to aged care providers with expertise in the provision of low vision aids.

Consideration should therefore be given to:

1. **The development of a nationally funded aids and equipment program.** Consumer choice requires the urgent development of a nationally funded aids and

equipment program separate from the aged care system, and intended for people aged over 65 as well as those under 65 who do not qualify for supports under the NDIS. This system could be administered at the state level, however federal oversight and funding would ensure equity of access for all Australians.

Currently, where you live can determine how well you can see or read (and hence whether you can live independently). By separating this program from the CHSP and Commonwealth Home Care Packages, people who do not need ongoing frail aged supports could still access their necessary supports to maintain their independence. It is also likely that fewer people would need to access a more expensive CHSP or Commonwealth Home Care Packages, or their need for higher services would be delayed by some years. Such a program would give consumers greater choice when making decisions about their future, at a lower overall cost to the human services budget. This would also overcome the current restriction on the purchase of aids and technology within a Commonwealth Home Support Package.

It should be stressed that although some of the states may provide limited low vision aids and technology programs, there is great variation between jurisdictions regarding the scale of these programs, who is covered and the costs involved.

Some states do not provide any programs at all. In other states, the programs are being scaled back or stopped altogether due to the increasing role of the NDIS in this area. For people who do not qualify for the NDIS (and especially for those aged over 65 years old), this leaves a huge gap with no alternative means to access subsidised aids and technologies. For pensioners and others on limited incomes, this can mean these enabling devices are simply unobtainable and the consumer may have to use more expensive, inappropriate and unsatisfactory home support or home care services.

Such a program could also be of benefit to the significant number of people living in residential aged care facilities who are currently unable to obtain the (limited) access to low vision aids, as the provision of low vision aids is dependent on decisions made by the residential care provider.

2. **Increased contestability for disability services such as low vision support in rural and regional areas.**
   Currently, specialised low vision providers are typically not listed on MyAgedCare in most rural towns. The major providers primarily focus on major towns or cities and while some provide limited outreach services, availability is patchy.

   Potentially suitable, qualified providers such as optometrists are commonly located in most regional towns, however they rarely provide a low vision service as Medicare reimbursement is minimal (and is not enough to cover costs) and the establishment costs to provide a low vision service can be significant. As a result people with low vision, in such locations, typically go without or have to travel large distances to access suitable services.

3.0 Increasing consumer choice of location for treatment to reduce costs

Recommendation: A Federal Government report on the existing access to public care for macular diseases and other conditions be produced. There is an urgent need to increase the availability of public outpatient clinics for the treatment of certain conditions such as macular diseases to ensure ongoing sight-saving care for people with limited income. This need is particularly high in rural and regional centres.

Currently, the overwhelming majority of people requiring ongoing treatment (eye injections) for macular degeneration, diabetic macular oedema, retinal vein occlusions and other similar conditions receive these in a private ophthalmologist's rooms.

Most of these people are elderly, and they are commonly pensioners or limited income retirees. Unfortunately, less than 18% of these injections (Medicare item 42738) are bulk-billed (Medicare, March 2015). For people who are not bulk billed, the average fee charged is $204 above the Medicare rebate per injection (Medicare, March 2015).

Even when a person qualifies for the Extended Medicare Safety Net, the average injection fee charged will entail a $40 out of pocket cost, not including other costs for diagnostic tests and normal consultation fees. As these injections may be be required as often as monthly (or twice a month if both eyes are affected) the out of pocket costs for pensioners and retirees on limited fixed incomes can be significant.

It is also a concern that the already low levels of bulk-billing for these injections will be forced even lower with the proposed freeze on Medicare rebates, leading to even greater financial stress for many people.

Patients do struggle with these costs and there is always the risk, as indicated by some Foundation clients, that their choice is either "stopping treatment and going blind or continuing treatment and going broke".

One option for people who have had difficulty paying for these injections given privately is to receive treatment in one of a limited number of public outpatient retina clinics, however these are typically only found in two or three of the major teaching hospitals in state capital cities.

These clinics invariably have long waiting lists to receive treatment, highlighting the level of demand from people who cannot afford private care. Unfortunately however, treatment for 'wet' macular degeneration and similar conditions cannot wait. A delay longer than a few weeks can result in significant and permanent vision loss. Public outpatient retina injection clinics are underfunded, under-resourced and in very limited supply.

The Foundation is aware that some outpatient clinics are now in a position of being unable to provide treatment as they have no further capacity, while others are treating people for two or three months and then referring to the private sector for maintenance of treatment.

Patients may now be forced to choose between extreme financial hardship or stopping treatment, as they are unable to afford ongoing private care, with permanent vision loss or blindness being the consequence.

It is also noteworthy that there are almost no public outpatient clinics providing injections for macular diseases away from the capital cities. In some rural and regional communities, patients have little or no choice of treating specialist and are therefore unable to 'shop around'. Without the option of public care, they have essentially no choice.

The acute shortage of public care for many specialist services (including treatment of macular diseases) is a complex and long-standing issue, with no easy solutions. It is unacceptable however for people to be losing vision or going blind when we now have extraordinarily effective and safe treatments that are available via the PBS, but are being underutilised. The cost of blindness will always greatly exceed the cost of treatment, and hence greater efforts must be made to address the lack of public care and thereby increase choice for the most vulnerable in society.

A Federal Government report on the existing access to public care for macular diseases and other conditions is essential to drive solutions for informed consumer choice ensuring that Australia continues to provide accessibility and affordability of care for all Australians, regardless of their income.

4.0 Giving people with private health insurance greater choice and better value

Recommendation: The Private Health Insurance Act Complying Product Rules (2015) should be changed to allow private health reimbursement of certain specialist surgical and related procedures when performed in-rooms, providing there is evidence that this is safe, and where this will reduce overall health costs.

Currently, the Private Health Insurance Act prevents private health insurers from providing coverage for minor surgical or related procedures performed in a specialist's rooms. This restriction has the unintended consequence of limiting choice, innovation, and in some cases, encouraging the unnecessary use of more costly treatment in a hospital or day case facility.

Moreover, privately insured patients are financially penalised if they opt to receive certain treatments in what may be the most cost-effective location - the specialist's rooms - as they do not obtain full gap coverage with Medicare benefits. Somewhat perversely, if the same procedure is performed in a private hospital setting, at considerably higher overall cost, the patient will pay nothing if they have no-gap cover.

Recent advances in treatments for some conditions (and perhaps other treatments that are likely to appear in the future) mean that a procedure which was previously only performed in a hospital/day case setting can now be safely performed in-rooms.

In-rooms treatment can provide a number of benefits:

a) the overall cost to the health system (including private insurers) would be reduced as patients do not need to be admitted or incur accommodation and facility fees

b) efficiency is improved as more patients can typically be treated in a rooms setting compared to a hospital setting. This is especially relevant in some specialties where there is a shortage of qualified practitioners
c) there may be more opportunities for patients in rural and regional locations to be treated closer to home, rather than in a private hospital some distance away
d) patients (many of whom will be elderly, high risk individuals) will have less exposure to nosocomial (hospital acquired) infections.

Providing there was evidence that performing a procedure in-rooms was safe and more cost-effective than in-hospital treatment, the provision of private insurance rebates for certain in-rooms specialist procedures would generate additional advantages:

a) the shift from expensive in-hospital treatment to much cheaper in-rooms treatment will likely result in significant cost reductions for private insurers
b) the burden on the Extended Medicare Safety Net will be reduced as privately insured patients will be able to claim gap benefits via their fund
c) the ability to obtain no-gap cover would encourage patients and providers to utilise the more cost-effective approach.

In some situations, these procedures are already being performed in-rooms, at least for a proportion of patients. This means that privately insured patients are effectively paying twice - once for their private cover, for which they are receiving no benefit (or value) and again with gap payments (the difference between the Medicare rebate and the schedule fee) and additional out-of-pocket costs (where the doctor charges more than the schedule fee). For these patients, allowing private health rebates will give them significantly greater choice, better value for their premiums, and increase the likelihood that they will be able to afford ongoing treatment and maintain private cover.

About Macular Disease Foundation Australia

Macular Disease Foundation Australia is a national, independent charity established in 2001. It is the only organisation in Australia that specifically supports the needs of the macular disease community.

- Every day the Foundation is working to save the sight of all Australians and has done so for 15 years.
- The Foundation is recognised nationally and internationally as the Australian peak body for macular disease.
- The Foundation is a robust organisation with a strong governance model:
    - An experienced Board of Directors set the strategic direction of the organisation
    - State Chairs represent the macular disease community in their respective states.
    - Four expert Committees including a Medical Committee, comprising 11 of

Australia's leading retinal specialists who provide expertise across all macular diseases, guiding the Foundation on major matters related to prevention, treatment and patient outcomes.

- The Foundation's National Research Advisor, Professor Paul Mitchell, Professor of Ophthalmology University of Sydney, is a world expert on macular disease and is a key source of information and support.

- The Foundation has experienced senior staff with backgrounds in science, education, communications, pharmaceutical and medical industries, government policy, media and business. The CEO was a recipient of a Harvard Fellowship in 2013 to study *Strategic Perspectives in Non-Profit Management*.

- The Foundation has a broad national membership of almost 52,000, across all states and territories, comprising: those at risk of developing, or living with macular disease, their family and carers; eye care and allied health professionals including optometrists, ophthalmologists, orthoptists, occupational therapists, dietitians, pharmacists, GPs, diabetes organisations, residential aged care facilities, university faculties and students, low vision rehabilitation providers; CALD communities; industry groups, key interest and advocacy groups.

- The Foundation's work in education, awareness and support services directly correlates to and supports the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness in Australia*.

- The Foundation has a highly regarded position in representing the views of the membership to government in a collaborative environment in order to make a positive impact on patient outcomes. This is evident in the marked improvements in access to treatment and rehabilitation, support and subsidies for patients, families and carers. Given government's emphasis on chronic disease and improving health outcomes, the Foundation, as a peak body and in its advisory roles, can continue to play a significant role in reducing the incidence and impact of Australia's leading cause of blindness.

- The Foundation has a powerful voice in the eye health sector for its members, and has developed tools and expertise to ensure it effectively communicates and represents the views of members.

- The Foundation has a proven track record of outcomes for public health in Australia which has been recognised on the world stage, with the publication of its work in leading international, peer-reviewed journals: *Aging and Mental Health***Error! Bookmark not defined.***, American Journal of Public Health* (AJPH)[1] *, Clinical Ophthalmology*[2], *Eye*[3] and *Value in Health*[4].

- The Foundation has been regularly invited to share its outstanding achievements in local and international fora, including at major international conferences and events in Europe, South America and Asia Pacific. Given the recognition of its best practice approach to public health in relation to macular degeneration, the Foundation organised and co-hosted the first-ever *Global Ageing and Vision Advocacy Summit* in April 2013 in Barcelona, Spain in collaboration with the International Federation on Ageing.

Macular disease in Australia

- It is estimated that there are approximately 8.5 million people **at risk** of macular disease and over 1.19 million Australians with **some evidence** of macular disease.[5]

- Macular disease is the greatest contributor to chronic disease in eye health in Australia.[5]
- Macular disease is a large group of sight-threatening diseases that affect the central retina at the back of the eye, which is responsible for detailed central vision. These diseases include macular degeneration, diabetic retinopathy, retinal vein occlusions and numerous other macular dystrophies.
- Macular degeneration and diabetic retinopathy have been categorised as priority eye diseases for the prevention of blindness and vision impairment by the World Health Organisation.
- Early detection of macular disease is vital. Treatment, along with diet and lifestyle measures, can slow progression of macular disease and, in the case of treatment, save sight.[5]
- The most common macular disease in Australia is macular degeneration:
    - **Macular degeneration is a chronic disease with no cure.**
    - It is the leading cause of blindness and severe vision loss in Australia and is the cause of 50% of blindness in Australia. [5]
    - 1 in 7 (1.19 million) people have some evidence of macular degeneration.[5]
    - **This is estimated to increase 70% to 1.7 million by 2030**, in the absence of adequate treatment and prevention measures.[5]
    - Primarily affects those over the age of 50 and the incidence increases with age. [5]
    - Macular degeneration is a major chronic disease with prevalence 50 times that of multiple sclerosis and 4 times that of dementia.[5]
    - The impact of macular degeneration on quality of life is equivalent to cancer or coronary heart disease.[6]
    - Smoking is a key risk factor as it increases the risk of developing macular degeneration by 3 to 4 times and smokers, on average, develop macular degeneration 5 to 10 years earlier than non-smokers[5].
- Diabetic eye disease is the leading cause of blindness among working age adults in Australia:[7]
    - Almost 1.1 million Australians have diagnosed diabetes. Of these, over 300,000 have some degree of diabetic retinopathy and about 65,000 have progressed to sight-threatening eye disease.
    - The longer you have diabetes the greater the likelihood of sight threatening eye disease.
    - One in three people over the age of 50 with diabetes has diabetic retinopathy.
    - The expected growth in the number of Australians living with diabetes will lead to a corresponding rise in diabetic eye disease and vision loss – numbers are expected to at least double between 2004 and 2024.
    - Almost everyone with type 1 diabetes and more than 60% of those with type 2 diabetes will develop some form of diabetic eye disease within 20 years of

diagnosis. Significantly, many people with diabetes are diagnosed late, by which time retinopathy may already be present.

- Almost all cases of vision loss from diabetic retinopathy can be prevented with regular eye tests, careful management of diabetes, the use of certain medications such as fenofibrate, and in some cases, treatment with anti-VEGF agents and/or laser and/or steroids.

Socio-economic costs of vision loss in Australia

- **There is a high cost of vision loss from macular disease to government. Even a modest reduction in the proportion of people who progress to vision loss will generate significant savings.**
- Visual impairment prevents healthy and independent ageing and is associated with[6]:
  - Risk of falls increased by two times.
  - Risk of depression increased by three times.
  - Risk of hip fracture increased by four to eight times.
  - Admission to nursing home three years earlier.
  - Social independence decreased by two times.
- Vision loss from macular degeneration:
  - In 2010, the total cost of vision loss, including direct and indirect costs, associated with macular degeneration was estimated at $5.15 billion, of which the financial cost was $748.4 million ($6,982 per person).[5]
  - The socio-economic impacts of macular degeneration include:
    - Lower employment rates.
    - Higher use of services.
    - Social isolation.
    - Emotional distress.
    - An earlier need for nursing home care.
- Vision loss from diabetic retinopathy:
  - As diabetic retinopathy frequently affects people of working age, the social and economic impact of vision loss can be dramatic and long-lasting. People with vision loss from diabetic retinopathy experience higher rates of unemployment and underemployment, reduced safety in the workplace and home, increased rates of depression and greater dependence on carers due to an inability to drive, mobilise independently and undertake common activities. It is clear that even modest reductions in the proportion of people who progress to vision loss will generate significant savings to government.[7]
  - Vision loss from diabetic retinopathy is nearly always preventable, however thousands of Australians continue to lose vision from the disease. Awareness of the risk of blindness from diabetes is low, and compliance to recommended

testing regimens, risk reduction strategies and treatment protocols remains unacceptably poor.[7]

- Vision loss in patients with diabetes also directly interferes with essential tasks to manage diabetes such as insulin administration, glucose monitoring, and exercise, making diabetes progression and other complications more likely.[8]

References

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