# *AUSTRALIAN BLINDNESS FORUM*

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## Submission to the Productivity Commission Inquiry into Caring for Older Australians

Reform of the aged care system is essential to meet the challenges created by the ageing of the Australian population. The increased need for services, generated by the highest number of aged people ever to exist in Australia, is anticipated to be accompanied by funding restrictions from a reduced taxation base, a skills drain from structural waves of retirements, and a limited replacement workforce who have more opportunities than ever before due to low unemployment. Older people with disabilities are already being failed by the present system. They fall through the many gaps created by the poor integration of the healthcare, aged and disability systems. Their rights to dignity and inclusion are diminished by the continual erosion of the funding dollar and a sustained lack of investment in infrastructure. Their value to society and potential to still contribute is ignored by legislation and overlooked by policy. Yet, as the incidence of disabling conditions increases exponentially with every year of life past the age of 65, they are one of the fastest growing sectors of society.

The pervasive myth that blindness or vision impairment is part of the 'natural' process of ageing is used as a false justification for continued neglect of the needs of older people with blindness or vision impairment. While the incidence of vision impairment does increase with age (mostly due to cumulative factors of exposure and poorly managed chronic illness) it must be recognized that age alone is not the cause of blindness or vision impairment. This myth also ignores the significant positive impacts which can be achieved by investing in appropriate assessment, treatment and low vision rehabilitation for older people. Investment which is more than repaid by improving health and wellbeing outcomes; primarily through the reduction of falls risk and lowering the incidence of depression. Similarly, people who have experienced lifelong blindness or vision impairment are not well-supported by the current aged care system. Ideally, disability and aged care should be part of a seamless system. When a client with a sensory disability turns 65 they should still receive the disability supports according to their need regardless of whether the funding source is a state/territory or the Commonwealth. The Australian Blindness Forum welcomes the opportunity to provide this submission to the Productivity Commission Inquiry into Caring for Older Australians to demonstrate the need for a blindness or vision impairment strategy to be integral to all parts of a future system to enable appropriate care for older Australians.

## Blindness and Vision Impairment in Australia

The terms blindness refers to someone who may be totally blind (i.e. without any perception of light) of someone who is legally blind. Legal blindness means that someone cannot see at 6 metres what a person with normal vision can see at 60 metres, and/or that they have a visual field which is less than $10^{o}$ (compared to a normal visual field of around 100-135 $^{o}$). Similarly, vision impairment does not mean all people who wear glasses. It means that a person cannot meet the legal vision requirements to be able to drive a motor vehicle, even when using glasses or other vision aids.

Access Economics[1] estimates that in 2009 over 575,000 Australians aged over 40 had vision loss (and around 70% of these are aged 70+). The report also estimates that approximately 66,500 people of the above group have blindness. The top five causes of blindness are: macular degeneration, glaucoma, cataract, diabetic/retinal disease and refractive error. A quarter of all visual impairment is preventable. Risk of vision impairment is significantly increased for people who have diabetes, people who smoke, and people with a family history of eye disease. Excessive sunlight exposure is also a major risk factor for acquired vision loss.

There is evidence that there are higher rates of blindness and vision impairment in Aboriginal and Torres Strait Islander people, especially due to diseases of the eye and adnexa, cataracts and the higher incidence of diabetes[2]. Interestingly, a higher incidence of vision impairment is reported in non-remote areas[3]; however, this may be due to factors such as difficulty in accessing treatment and lack of awareness about treatment options rather than an indicator of better eye health in rural and remote regions[4].

As noted above, the prevalence of blindness and vision impairment does increase with age, even though it is not an inevitable outcome of ageing. Increased incidence is mostly due to the cumulative effects of exposure to risk factors, such as sunlight or smoking, and the long-term impact of other health conditions (including obesity and high cholesterol). Based on current incidence rates, by the time a person is aged 60-69 they have a 1 in 20 chance of a level of vision impairment which prevents them holding a driving license. By the time the person is aged 90, the chance of having vision impairment increases to 2 in 5. Accordingly, 3 out of 5 people at age 90 will have a 'natural' level of vision appropriate to their age, and - while they may need glasses - they will not have

[1] Access Economics (2010) *Clear focus: The economic impact of vision loss in Australia in 2009*. Canberra: Access Economics for Vision 2020 Australia.
[2] Pink, B., Allbon, P. (2008) *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. Canberra: Australian Bureau of Statistics and Australian Institute on Health and Welfare.
[3] ibid (2)
[4] Vision 2020 (2008) *Eyes on the future: Case studies*. London: International Agency for the Prevention of Blindness

blindness or vision impairment. However, the overall ageing of the population means that specialist services for people with blindness or vision impairment will become even more essential to ensure that appropriate support is available for the increasing number of people with blindness or vision impairment. Specialist services offer proven and cost-effective ways to maximize independence in living, reduce demand for costly high-care services and improve overall social inclusion and quality of life or people with blindness or vision impairment.

It is important to recognize that there are two distinct sub-groups when looking at ageing issues for people with disability:

1. People with blindness or vision impairment acquired earlier in life, who are now ageing

2. People who acquire their vision impairment or blindness on or after the age of 65

While there are many areas of common ground between the two groups, there are also inherent differences which may require alternative responses. For example, people from the long-term disability group may face the future with greater trepidation due to the cumulative stresses and additional barriers experienced by people with impairment. This stress is often combined with worry about insufficient resources, from reduced economic participation across the lifespan, to ensure a comfortable retirement. Many people with disability also express trepidation about how the ageing process will further impact upon their quality of life, and whether future supports will be available to meet their needs.

People who are over 70 currently make up the largest proportion of all people with blindness and vision impairment (currently around 70%) and this cohort will continue to grow with the ageing of the Australian population. There is, therefore, fundamental need to better integrate the work of specialist disability services with aged care services to ensure a more efficient and efficacious response to the increasing numbers of aged people with blindness or vision impairment.

## Impact of Blindness and Vision Impairment

Vision impairment alone should not have any other inherent negative impact upon general health and wellbeing. Yet, significant negative impacts are often experienced by many people with blindness and vision impairment due to their impairment being overlooked, diminished and under-supported. Longitudinal Australian research indicates that dependency in instrumental activities of daily living, (such as being able to shop, garden/do minor home maintenance, prepare

meals and do housework on one's own) increases the likelihood of entry into residential care by 70% [5].

Rehabilitation support available through specialist blindness services helps to build independent living skills, assisting people of all ages to remain living in their own homes. Older people with blindness or vision impairment often experience a higher level of risk to their physical health, especially for due to the impact of falls and fractures[6]. Dual sensory disability (vision impairment combined with a hearing impairment) greatly increases the risk of falls due to the loss of compensatory information relating to posture, balance and environment[7]. People aged 65+ make up 97% of the population with dual sensory impairment. Orientation and mobility training provided by specialist blindness services can significantly reduce falls risk.

Mental health is a significant, and highly preventable, issue for many people with blindness and vision impairment. It is mostly due to the prolonged struggle for inclusion and the high levels of social isolation experienced across the lifespan[8]. International studies have found that people with vision impairment experience a higher risk of depression (between 2 to 5 times higher) [9] and between 25-30% of all older people with vision impairment demonstrate some evidence of depressive symptoms[10].

## Barriers to Care and Inclusion

- **Assessment and Early Intervention**

Loss of vision can be easily overlooked by aged persons, by their family/carers, or by treating health professionals[11]. It can be hard to notice a gradual loss of vision; or it is mistakenly perceived as 'normal' ageing. Also, people who have a gradual loss of vision can often cover up the extent of their condition by compensation and avoidance strategies. Australian research indicates that failure of these strategies inevitably leads to communication breakdowns, causing the person with disabilities to start withdrawing from socialization and

[5] Kendig, H., Browning, C., Pedlow, R., Wells, Y., Thomas, S. (2010) Health, social and lifestyle factors in entry to residential aged care: an Australian longitudinal analysis. *Age and ageing*, 39, pp342–349.
[6] Kulmala, J. et al. (2009) Poor vision accompanied with other sensory impairments as a predictor of falls in older women. *Age and Ageing*, 38, pp162-167
[7] Horowitz, A. (2003) Depression and vision and hearing impairments in later life. *Generations*, Spring, 27, 1, pp32-38
[8] Iwasaki, Y., Mactavish, J. (2005) Ubiquitous yet unique: Perspectives of people with disability on stress. *Rehabilitation Counselling Bulletin*, Summer, 48, 4, pp194-208
[9] Horowitz, A. (2003) Depression and vision and hearing impairments in later life. *Generations*, Spring, 27, 1 pp32-38
[10] Lidoff, L. (2003) Public policy and age-related sensory loss. *Generations*, Spring, 27, 1, pp78-82
[11] Lidoff, L. (2003) Public policy and age-related sensory loss. *Generations*, Spring, 27, 1, pp78-82

interactions with the people around them[12]. People who have experienced vision impairment commonly describe impacts such as loss of self-confidence, frustration with communication and mobility difficulties, and increased anxiety or lethargy. All of which quickly leads to a pattern of decreased socialization[13]. The impact of dual sensory loss is particularly critical. Loss of vision accompanied by a decline in hearing ability (dual sensory disability) can have a highly negative impact upon communication and psychosocial health[14].

Whether in the community or in residential aged care, all older people will potentially benefit from improved access to vision assessment services. The senior health assessment, conducted by GPs, should include vision assessment as a mandatory rather than optional requirement. Mandatory assessment will improve timely referral to optic clinical and rehabilitation services. Access to low vision clinics enables simple, low cost strategies to be quickly introduced to support remaining vision, prevent diminishment of quality of life and enable social connections to be maintained. Early referral to rehabilitation services can assist people waiting for corrective surgery to maintain optimal independence and functional capacity.

International studies reveal that there are comparatively low utilization rates for existing rehabilitation services, especially orientation and mobility support services, which can have a profound impact in improving independence and reducing falls[15]. This research finding is reflected in the current experience of major blindness and vision impairment service providers in Australia. People with age-acquired vision impairment are less likely to identify with the blind community and are unlikely to self-refer to blindness services.

A National Vision Loss Rehabilitation Services Plan is required to complement the existing National Eye Health Plan. A national plan will improve the rehabilitation of all people with vision loss and ensure a continuum of care between health and rehabilitation sectors. Older people with vision loss need timely and sufficient access to rehabilitation support and appropriate technology/aids. This access enables greater independence, increases mobility, improves outcomes for health and wellbeing, and reduces long-term healthcare costs.

- **Social Isolation**

Social isolation and enduring poverty are both recognized factors in contributing to depression. Accessible socialization opportunities can be vital for reducing

[12] Heine, C., Browning, C. (2004) The communication and psychosocial perceptions of older adults with sensory loss: A qualitative study. *Ageing and Society*, 24, pp113-130.
[13] ibid.
[14] ibid..
[15] Berry, P. Kelly-Bock, M., Reid, C. (2008) Confident living program for senior adults experiencing vision and hearing loss. *Care Management Journals*, 9, 1, pp31-35

depressive symptoms in older people with blindness or vision impairment. Older people with blindness or vision impairment may need support to learn successful communication strategies to enable their participation in recreation and leisure activities. Failure to appropriately support people with sensory impairment makes it impossible for them to maintain adequate levels of social inclusion and economic participation. For example, many people with blindness or vision impairment experience much greater levels of fatigue. This is due to the sheer effort it takes to communicate, orientate, obtain the information needed to participate, and to complete everyday tasks.

Legal blindness prohibits access to a driving license, leaving many older people dependent upon public transport, family/friends or community transport services. High demand and low availability of community transport services can make support for social excursions a low priority. Yet, access to peer groups is critical for supporting the positive psycho-social adjustment to the onset of blindness or vision impairment in later life[16]. People with blindness or vision impairment who are residents in aged care facilities are also ineligible for HACC funding to access external specialist support activities, such as low vision social/recreation groups offered by disability service providers. The provision of generic recreation options is seen as sufficient, even if these options are inaccessible to the person with blindness or vision impairment.

Access to required aids and equipment is essential to keep older people connected and participating, especially to enable continued access to information. In general, aids and equipment are under-utilized by older people with late onset vision impairment. Access to information is critical at every stage of the lifespan for all people with blindness or vision impairment. Older people may need some support to start using accessible technology and equipment, such as accessible mobile phones, text reading software (i.e. JAWS, Dolphin or Zoomtext), electronic magnifiers or talking GPS systems. Yet introduction of these aids can have immediate positive impacts in enabling participation.

- **Costs of Disability**

Typically, many people with long-term blindness or vision impairment experience additional financial stress, from the costs imposed by the needs of their disability throughout the lifespan and/or from reduced workforce participation.

The majority of older people who are blind or vision impaired have a priority need for access to equipment that enables them to offset the effects of their disability and live independently in the community. Cost of accessible technology is a significant barrier for all people with blindness and vision impairment. Older people who are dependent upon government support often find that they have no

[16] Berry, P. Kelly-Bock, M., Reid, C. (2008) Confident living program for senior adults experiencing vision and hearing loss. *Care Management Journals*, 9, 1, pp31-35

possible means for replacing a much-used piece of technology once they are no longer in the workforce due to ageing, and the means for purchasing new technology such as an accessible mobile phone may be completely out of reach. As mentioned previously, people who are ageing can often face additional barriers with obtaining and using accessible technology solutions and cost is a significant part of this problem.

There are additional 'hidden costs' associated with blindness or vision impairment. Typically, a person with blindness or vision impairment needs to live close to public transport, shops and other community amenities. Such proximity incurs higher housing costs when the home is purchased or privately rented. Also, housing choice is further limited by needs to find an accessible residence. Ongoing costs include regular requirements to pay for home maintenance services, as many people with blindness or vision impairment cannot do painting, climb ladders to change light-bulbs, use power tools or mow a lawn. As a person with blindness or vision impairment cannot drive, there are significant costs associated with obtaining suitable and accessible transport. Similarly, everyday consumables may also be more expensive. People with blindness or vision impairment may need to purchase from smaller, local shops where they can navigate the environment and obtain assistance more easily. For those people who do use the larger shopping centres, they miss out on selecting special or discounted products as price information is all visually presented.

- **Rural and Remote Access**

There is a clear need for improved services and supports for people with blindness and vision impairment in rural and remote areas, especially for people whose needs are changing as they age. Significant barriers are experienced due to lower levels of general health infrastructure and due to the restricted availability of specialist support services.

Key issues include:

- lack of information about treatment options;
- limited access to aids and accessible technology;
- lack of flexibility in funding to support transport to places where treatment and support (e.g. to visit a low vision centre); and
- lack of training to enable general healthcare/disability support staff to better identify early vision loss and refer for assessment and early intervention.

- **Hostel Accommodation**

There is concern in the disability sector that some short-stay hostels are becoming de-facto aged care facilities, as many older people with blindness or vision impairment are finding it difficult to obtain a place in a suitable residential

aged care facility. Such hostels are not subject to the accreditation process required by aged care facilities, and there is concern that consumers with blindness or vision impairment may be placed at risk by being in environments that can provide the level of care which is suitable for their needs.

## Improving the Aged Care System

- **Universal Design**

There is a need for inclusive design at all levels of society - from technology to recreation - and most especially in physical structures. Improved access is needed for a greater number of private buildings and all public infrastructures to promote way-finding for all older people with sensory impairment. The recent adoption of the Premises Standards is an important first step in improving accessibility for people with blindness or vision impairment. New aged care facilities and services need to be designed to the highest standards of accessibility for people with any kind of sensory impairment. Consideration also needs to be given to making requirements under accreditation or providing incentives within funding structures to assist residential aged care providers to retro-fit their facilities to meet a higher standard of accessibility for people with sensory impairment.

Aesthetic design features are particularly a problem, such as ‘stepping stone’ pathways, water features with no barriers or tactile indicators, uniform colour schemes or decorative lighting designs. Each of these can cause difficulty in navigation for a person with low vision and can greatly increase their risk of falls. Aesthetic features are particularly a problem within the ‘resort-lifestyle’ section of the aged care market. People with blindness or vision impairment living in these facilities often end up confined to their rooms, as they are unable to navigate the wider environment without direct assistance from staff or visitors. One service provider participating in the consultation for this paper recounted a case history of a couple aged in 50s, both with blindness, who were looking for an aged care facility in one of the largest cities in Australia. Only one facility out of the many contacted was feasible, due to the inaccessible design factors in all other facilities.

Such difficulty is more widely reflected across the community, as more people with blindness or vision impairment have reported difficulty in finding suitable aged care placements. Many report that aged care homes say they are ‘not set-up for someone who is blind’. Service providers indicated that they have provided additional in-home support to people with blindness or vision impairment who have been unable to obtain a place in residential aged care. However, this is not a consistent problem across the nation as services in other states report that suitable placements are not difficult to find.

Amenities within the aged care facility also need to be accessible. All people with blindness or vision impairment need an environment which maximizes opportunities for independence. Yet, increasingly, electrical appliances, such as microwaves, radios, telephones and televisions use visual displays (e.g. menu select using arrows on a remote). This means that many items in communal areas of aged care facilities are effectively unusable. Social and recreational activities offered are also not always accessible to people with blindness or vision impairment. These barriers create segregation. Staff members in facilities need improved awareness that residents may be staying in their room because of accessibility barriers, rather than because of personal choice, and may be reluctant to disclose their inability to participate.

Accreditation process for aged care focuses on generic structural issues such as number of staff, buildings and facilities, but may fail to adequately consider the needs of each specific resident group within the facility, especially in regard to accessibility. Accessibility audits need to be part of the accreditation process. Given the generally high level of disability experienced by residents of aged care facilities there is also substantial merit is aligning the accreditation process to the principles of the UN Convention of the Rights of Persons with Disabilities.

- **Integrating Aged and Disability Services**

Aged care packages for community support need increased capacity and flexibility to adequately address the double level of need created by ageing and disability. Older people with disability are constantly fighting perceptions that they are 'double-dipping' when trying to access supports or when attempting to increase the flexibility of services to enable them to better meet their needs. Improved flexibility in funding guidelines is essential for improving the responsiveness of community care packages. Funding guidelines need to be improved to enable aged care services to access specialist services as required for a person with blindness or vision impairment, and this access needs to be enabled across HACC funding boundaries where it cannot be provided within that region.

There is also the issue that blindness or vision impairment alone is not adequately recognized as a priority need for HACC services. The aim of the HACC Program is to support "people to be more independent at home and in the community, and reduce the potential or inappropriate need for admission to a residential care facility"[17]. Older people with blindness or vision impairment certainly fit within these criteria, and do need regular support with domestic services, home maintenance and community transport. However, the fact that HACC funding specifically excludes "rehabilitative services directed solely

[17] http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm

towards increasing a person's level of independent functioning"[18] ignores the fact that access to orientation and mobility and independent living services actually achieves the outcome of delaying entry to residential care.

There is significant scope for improved integration between the aged care and disability sectors. There may be a case for enabling aged-care providers to 'buy-in' specialist disability support services as required. There is a need for improved awareness of the advice and support that can be offered by specialist disability organizations, especially for services which are currently enabled by fundraising or other funding sources. For example, one organization reported assisting a residential facility with support for a new resident who was moving in with their guide dog. Alternatively, specialist disability services could directly access aged care funding to provide services which enable increased capacity to support people with younger onset blindness or vision impairment to age in place. From the perspective of the person with a disability - ageing and disability services should be seamless, consistent and suitable to their needs.

- **Improving Community Care**

People with blindness or vision impairment can struggle to get timely or sufficient access to needed services, especially domestic support and community transport. Yet, access to support services to help with daily living activities such as shopping, banking, housework and gardening can significantly improve outcomes for people with blindness or vision impairment and delay premature entry to residential aged care. Inflexibility in funding guidelines and arbitrary sector or scope boundaries also disadvantage people with blindness or vision impairment. For example, community transport in many areas is only available for travel within the municipality because the scheme is mostly or entirely funded by the local council. Yet, people with blindness or vision impairment may need to travel outside of their local area to access the specialist support services which are more suitable to their needs than the generic aged care services available locally.

There is an identified need for all HACC information and funding information to be supplied in accessible formats (both the low cost options of large print or audio and in Braille for those people who cannot access other options, such as people with deafblindness). Older people with blindness or vision impairment can experience difficulties in accessing information at a sufficient level to inform their choices. Service providers also report cases where older people with blindness or vision impairment have accepted services without being properly informed of the costs involved, and have been very distressed when they receive a bill for those services. Other people with blindness or vision impairment can be hesitant to agree to getting services in (even when those services are free)

[18] http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-eligibility-services-outside-scope.htm

because they fear potential costs involved. Upfront, simple disclosure of costs and options available would be beneficial to all clients of HACC services.

There is already huge variance across HACC schemes at the local level, especially in home care services. Nationally, there are inequities created by the variation in the types of services offered, the eligibility criteria, and the amount of user contribution expected. However, most of the difference in service level is due to the additional contributions made by local governments and the variability of service providers and the products they can deliver within each HACC region. It would be a mistake to reduce the scheme to a 'lowest common denominator' model, but equally some work should be undertaken to identify ways to create improved national consistency and equity. The level of support which aged people receive to remain in their homes should be determined by their needs rather than their postcode. It would also be beneficial to align the scheme with the principles of the UN Convention of the Rights of Persons with Disabilities given that the majority of older people will experience some level of disability in later life.

- **Improving Residential Aged Care**

Historically, many organizations previously provided blind-only or deaf-only aged care facilities, but these are now the exception rather than the norm in aged care services. Closure of single-disability facilities is due to shifts in philosophy about inclusion as well as changes in market demand and general cost feasibility issues. However, people with blindness or vision impairment need access to choices. Whether they would like to move to a specialized facility (for blindness, for cultural reasons or for religious orientation) or stay at a generic aged care facility within their local community, they need an environment and organizational culture which supports them to maintain an optimum level of independence within that facility.

People experiencing younger onset blindness or vision impairment may not have the same opportunities to acquire wealth across their lifetime, due to barriers preventing workforce participation. The high entry cost of many aged care facilities indirectly discriminates against large sections of the blindness or vision impairment community due to their inability to draw on substantial assets. It is also essential that ongoing costs based on a percentage of a pension incorporate an equity assessment regarding the additional costs created by disability

People with blindness or vision impairment who are residents in aged care facilities are ineligible for HACC funding to access external specialist support activities, such as the low vision social/recreation groups offered by disability service providers. The provision of generic recreation options is seen as sufficient, even if these options are inaccessible to the person with blindness or vision impairment.

There also needs to be improved recognition that some people with blindness or vision impairment may wish to have contact with peers who also have similar sensory disability. People with younger onset blindness or vision impairment may be part of a close-knit community, especially people with deafblindness who are ageing (due to the relatively low incidence in younger-onset cohorts). It is important that strategies are enabled within the aged care environment to keep people in touch with the communities of their choice.

Residential aged care facilities need proactive strategies to ensure that residents' civic rights are supported rather than not eroded. Civic rights include a say in how their facility operates as well as involvement in their local community. Strategies need to be developed to support those people who wish to participate. This is especially important for ongoing participation in elections, as options to be removed from the electoral rolls should only be used if the voter is incapable of understanding the electoral process. Regretfully, older people with sensory impairment may be more at risk of having this decision made on their behalf rather than being appropriately supported to continue to participate.

There is a vital need for all financial information and contracts information relating to residential aged care to be supplied in accessible formats of the client's choice. In order to make an informed choice, people with blindness or vision impairment need accessible information about alternative options. Facilities also need to be aware that information about activities and events should also be accessible (both the low cost options of large print or audio and in Braille for those people who cannot access other options, such as people with deafblindness). Consideration should also be given to low literacy levels and additional communication barriers such as English as a second language. Residential facilities should have access to supports for communicating with people with complex needs, and this should include the ability to bring in specialist translators or other supports as required.

- **Interfaces with Health and Allied Care**

There is an identified need for improved integration of the aged care system with health and allied care sectors. People with blindness or vision impairment can face consistent barriers and experience poor outcomes because of lack of communication, rigid and bureaucratic processes, and systemic failure to understand and appropriately respond to individual needs. The entire system needs to learn from improvements in transition support and interfaces between different clinical/disability/residential care domains. For example, there is excellent work being done in NSW Statewide Ophthalmology Service Agency for Clinical Innovation to improve clinical handover practices, both within services and between services for people with blindness or vision impairment. There

would be significant benefits if such innovations were supported to improve services on a national level.

Availability to allied services is also highly limited within the aged care system. Not all older people have access to private health insurance, and those people exist on pensions and part-pensions can face significant financial disadvantage as general costs of living continue to increase. Yet there is a need for access to appropriate allied care such as psychology, physiotherapy or occupational therapy to improve outcomes and prevent the development of additional chronic conditions. For example, adjustment to the process of losing vision is a highly individualized response, yet very few people in the aged care system are offered a choice to access psychology or counseling services. Given that research indicates that the most common outcome of unsupported sensory loss is social isolation and higher risk of depression, it makes good economic sense to support improved access for older people with blindness or vision impairment.

- **Workforce and Training**

Greater professional education and awareness-raising is needed for the entire aged care sector, to enable improved early identification and faster referral pathways for older people who are experiencing vision impairment. The perception that sensory loss is a 'normal' part of ageing does not encourage staff to seek assessment or support for residents. Basic skill sets for supporting people with blindness or vision impairment need to be improved across the entire sector. Poor practices involve procedures which do not let a person with blindness know what is happening to them and who is there with them. Good practices use appropriate communication and sensible strategies, such as placing medication in a person's hand, saying what it is and how many pills are there to enable the dose to be taken safely and with dignity.

High workloads within aged care services in general mean that there is currently little time to attend to issues such as protection of dignity and improved wellbeing. Yet, investment in supporting skills retention and enabling greater independence (whether within the community or within a facility) helps to reduce the overall workload by reducing the amount of one-to-one support demanded of staff members.

Communication support is critical for improving outcomes within aged care services. Regretfully, it is not uncommon for an older person to be assumed to have dementia or other cognitive decline when they are actually struggling with communication because they are missing visual cues or cannot hear. These difficulties cause huge frustrations for the person with blindness or vision impairment, leading to increasing isolation and higher risk of developing depression.

The majority of the aged care workforce needs access to additional training opportunities and support within the workplace, including improved access to ongoing professional education. Training programs offered through both VET and tertiary systems need to include stronger components on sensory awareness. Improved focus on disability also needs to be included in all related qualifications where people may go on to seek employment in the disability, aged care or healthcare sectors such as social work, psychology and allied health workers.

Increasing 'casualization' of positions and high burnout levels in the aged care workforce has resulted in a recognized turnover problem across the sector. Work is not well paid or 'glamorous' so the sector struggles to attract and keep good staff. High turnover affects the quality of support for people with blindness or vision impairment, as information is lost about client needs. Additionally, cost/profit issues can mean that there may only be 1 or 2 skilled or trained people among many low skilled or unqualified workers. Reduced proportions of skilled to unskilled workers and high workloads means that opportunities to support and teach are often not realized. Staff mentoring programs and an expanded program of skills-enhancement linked to accreditation and/or increased funding allocations would provide incentive for employers to invest in training and retaining skilled staff. Aged care services and residential facilities consistently report to service providers that they are unable to spare staff (even to attend free sensory awareness and support training sessions) due to the high workloads and insufficient resources to pay replacement staff.

Volunteers also need to be well trained and supported. The use of volunteers in the aged care sector needs enough regulation to protect and support their involvement, but not so much to create a regulatory burden which inhibits participation. Pro-active volunteer support programs encourage long term commitment, but many providers may need support on developing strategies around recruiting, valuing and retaining their volunteers. However, it is essential that increased participation of volunteers in aged care should not replace paid positions. Volunteers should be involved in activities which support social inclusion, recreation and leisure for older people rather than providing direct care services.

- **Improving Complaints and Feedback Processes**

Complaints, consultation and feedback processes within the aged care system need to be accessible to people with blindness or vision impairment. These processes also need to be independent and impartial, and offer options for anonymous or confidential feedback to be provided. There also needs to be improved awareness of the external supports available to assist people with entry to facilities, as well as consumer support while within a facility, e.g. for legal advice or consumer information.

Service providers report that many people in facilities approaching specialist organizations for support want advice rather than advocacy. Access to advocacy services need to be improved overall, as consumers may fear negative impacts from making a complaint, such as reduced services. Consumers with blindness or vision impairment receiving in-home services or who are resident within an aged care facility are more likely to feel vulnerable when using complaints systems and be in need of additional support.

- **Future Planning and Transition Support**

People with age-acquired blindness or vision impairment often report strong levels of concern about their ability to stay in their own home if/when their partner dies. This may reflect a general lack of information about options and supports available, but may also indicate a need for more proactive transition and future planning support. The current disability system is predominantly crisis-responsive, with little funding available to assist with future planning or transition support. Lack of planning and inefficient support can cause anxiety, waste scarce resources, and may create negative outcomes through uninformed choices. People with blindness and vision impairment need to be actively consulted and included at every level of decision-making about their own future care. They also need to be supported by a service environment which is respectful of, and responsive to, their choices.

A significant issue facing people with blindness or vision impairment is the barrier preventing the transfer of equipment when they transition between services. When moving from state/territory-funded disability support to Commonwealth-funded aged care, it is inefficient, unproductive and inequitable to demand that a person return customized and familiar equipment, and then go on a waiting list for new equipment (or simply have to manage without it). There is positive potential in introducing a process which enables the transfer of small assets between services or in granting free life-time lease directly to the person with blindness or vision impairment. However, pathways for responsibility for maintenance and repair of the item need to be clearly defined as this can incur ongoing costs across the lifetime of the asset.

Retirement from the workforce should not mean that a person with blindness faces a loss of support services or a restriction in opportunities for social participation. This is relevant both for a person in the open workforce or for someone employed at an Australian Disability Enterprise (ADE). Yet, restrictions in accessing many state-funded support services are preventing people with blindness and vision impairment who are currently employed in Commonwealth-funded ADEs from achieving retirement at a time of their own choosing[19].

[19] Australian Institute of Health and Welfare (2000) *Disability and ageing: Australian population patterns and implications*. Canberra: AIHW Cat no. DIS 19

People with disability who are ageing also need greater support for dealing with issues associated with ageing, including bodily deterioration and preparation for death (of self and/or of carers). Research indicates that these subjects are often neglected due to issues of personal discomfort for service workers and a lack of training about how to appropriately respond to such issues[20]. There needs to be better support for people with blindness and vision impairment to access information about how ageing may affect them, both in general and in relation to their specific disability.

Also, legal issues may create barriers to achieving sound future planning. Many people with younger onset blindness and vision impairment are dependent upon government support or on low incomes across their entire lifespan. They have limited access to legal and financial advice for ensuring their future security. Appropriate planning depends upon sound advice from qualified professionals who understand the special needs of disability. Greater awareness of such professionals and improved access to them would greatly assist many people with disability who are ageing to more effectively plan for their future.

## Improving Public Awareness

Achieving greater inclusion for people with blindness and vision impairment and enabling the development of a system which more effectively supports their needs as they age is dependent upon public awareness and support. The average person has little awareness of what it means to have sensory impairment, and may even have significant misunderstandings. Indeed, research into public perceptions indicates that the fear of going blind is only equalled by a fear of getting cancer.

Public education campaigns are needed to improve cross-community awareness and to encourage positive images of people with blindness and vision impairment. Positive campaigns will also encourage early identification of vision loss in older people, especially those who already have other disabilities. Early identification enables timely referral to supports and/or treatment options, significantly improving outcomes and reducing the long-term healthcare and social welfare costs incurred by preventable vision loss.

Greater public awareness is also still required regarding the use of assistance animals. Many people still discriminate against guide dog (and other service animals) access in public places, such as restaurants and taxis. In the wider

[20] Bowey Laura and McGlaughlin Alex (2005) Adults with a learning disability living with elderly carers talk about planning for the future: Aspirations and concerns *British Journal of Social Work*, 35, pp1377-1392; Dillenburger Karola and McKerr Lyn (2009) "40 years is an awful long time": Parents caring for adult sons and daughters with disabilities. *Behaviour and social issues*, 18 pp1-20.

community, improved understanding of protocols of not patting or feeding guide dogs will prevent these distracting actions and ensure the safety of the person with blindness or vision impairment. A person who is ageing who uses a guide dog may have less agility and a lower level of hearing to enable them to react if the dog is distracted. Regretfully, a number of severe injuries have been caused in Australia by people inadvertently distracting guide dogs, especially when they are working near stairs or in traffic.

Development of public awareness campaigns about blindness or vision impairment are essential for improving visual health, enabling improved access to services and achieving greater inclusion for people with blindness and vision impairment who are ageing and also for people with other disability who experience age-acquired sensory impairment.

## Sector Reform

The recently announced National Health and Hospitals Agreement transferred funding responsibility for specialist disability services delivered under the National Disability Agreement to the Commonwealth. Implementation of this reform will need to ensure that people with blindness and vision impairment do not experience any real term loss of services when transitioning between state/territory-funded and Commonwealth-funded services. Regardless of the funding source, 'ageing in place' needs to be a substantive principle underlying the delivery of all care and supports to people with blindness or vision impairment. The Commonwealth has core responsibility for legislation, policy, regulation, accreditation and quality control across the aged care system, but it also has responsibility to be more attuned to the needs of older people with a disability who are within that system.

The current Productivity Commission review into the development of a long-term disability support scheme will also need to consider many of the issues raised in regard to the needs of people with disability who are ageing. The Australian Blindness Forum supports the need for a National Disability Insurance Scheme to meet the needs of people with severe or profound disability. However, such a scheme is anticipated to be part of the solution to meet need, not the whole solution, as disability affects many more people than just those with a severe or profound impairment.

The introduction of any entitlement scheme would necessitate key considerations such as equity of service delivery for people in rural and regional areas, the level of interface with the health, aged care and charitable sectors, and consideration of overall funding streams. A wide vision for reform offers a unique chance to provide an integrated and seamless service which more efficiently meets the

current and changing needs of people with blindness or vision impairment throughout their lifespan.

The recommendations of the Henry Review into Australia's Taxation and Transfer System also offer a complementary way to move forward. Recognition of the increased need to support workforce engagement and improve the economic inclusion of people with blindness and vision impairment is welcomed by the Australian Blindness Forum. The right to education, the right to equitable access to information, the right to contribute and participate are all key issues for redressing the marginalisation of people with blindness and vision impairment. To put it simply, reducing wasteful or inefficient practices and redirecting investment to support people to achieve their potential makes good sense economically. The challenge for government and the sector is now to agree on the best pathways to achieve such a vision.

Forward pathways depend upon maps – which need to contain accurate data about the terrain ahead. There is a sector-identified need for improved data on blindness and vision impairment, especially in regard to patterns of access, geography of unmet need, demographic characteristics, and awareness of people with dual or multiple disabilities. Better data enables improved planning and efficient delivery of services where and when needed, reducing waste and improving outcomes for people with disability.

Sector reforms need to be integrated into a comprehensive system which better supports the needs of people with blindness or vision impairment, to ensure they can achieve an equitable quality of life and to eliminate the present gaps and inequities in both the disability and ageing service models.

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This submission has been prepared by the Australian Blindness Forum in consultation with its membership. The ABF would particularly like to acknowledge the participation of Blind Citizens Australia, Guide Dogs NSW/ACT, Macular Degeneration Foundation, the Royal Institute for Deaf and Blind Children, the Royal Society for the Blind in South Australia and Vision Australia to inform the preparation of this submission.

## About the Australian Blindness Forum

The Australian Blindness Forum was formed in 1992 and was registered as an Australian public company limited by guarantee in 2007. It is funded through the contributions of its members, which are the major Australian organisations providing services to people with blindness or vision impairment and the consumer organisations, Blind Citizens Australia and Blind Citizens WA.

Members of the Australian Blindness Forum are committed to assisting people who are blind or vision impaired to become and remain independent, valued and active members of the community. Services provided by members include - adaptive technology, advocacy, accommodation support, Braille training and support, computer training, community support programs, counselling, education and training, employment services, equipment, guide dogs, independent living training, information in alternative formats to print, library services, orientation and mobility, recreation services, support for low vision, systemic advocacy and design advice, and transport.

Further information on the Australian Blindness Forum may be found via the website at http://www.australianblindnessforum.org.au.