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Forward Thinking: Issues and Services for People with Blindness or Vision Impairment who are Ageing

Submission to the Inquiry into Planning Options and Services for People Ageing with a Disability, Senate Community Affairs References Committee

Campaigns around positive and active ageing promote social inclusion and aim to reduce social isolation experienced by older people. They encourage older people to lead independent lives by participating in community life, engaging in regular exercise and enjoying recreational activities. They also support ageing in place – encouraging older people to remain living in their own homes for as long as they choose or as long as is feasible. Such campaigns often fail to address the additional needs of people with a disability who already struggle to achieve independent living and participation. Indeed, the process of ageing often just adds another level of challenge for people with disability.

People may be born with blindness or vision impairment or they may acquire blindness or vision impairment during their lifetime. Independent living, mobility, participation and inclusion for people with blindness and vision impairment are all goals supported by the services and consumer groups who make up the membership of the Australian Blindness Forum. These goals are achievable for people with blindness and vision impairment; both throughout their lifetime and as they age. Accordingly, the Australian Blindness Forum welcomes the opportunity to provide this submission to the Senate Community Affairs References Committee for the Inquiry into Planning Options and Services for People Ageing with a Disability.

Blindness and Vision Impairment in Australia

Visual disability is most often described in terms of blindness and vision impairment. A person is legally blind when they cannot see at 6 metres what a person with normal vision can see at 60 metres, or they have a visual field which is less than 10^{o} (compared to a normal visual field of around 100^{o}). Vision impairment does not mean all people who wear glasses. A simple way to define vision impairment is to remember it as those people who cannot meet the legal

vision requirements to be able to drive a motor vehicle, even with the assistance of glasses or contact lenses.

In 2004, Access Economics[1] estimated that over 480,000 Australians had visual impairment in both eyes, with over 50,000 people having 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].

Prevalence of blindness and vision impairment does increase with age, mostly due to the cumulative effects of exposure to risk factors, such as sunlight, and the long-term impact of other health conditions (including obesity and high cholesterol). By the time a person is aged 60-69 they have a 1 in 20 chance of having vision impairment at a level high enough to mean a loss of their driving license. However, by the time they are aged 90 this will increase to a 2 in 5 chance of visual impairment. The overall ageing of the population means that by 2024 approximately another 800,000 people will be in need of services for visual impairment and more than 87,000 people will be blind[5].

The higher incidence of age-related blindness and vision impairment means that two groups of people must be considered when looking at ageing issues for people with disability, as defined by the terms of reference of the Inquiry:

1. People with blindness or vision impairment acquired before age 65, who are experiencing other issues because of the ageing process

[1] Access Economics (2004) *Clear insight: The economic impact and cost of vision loss in Australia*. Canberra: Access Economics for the Centre for Eye Research
[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
[5] Access Economics (2004) *Clear insight: The economic impact and cost of vision loss in Australia*. Canberra: Access Economics for the Centre for Eye Research

2. People with another type of disability acquired before age 65, who then experience age-acquired vision impairment or blindness on top of their existing impairments

People from each of these groups often face the future with greater trepidation than their non-disabled peers. This is due to the cumulative stresses and additional barriers they already face from their current level of impairment, often combined with worry about insufficient resources to ensure a comfortable retirement. Many people with disability express trepidation about how the ageing process will further impact upon their quality of life. They also have high levels of uncertainty about the availability of appropriate supports to adequately meet their needs.

People with age-acquired impairment make up the largest proportion of all people with blindness and vision impairment, and this proportion will continue to grow with the ageing of the Australian population. There will be a fundamental tension in balancing the funding of specialist disability services with generic aged care services.

- **Sufficient interfaces need to be created for people who are ageing and in need of specialist services, without absorbing all of the funding which will be required to meet the needs and invest in the capabilities of younger people with blindness and 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. It is also a significant factor in premature entry to residential care facilities[6]. Many of the negative outcomes of blindness and vision impairment are easily preventable through appropriate and timely access to assessment, support and rehabilitation services.

- **Rehabilitation services provided by specialist agencies are essential for all people who have blindness or vision impairment - no matter at what age the impairment occurs.**

Rehabilitation services provide training and equipment to maximize independence and assist people of all ages to remain living in their own homes. Orientation and mobility training provided by rehabilitation services greatly assists

[6] Australian Institute of Health and Welfare (2007) *Current and future demand for specialist disability services*. Canberra: AIHW

in reducing falls, with a resultant reduction in costly and debilitating hip fractures in particular. Low vision centres and social support services can provide aids and equipment to keep people connected and participating, reducing the isolation which too often leads to depression.

Loss of vision is often overlooked by people with disability, their family or carers, or by treating health professionals[7]. It can be hard to notice a gradual loss of vision; and it can often mistakenly be perceived as a 'normal' part of the ageing process. Also, people who have a gradual loss of vision can often cover up the extent or their vision loss through 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 interactions with the people around them[8].

- **Strategies are needed to improve awareness that vision loss may be experienced by people with disability who are ageing.**

People with multiple disabilities can also find that their vision loss is easily overlooked in the press of other issues. For example, care plans in residential facilities may not include regular opportunities for vision assessment, and community-based disability support workers may not be sufficiently trained to recognize signs of vision loss. Also, people with other communication or cognitive impairments can struggle to let others know that they are experiencing vision loss. The impact of dual sensory loss is particularly critical. Loss of vision accompanied by a decline in hearing ability can have a highly negative impact upon communication and psychosocial health[9].

Many people with disability who live in the community also face barriers when accessing primary healthcare services, such as transport, cost and time. Multiple health issues and/or communication difficulties can also mean that there is no time for discussing 'extra' issues when with a treating healthcare professional, which can prevent early identification and treatment.

- **Long consultation times should be provided for people with blindness and vision impairment when needed and at no extra charge.**

Further, the vision assessment currently provided as part of the senior health assessment, conducted by GPs, needs to be a mandatory requirement rather than an optional extra. However, basic assessment should not be considered as a substitute for a comprehensive vision test and should only be used to identify a need for referral to both clinical services, such as optometry and ophthalmology,

[7] Lidoff, L. (2003) Public policy and age-related sensory loss. *Generations*, Spring, 27, 1, pp78-82
[8] 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.
[9] 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.

and rehabilitation services. Early referral to rehabilitation services can also assist those that may be waiting for corrective surgery in terms of independence, functional capacity, mental health and general coping skills. Referral to rehabilitation services also needs to be considered as part of the triage process as opposed to a last step when all medical intervention has been exhausted.

- **Vision assessment and early referral to vision loss rehabilitation services need to be a core part of healthcare plans for all people who are ageing.**

It is not well recognized that many simple, low or no-cost strategies can be quickly introduced to support remaining vision, prevent diminishment of quality of life and enable social connection to be maintained. Low vision services, currently available in all states and territories, have a range of training, aids and equipment which can have an immediate beneficial impact by helping to restore lost activities for people with vision impairment. For example, low cost portable magnifiers can give older people back the ability to read their own mail or to identify the items they need from the pantry.

- **Low vision centres offer a range of supports which can significantly improve quality of life for all older people with vision loss.**

Social isolation and enduring poverty are both recognized factors in contributing to depression. 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[10]. International studies have found that people with vision impairment experience at least 2 to 5 times the risk of depression than other people, even when factors of age, gender, culture and co-morbid conditions are controlled for[11]. These studies have also found that between 25-30% of all older people with vision impairment have depressive symptoms[12].

- **Policies promoting early identification and rehabilitation services to people with vision loss are needed to improve long term outcomes and avoid preventable negative impacts on mental health.**

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[13]. Dual sensory disability (vision impairment combined with a hearing

[10] Iwasaki, Y., Mactavish, J. (2005) Ubiquitous yet unique: Perspectives of people with disability on stress. *Rehabilitation Counselling Bulletin*, Summer, 48, 4, pp194-208
[11] Horowitz, A. (2003) Depression and vision and hearing impairments in later life. *Generations*, Spring, 27, 1 pp32-38
[12] Lidoff, L. (2003) Public policy and age-related sensory loss. *Generations*, Spring, 27, 1, pp78-82
[13] 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

impairment) greatly increases the risk of falls due to the loss of compensatory information relating to posture, balance and environment[14]. People aged 65+ make up 97% of the population with dual sensory impairment. Fall risks can be minimized and subsequent healthcare costs greatly reduced by the introduction of adequate fall prevention strategies. Of particular note is the cost of hip fractures, which has high medical and social costs, and often leads to premature entry to residential aged care. Hip fractures are also a significant contributor to early morbidity in older persons. Key components of such a strategy needs to include timely assessment of vision impairment, referral to vision rehabilitation services, and guaranteed access to the aids and equipment needed to maintain safety and quality of life.

- **Early identification and vision rehabilitation services are a key component in falls prevention programs aimed at reducing premature entry of people with disability into residential aged care.**

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.

Rehabilitation and low vision services are already available to some degree in every state and territory in Australia, but improved assessment and referral pathways are needed to best utilize these services and support their expansion to a level to meet the anticipated need from the ageing population. Appropriate funding, strategies and services are needed to address growing rate of blindness and vision impairment from the ageing of the population.

A National Vision Loss Rehabilitation Services Plan is also required to complement the existing National Eye Health Plan. A national plan will improve the rehabilitation of people with vision loss and ensure a continuum of care between health and rehabilitation sectors. No matter when impairment occurs, timely and sufficient access to rehabilitation support and appropriate technology/aids is proven to enable greater independence, to increase mobility and to reduce negative impacts on health and wellbeing – reducing overall long-term healthcare costs.

[14] Horowitz, A. (2003) Depression and vision and hearing impairments in later life. *Generations*, Spring, 27, 1, pp32-38
[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

- **A National Vision Loss Rehabilitation Services Plan will improve outcomes for people with disability due by reducing the incidence of preventable chronic conditions.**

Improving Inclusion and Participation

Failure to appropriately support people with sensory impairment makes it impossible for them to maintain adequate levels of social inclusion and economic participation. People with disability already face greater barriers towards achieving inclusion than most other people. 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, and obtain the information needed to participate and to complete everyday tasks.

Typically, many people experience additional financial stress, from the costs imposed by the needs of their disability throughout the lifespan. People with blindness or vision impairment also still face significant barriers due to direct and indirect discrimination in the open employment market. There are also limited options for supported employment, because of insufficient funding for Australian Disability Enterprises to meet the current identified levels of need.

People who are blind or vision impaired need equity of opportunity to participate in education, and to obtain and remain in employment. Employment enables people to live as independently as possible and to contribute to the community. However, as people with disability age they may find their needs change and they may require some extra support to remain in employment. The 'Jobs in Jeopardy' program provides valuable assistance in assessing need, negotiating change and enabling strategies to help people with blindness or vision impairment to remain engaged in productive and meaningful employment. This program is also of huge benefit to employers, as they do reduce knowledge and skills loss from their business and minimize recruitment costs.

- **People with sensory impairment face multiple barriers to achieving social and economic inclusion; these barriers need to be better recognized and addressed in policies relating to workforce and social participation.**

Access to information is critical at every stage of the lifespan for all people with blindness or vision impairment. Reading – whether for information, for study or work or for pleasure - is currently restricted to the very small percentage of texts currently available in accessible formats. Access to information and reading materials needs to be in the individual's format of choice, as there are a number of systems available in Australia, which have advantages and disadvantages depending on individual user needs. For example, if someone with low vision is using a screen reader program or magnifiers all day for work or study, they may

prefer to access audio material for their reading leisure in the evening. Similarly, people who are retiring from the workforce who use Braille still depend upon continued access to Braille-related equipment and timely access to sufficient information in Braille to meet their communication needs.

- **Improved access to information, in the format chosen by the user, is essential for maintaining social participation as people with disability age.**

The majority of 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 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. People who are ageing can often face additional barriers with obtaining and using accessible technology solutions. For example, older people with vision impairment may need greater support to access Internet-based technology or support, as they can have a lower general level of computer literacy. In general, aids and equipment are under-utilized by people with age-acquired vision impairment. Yet introduction of these aids can have significant and immediate impacts in reducing isolation, identifying needs and improving access to primary healthcare.

- **Timely access to accessible technology, aids and equipment is vital for enabling quality of life for people with a disability who are ageing.**

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.

Principles of ‘ageing in place’ can be better maintained with the provision of more support in rural and regional areas. Forced relocation creates significant stress for people with blindness or vision impairment, as they lose the reassurance of

familiar environments and face extra barriers in maintaining highly valued connections to people in their local area.

- **Improved access to vision assessment and support is essential for achieving better outcomes for people with disability in rural and regional areas.**

People with age-acquired sensory disability are less likely to identify with the blind, deaf or deafblind communities and are also unlikely to self-refer to specialist services. Yet, contact with age-acquired peers can have a highly positive effect in improving outcomes[16]. Many people find that the acquisition of vision impairment can require a period of adjustment to come to terms with their new situation. 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[17]. People with acquired blindness and vision impairment gain positive benefits by having opportunities to build confidence in their communication skills as part of a rehabilitation program. The strength of peer support programs lie in shared experience and new learning. Each older person has lived a life which is full of meaning; they have knowledge and experience to share with others; and they have opportunities to learn and enjoy, be valued and contribute, which is enabled by joining in a vision rehabilitation program.

People with existing disabilities who acquire vision impairment can already have insufficient avenues to interact with other people with similar abilities or experiences. These opportunities for peer contact can be further diminished as communication and mobility gets more difficult with ageing. Many older people also find they have more limitations which impede them from meeting new people. Ageing in place is critical for retaining contact with informal social support networks, including family and friends in the community; a move of just a few suburbs to enter residential aged care or a change in day-programs, combined with a lack of transport/social support, can be enough to mean that a person with a disability can quickly lose contact with their entire support network.

- **People with disability who are ageing need improved pathways to enable better access blindness or vision impairment support services, especially for rehabilitation, social inclusion and peer support programs.**

[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
[17] 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.

There is also 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 (especially aged care facilities and mainstream services buildings) 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.

The combined effect of ageing and vision impairment means that all buildings need to incorporate audio, visual and tactile information to assist with way-finding, as well as having accessible facilities and guide-dog friendly policies. The benefits of improved access are manifold. For example, audio-description means that older people with vision impairment can retain the pleasure of attending the cinema with their grandchildren, and also be able to discuss the movie with them afterwards.

- **Improved requirements for inclusive design will benefit all older people in society, and ensure that people with disability who are ageing can retain access to services.**

Integrating Aged and Disability Services

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. A disability doesn't go away just because a person has reached the age of 65. Indeed, there is an under-recognized extra layer of need for care and support which is generated by the added effects of ageing. This increased level of need is rarely met by aged care support packages, such as EACH and CACP, which were designed for people who had generic ageing issues and support needs.

For example, there is often a problem with an EACH package for many people with a disability because the EACH status then disqualifies them from accessing other specialist disability funding options, such as equipment funding. An EACH is often seen as all-inclusive answer to care needs, but in real terms it is quickly used up by nursing care, personal care and domestic support. There can be little or no funding left over for therapy, modifications or equipment. Also, clients can't roll-over any funding from year to year to 'save up' to assist with bigger periodical costs such as a replacement electric wheelchair or a new accessible mobile phone. The policy seems to have a 'spend it or lose it' focus rather than truly being centered upon individual client needs.

- **Aged care packages for community support need increased capacity and flexibility to adequately address the double level of need created by ageing and disability.**

The mainstream services sector may also struggle to adequately meet the needs of people who are ageing and who have blindness or vision impairment. Many not-for profit services have a shoe-string budget which means they are housed in older buildings which are often difficult to access for people with sensory impairment. Signage in many mainstream services may not be in Braille or audio format, and there may also be a lack of tactile markers for steps or ramps. There may also be other access problems, such as poor lighting, degraded footpaths, or even obstacles placed in corridors due to lack of space. There may also be few people able to assist with way-finding, especially in shared buildings, which all adds to the frustration and discouragement of a person with blindness or vision impairment who is seeking access to that service.

People with dual sensory disability often experience extra difficulty in accessing mainstream services, as these services rarely have the extra funding needed to educate or employ staff members who are able to communicate in alternative formats (such as Auslan or tactile finger-spelling). Access to translator services is under-utilized because of a general lack of awareness and inflexibility in funding guidelines. It is inequitable to expect translation costs to be deducted from the overall funding needed to provide other core services to that person.

Expanding information access is also critical for improving all services to people with blindness or vision impairment. Mainstream services are rarely funded to a level where they can offer all documents in alternative formats; including Braille, large print and audio. However, there is also a need to build a more general awareness of low-cost accessibility strategies across all services in the disability sector. For example, few mainstream disability services offer all electronic documents on websites in MS Word and/or html format. Yet, this is required to enable them to be read by the screen readers used by people with blindness and vision impairment (as PDF files cannot be read by accessible software).

Services may also be difficult to access for people who can no longer drive because of vision loss and age-related mobility problems. If they are unable to access public transport, then they may be completely dependent upon scarce community transport options - especially if they cannot afford taxi fares. Increasing budgetary constraints on many services means that agency car-pools and outreach services are being cut, which further limits options for accessibility. This has an impact on quality of service, as many people with multi-sensory loss depend upon person-to-person contact to overcome the communication barriers. It may also be necessary that people are assessed in their own homes, to appropriately address their level of need and to adequately comprehend their level of ability in a familiar environment.

- **Funding to all disability service providers needs to enable improved supports for people with sensory disability, including capital development funding to enable buildings to be retro-fitted to meet the new Premises Standards for accessibility.**

There is also insufficient funding to enable staff in residential aged care to acquire the ability or be supported to communicate with people with multiple or complex sensory disabilities, such as deafblindness. The need for translation support does not exist only between 9am to 5pm on weekdays. A person who is in pain at 3am on a weekend needs to have an appropriate way to communicate that need to the person who is caring for them and to have those needs adequately met in a timely manner.

When the time comes that a person who has had long-term blindness or vision impairment needs to transition into residential aged care services, it needs to be recognized that this can mean a significant disruption in long-established relationships and support arrangements. There may be a case for redesigning the whole system to enable aged-care providers to 'buy-in' specialist disability support services as required, or there may be a better option which can be worked out in consultation with both the aged and the disability sectors. Alternatively, specialist disability services could access funding for aged care through the provision of services which enable increased capacity for people with disability 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. Present inflexibility in funding guidelines creates significant inequities, which are mostly due to redundant or bureaucratic practice rather than logical or efficient rationale.

Greater 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. There is a huge opportunity to improve quality of life for all people with disability who have age-acquired blindness or vision impairment. Assisting them to maintain independence and reduce preventable negative impacts such as falls and isolation. Access to low vision support, appropriate access to aids and equipment, and rehabilitation services for orientation and mobility are all essential for improving long-term outcomes and reducing care costs of preventable chronic conditions and injuries.

A significant issue facing people with blindness or vision impairment is the barrier they face in taking equipment with them when they transition between services. Whether moving from school to work, or work to retirement, or 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 have to go on a waiting list for new equipment or simply do without that item from thereon. There is huge wastage caused by customized equipment sitting in storerooms around Australia. There is huge positive potential to be realized through introducing a process which enables the transfer of these very small assets (in accounting terms) between services or even in granting individual ownership to the person with blindness or vision impairment on the condition that the equipment is then donated to a recognized Disability Equipment recycling scheme when it is no longer required.

- **Residential aged care needs improved capacity to better integrate with specialized disability service providers to meet the dual level of need created by ageing and disability, especially to enable improved outcomes for people with blindness or vision impairment.**

Future Planning

People with disability may feel disempowered by people working towards what is thought to be best for them, rather than what the person with a disability wants for themselves. There may also be a complex and interdependent relationship between people with disability and their family carers. As disability funding is predominantly used in response to crisis situations, there is little available to support future planning. Appropriate and sufficient transition support can also be hard to find, if the person with a disability needs to enter into alternative care arrangements. Lack of planning and inefficient support can cause significant and unnecessary anxiety, can waste scarce resources, and may create negative impacts on health and wellbeing. People with blindness and vision impairment need to be actively consulted and included at every level of decision making about their own future care and receive useful services which are respectful and supportive of their choices.

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[18].

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

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

training about how to appropriately respond to such issues[19]. 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. Often the medical model of care can hesitate to predict outcomes for fear of litigation, and the social support model of care has insufficient medical understanding to do more than respond to events after they have happened. There are also social mores which inhibit discussion of bodily dysfunction, decay and death. These need to be overcome in a supportive manner to enable people to choose their future path with confidence and compassion – similar to palliative care models - but over a longer timeframe.

Also, legal issues may create barriers to achieving sound future planning. Legislative issues regarding guardianship, power of attorney and future care directives vary greatly between states and territories in Australia. Many people with blindness and vision impairment are dependent upon government support or on low incomes, so have limited access to legal and financial advice for ensuring their future security. Appropriate planning depends upon sound advice from qualified professionals who specialize in 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.

- **People with disability who are ageing and who have blindness or vision impairment need access to a range of supports and resources to assist with planning their future and achieving a satisfactory retirement.**

Sector Reform to Improve Long-Term Outcomes

The recently announced National Health and Hospitals Agreement has 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 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

[19] 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.

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.**

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 access in public places, such as restaurants and taxis. In the wider 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.**

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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.