

AUSTRALIAN BLINDNESS FORUM

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Submission to the Productivity Commission Inquiry into Disability Care and Support

The construction of disability as a 'crisis' is realized by a system based on piece-meal handouts and band-aids. By definition, a crisis is a short-term response, a turning point (for better or worse) or a condition of instability or danger. Building a system around crisis response ignores responsibility for long-term outcomes. The current disability system is characterized by a lack of investment in rehabilitation and forward planning to better support unmet need and to realize the potential of the many people with disability and their families.

Despite the best efforts of many organizations and individuals, the current system is a response rather than a resource; which is unproductive, inefficient and wasteful. People with blindness or vision impairment continuously fall through gaps created by the poor integration of the healthcare, aged and disability systems. They are systematically excluded from achieving equity in education and employment. They are left without opportunities to participate in sport, culture and community life. They are denied independence, dignity and respect.

The introduction of a new, national disability care and support scheme requires a fundamental shift in thinking. The concept of 'burden of disability' must be rejected and replaced by investment in potential. As one participant in the consultation process underpinning this submission said, "I am blind, but I am not disabled!" A system which directly or indirectly encourages inequity and dependence, while also ignoring genuine need for support, is not in the interests of the wider community.

The Australian Blindness Forum, with membership from consumer groups and service organizations, wants to see a system of entitlement established which both supports individual need and values investment in potential – for the benefit of the whole community. Such a system must be embraced by the whole of government, supported by appropriate legislation and enabled by effective policy. The introduction of an entitlement scheme will also help to realize the improved supports and equity in outcomes for people with disabilities required by Australia's ratification of the UN Convention on the Rights of Persons with Disabilities

The Australian Blindness Forum welcomes the opportunity to provide this submission to the Productivity Commission Inquiry into Disability Care and Support to demonstrate the need for people with blindness or vision impairment to be an integral part of a future system which enables them to live and participate with independence and dignity as part of the community.

1. Blindness and Vision Impairment in Australia

Australian Bureau of Statistics dataⁱ indicates that in 2007-2008 at least 412,700 peopleⁱⁱ aged less than 65 years old were living with blindness or vision impairment in Australia. Of these, approximately 61,000 are estimated to have blindnessⁱⁱⁱ. The term blindness refers to someone who may be totally blind (i.e. without any perception of light) or someone who is legally blind. Legal blindness in Australia is set at visual acuity of 6/60 or a visual field of less than 10°. Visual acuity of 6/60 means that someone cannot see at 6 metres what a person with normal vision can see at 60 metres. A normal visual field is around 150° wide. Vision impairment does not simply mean all people who wear glasses. A person has vision impairment when, even when using glasses, they cannot meet the legal vision requirements to be able to drive a motor vehicle.

Different age cohorts are associated with different causes of blindness or vision impairment. The Australian Childhood Vision Impairment Register^{iv} preliminary data indicates that causes of childhood vision impairment include Cortical Vision Impairment; Nystagmus, Myopia, Optic Nerve Hypoplasia, Lebers Congenital Amaurosis, Retinopathy of Prematurity, Glaucoma, Retinal Dystrophy and Optic Atrophy.

Access Economics^v reports that the top five causes of blindness in people aged over 40 years are: macular degeneration, glaucoma, cataract, diabetic/retinal disease and refractive error. A quarter of all vision 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^{vi}. While higher incidence of vision impairment in the whole population is reported in non-remote areas^{vii}; this may be due to factors such as difficulty in accessing treatment, lack of awareness about treatment options, or a reflection of forced relocations to access services in metropolitan areas, rather than an indicator of better eye health in rural and remote regions^{viii}.

There is a significant under-representation of people with blindness or vision impairment in current disability support services. Of users of all CSTDA funded services in 2007-08^{ix}, only 5112 people aged less than 65 years had blindness or vision impairment as their primary disability and only 3046 people aged less than 65 years had deafblindness as the primary disability. This represents approximately 3.5 % of all CSTDA users.

2. Principles to Underpin an Entitlement Scheme

The following principles are considered essential for developing a support system which is appropriate to the needs of people with blindness or vision impairment:

- Entitlement
- Universality
- Sustainability
- Self determination
- Equity
- Effectiveness and efficiency
- Respect for the person with blindness or vision impairment

3. Eligibility

The terms of reference of the inquiry specify that a disability care and support scheme is intended for those people in significant need of support. The Disability Investment Group recognized that people with sensory disability are within the group of people needing constant or frequent support^x. People with blindness or vision impairment will usually require significant access to early intervention (both early-in-age to meet critical development windows and early-in-onset for adults) and rehabilitation supports. Many people with blindness or vision impairment do achieve a high capacity for independence on a day to day basis, but most will require episodic access to services across their lifetime in response to changing need. For example, orientation and mobility support is required every time there is a change in circumstances, such as a new job or moving house.

Increased support from rehabilitation services is also often required to expand independence, under a continuous learning model, to continue to enhance quality of life. Incremental gains in skills and prevention of loss of skills remain important across the lifespan. The model of service provision to people with blindness or vision impairment is atypical when compared to usual disability support models. Usually, service supports increase in proportion to the level of functional impairment. However, people with blindness or vision impairment with potential to achieve a high degree of functional capability can only realize that potential through access to intensive rehabilitation and/or early intervention services. Once a high level of functionality is achieved, they will still need to return incrementally for additional services to maintain or improve their functional ability throughout their lifespan.

Ongoing need for support also includes assessment and access to appropriate aids and equipment; including training in the use of the equipment. Costs of meeting the needs of vision loss across the lifetime create significant disadvantage for people with blindness or vision impairment. Adaptive technology is not cheap.

However, seemingly substantial investments in technology (such as \$3,000 to \$5,000 for an electronic magnifier) can mean the difference between someone being able to read their mail and pay their bills independently rather than requiring support services to manage household affairs or being forced into a supported accommodation services. The cost-benefit of access to appropriate aids and equipment is clear. Yet, the current disability system is unable to invest in vision aids and accessible technology as chronic under-funding and generic disability focus prioritizes physical mobility. Unmet need for aids and equipment, across all areas of disability, will continue to create a higher level of long-term dependence on generic disability support services if not appropriately supported through an entitlement scheme.

Level of identified need is only one consideration. Eligibility for an entitlement scheme should be consistent with the target population under the National Disability Agreement; i.e. people with severe or profound disability and/or people assessed as needing specialist support to gain and/or retain employment, who require support services (always or sometimes). Such a definition is appropriate because it recognizes people who need episodic support across their lifetime.

The National Disability Agreement does not define eligibility because eligibility is defined in the similar (but not identical) State, Territory and Federal Disability Acts. However, employment services for people with disability, funded by the Commonwealth, are governed by the Disability Services Act 1986 which defines the target group as:

- (1) *The target group for the purposes of this Part consists of persons with a disability that:*
- a. is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments;*
 - b. is permanent or likely to be permanent; and*
 - c. results in:*
 - i. a substantially reduced capacity of the person for communication, learning or mobility; and*
 - ii. the need for ongoing support services.*

Under existing State and Territory arrangements, disability services are targeted at people who have a relatively severe disability, acquired before the age of 65 years, and who need support – at least occasionally - to live or work within their community. A key difference from current arrangements will be that the many people who are eligible under current arrangements but are denied services will actually receive them, and they should be reassured that their eligibility is secure.

The Australian Blindness Forum recommends, once deemed eligible, a person should remain eligible to receive support when required, for the rest of their life.

3.1 Fast-tracking Eligibility

People with some specified conditions should be fast-tracked in determining eligibility for the entitlement scheme, as this would simplify the process of application and result in administrative savings. It is possible, using existing information, to predict that people with some conditions are very likely to always or regularly require disability support services either now or in the future. This information should be used to develop a list of conditions who achieve fast-track eligibility.

Fast-track eligibility could be achieved via presentation of appropriate documentation. This would be compatible with processes currently used to determine eligibility for some forms of income support (e.g. Carer Allowance for a child aged under 16 years old).

Ophthalmic reports are easily obtained to verify levels of vision loss for people with blindness or vision impairment. Currently, 99% of clients accessing specialist blindness services come through the medical system first, so GP awareness of need for early referral to ophthalmic services is vital whenever vision loss is suspected.

The Australian Blindness Forum recommends that a list of recognized disabilities be established to enable fast-track eligibility for an entitlement scheme, and that this list include all people who are legally blind (visual acuity of 6/60 or visual field of <10°) and all people with deafblindness.

The Australian Blindness Forum further recommends that the World Health Organization measure for visual impairment (visual acuity of 6/18 or visual field of <20°) be considered as an appropriate measure for eligibility for an entitlement scheme.

3.2 Functional Assessment

All cut-off points to any scheme are arbitrary. In order to meet the principle of equity, it would be appropriate to offer functional capacity/needs assessment to determine eligibility for all other people with a type or level of disability that is not recognized via a fast-track eligibility list. The assessment process must respect the dignity of the person with a disability. It should be comprehensive, rigorous, appropriate and multi-dimensional. Simplistic 'one-size-fits-all' tools rarely assess the complexity of functional impairment with fairness and accuracy.

Such assessment should identify the level of functional impairment generating the need for support and take into account the context of individual capacity and/or any complicating circumstances. It should also include appropriate

measures of sensory impairment, due to the low level of recognition of sensory loss as an issue needing support in people with multiple disabilities.

The Australian Blindness Forum recommends that processes to determine eligibility be based on functional assessment and consider potential capacity. It further recommends that all measures or processes be appropriate, comprehensive, multi-dimensional and respectful of the dignity of people with disabilities.

3.3 Appeals and Review

A transparent and supportive process to determine eligibility for an entitlement scheme - which fairly assesses the person's capacity, functional ability and the complexity/impact of the disability - will help to reduce potential for appeals or litigation. Access to an independent review and appeals system is part of creating a just and equitable process. Such a process would also enable timely review for people who had previously failed to achieve entitlement, but who had experienced a change in circumstances which reduced their functional ability. This process would be equitable and efficient, as it would prevent people with these circumstances from having to repeat the entire assessment process from the beginning.

The Australian Blindness Forum recommends that people with disabilities should have access to an independent appeals and review system as part of an entitlement scheme.

3.4 Age of Onset

The terms of reference for the Inquiry specify that a scheme should cover disability present at birth or acquired through accident or health condition, but not due to the 'natural process of ageing'. It is a fact that 70% of people with BVI are over 70 years of age^{xi}, most of whom have an age-associated onset. The perception that blindness or vision impairment is part of a '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.

The Australian Blindness Forum supports a principle that all people with blindness or vision impairment should have access to appropriate supports to meet the needs of their disability. Access to support should not be limited by an arbitrary age barrier, as even small amounts of intervention can make a profound difference in outcomes. There is disproportionate representation of people with blindness or vision impairment among people in residential care

facilities in every age cohort. Yet, access to appropriate specialist services would significantly enhance capacity for older people to continue to live in their own homes and prevent entry to residential care facilities. The submission made by the Australian Blindness Forum to the Productivity Commission Inquiry into Caring for Older Australians calls for improved integration of the work of specialist disability services within the aged care services system (both community care and residential care) to ensure a more efficient and appropriate response to the increasing numbers of aged people with blindness or vision impairment.

The Australian Blindness Forum recommends that this Productivity Commission Inquiry take note of the Forum's submission to the *Inquiry into Caring for Older Australians* regarding the benefits to be achieved by providing access to specialist support for older people with blindness or vision impairment.

4. Entitlement

4.1 Planning and Assessment

Determination of eligibility should be followed by planning for support services. The planning system should be person-centred; i.e. based on the choices of the person with blindness or vision impairment. The delivery of an effective person-centred planning system depends upon two factors: firstly, people with blindness or vision impairment being supplied with sufficient information in accessible formats to enable them to make an informed choice, and, secondly, there must be a range of realistic and meaningful options to choose from. Too often, people with blindness or vision impairment experience difficulty in accessing generic or mainstream services which significantly limits their options.

However, as fiscal sustainability of the entire scheme will prohibit unlimited support, the level and type/s of support for each person eligible under an entitlement scheme should be determined through a planning process which considers:

- Individual capacity
- Level of psycho-social adaptation to impairment (critical for improving outcomes)
- Availability of informal support
- Access to community and mainstream services
- Environmental factors
- Goals and outcomes desired by the person with a disability
- Maximizing opportunities for participation and productivity

Assessment must be provided by people from specialist blindness organizations to appropriately identify the best strategies for support. Blindness or vision impairment support is a highly specialized knowledge area, especially in areas such as orientation and mobility, use of aids and equipment, and independent living skills training for people with vision loss. Due to the relatively small incidence of blindness or vision impairment, it is not uncommon for a professional such as an occupational therapist to practice for a decade and never have a client with blindness or vision impairment.

The Australian Blindness Forum recommends that person-centred planning assessments or services for people with blindness or vision impairment be delivered by professionals with specialist training/experience in blindness or vision impairment.

4.2 Support Types

The proposed entitlement scheme is about providing individual care and support services for people with disability. Care and support should include:

- All needed care, support, therapy or access based on the individual's functional impairment
- Person-centred services and supports based on the needs and choices of the person with a disability and their family
- Case management to facilitate independence, maximize potential and plan transitions
- Access to aids, equipment, home modifications and accessible technology
- Access to training and developmental opportunities to build self-esteem and independence

An entitlement scheme should be specific to disability, and not be used for the provision of goods or services generally considered 'ordinary life' expenditure, including food, rent/mortgages, general household appliances or holidays. However, support to enable independence should be eligible, e.g. the price difference between a generic appliance and an accessible one. Many people with blindness or vision impairment need regular support with domestic services, home maintenance and community transport.

People with blindness or sensory impairment also need opportunities to access peer supports, if desired. The relatively low incidence of blindness or vision impairment in younger people makes peer contact very important for developing personal identity, a sense of context around blindness, for sharing information and for learning new skills/strategies. Access to peer-based supports can be difficult under the current HACC disability support scheme, mainly due to restrictions

relating to provision of services within local areas, but the low incidence of blindness means that group activities must draw from a wider geographical area.

Recognition that people with disability and their families must have options about care and support also needs to include choices about how that support is delivered and managed. Individualized funding may be desired and appropriate in some circumstances, but not in others. Some people may wish to work with a case manager to 'buy in' services of choice from different providers; and others may wish have an allocation placed directly with a service provider to be managed for them. Some funding may also be provided directly to organizations. A disability entitlement scheme should have sufficient flexibility to enable choice and independence, and to respond to changing needs and to increase supports at times of transition. It also needs to have certainty of delivery when needed, to enable people to choose to reduce supports when not required without fear of loss of entitlement.

The Australian Blindness Forum recommends that services and supports for people with blindness or vision impairment encourage options and choices, be appropriate for individual needs, support access, promote inclusion and enable participation.

4.3 Early intervention

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. Improvement of early intervention is critical for reducing long term costs. Early intervention covers both young children (maximizing potential exploitation of 'critical window' development periods) and adults, through 'early-in-onset' intervention.

Children with blindness or vision impairment need coordinated and integrated specialist pediatric support from both health and disability providers. Disability support needs to be focused on developing essential skills – gross and fine motor skills, communication, learning and social skills with a view to optimizing future levels of independence. Funds from an entitlement scheme must not be drained by health and medical costs which are the responsibility of the health budget.

Education is also a vital interface for childhood early intervention. Similarly, an entitlement scheme should not be used to replace existing funding for learning supports, which must remain the responsibility of the education system. However, there is potential for more complementary approach to be developed between the education system and specialist disability support services. Education Departments around the nation are frequently hampered by time restraints, resource limitations and conflicting imperatives. Rehabilitation training for children

with blindness or vision impairment can be a lower priority in a system focused on achievement within the context of an educational curriculum. Improved outcomes could be achieved by enabling capacity for the education system to access specialist expertise to deliver comprehensive, age appropriate, rehabilitative interventions. Improved functional independence achieved within the educational environment would assist to reduce demand for post-school rehabilitation and independent living services.

Early-in-onset intervention for adults is vital for improving long term outcomes and minimizing later levels of functional incapacity. Early-in-onset intervention requires improved professional awareness to ensure earlier referral to support and rehabilitation services by general practitioners, optometrists and ophthalmologists. There is a common misperception that rehabilitation and support services are only of benefit once all options for medical treatment have been exhausted. Yet, co-referral to enable early intervention for people who are on waiting lists for surgery (i.e. cataracts) can significantly enhance quality of life and prevent reduction of community/workforce participation in the time between diagnosis and surgery. Early referral can prevent issues such as 'learned helplessness' from developing and reduces demand for costly attendant support costs in the long term.

The Australian Blindness Forum recommends that an entitlement scheme incorporate and promote early-in-age intervention for children and early-in-onset intervention for adults with blindness or vision impairment.

4.4 Rehabilitation

Longitudinal Australian research indicates that inability to complete activities of daily living, (such as being able to shop, garden, do minor home maintenance, prepare meals, or do housework on one's own) increases the likelihood of premature entry into supported accommodation by 70%^{xii}. People with blindness or vision impairment experience significant and proven benefit from investment in rehabilitation support, no matter what their age of onset. Building independence is essential for reducing long term demand for support services and overall costs for people of all ages with blindness or vision impairment.

Rehabilitation services needed by people with blindness or vision impairment include:

- Low vision services to assess the impact of vision loss and provide appropriate supports based on individual need
- Orientation and mobility training (including navigating internal and external environments, cane use or guide dog use) which has a profound impact in improving independence and reducing injuries, especially from falls^{xiii}.

- Independent living skills training (such as cooking, laundry or shopping) to assisting people of all ages to remain living in their own homes
- Information and counseling to help with adjustment to vision loss, including choice of individual support and/or peer support opportunities

There are comparatively low utilization rates for existing rehabilitation services, especially orientation and mobility support services, for people with low vision who are over 40 years old. People with onset of vision impairment who are over 40 years in age 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.

The Australian Blindness Forum recommends that an entitlement scheme incorporate systems which support the delivery of rehabilitation services appropriate to the needs of people with blindness or vision impairment.

4.4 Future Planning and Transition 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 are undergoing periods of transition, such as primary school to high school, and school to work or post-school activities. When moving between different programs and/or funding environments, 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 also often inequity created by workplace modification schemes which ignore the needs of people who need accessible equipment to build skills and assist them to obtain employment. 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.

People with disabilities who are in the workforce also often have to retire at a substantially earlier age than their peer group. This can be due to deterioration in their personal health, but it can also be due to cumulative fatigue from struggling to manage their disability without adequate supports both within the workplace and within their home environment. Improved support within the home and the workplace is essential for enabling more people with blindness or vision impairment to enter and remain longer in the workforce.

The Australian Blindness Forum recommends that an entitlement scheme enable improved planning and support for transitions, and improve integration between workplace and home supports, to achieve better outcomes for people with blindness or vision impairment.

5. Structure of a Scheme

5.1 Equity

There is a strong case for improving the consistency of rules and guidelines to apply equally to everyone, regardless of their type of disability, how it was acquired or where they live. The Australian Blindness Forum supports the principle that people with similar needs and similar goals need similar supports to enable their participation and independence. Currently, there is significant and inconsistent variability between services offered in different states and territories.

Of more concern is the fact that people with blindness or vision impairment living in regional, rural or remote areas have significantly reduced access to options and choices about services to support their needs. There is a clear and urgent need for improved services and supports for people with blindness and vision impairment located outside metropolitan areas, especially in rural and remote areas. Improvements are particularly vital for improving learning outcomes for children and young people, and for increasing levels of rehabilitation support for all ages. 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)
- Lack of training to enable general healthcare/disability support staff to better identify early vision loss and refer for assessment and early intervention

The Australian Blindness Forum recommends that a ‘no-fault’ entitlement scheme be developed to support all people with disability, regardless of how it was acquired.

The Australian Blindness Forum further recommends that an entitlement scheme recognize existing inequities caused by geographic location and seek investment in infrastructure and innovation to deliver improved outcomes and equity of benefit.

5.2 Efficiency and Effectiveness

An efficient and effective entitlement scheme should be underpinned by a simple structure which is easy for people to access and for services to deliver. Strong accountability processes are required within the model to ensure that public monies are used appropriately for disability and care support. However, it is important that accountability, reporting and quality management schemes are simple, transparent and efficient. Streamlining reporting and compliance processes offers opportunity to realize productivity gains across the disability sector.

The Australian Blindness Forum recommends that an entitlement scheme be efficient and effective, incorporating sound accountability and quality systems.

5.3 Complementary to Existing Supports

An entitlement scheme must have complementary interfaces with the existing health, education and aged 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.

However, it is vitally important that an entitlement scheme be reserved for funding specific disability care and support, and not be a target for cost-shifting from other sectors. The proposed entitlement scheme should also not be about funding accessible infrastructure development - which is the responsibility of local and state/territory governments. For example, wider ‘public good’ schemes, such as accessible public building access or improved footpaths are very important, but they should not be covered by an individual care and support entitlement scheme.

Similarly, the introduction of an entitlement scheme must not erode other national and state schemes already in place to support wider populations of people with disability and aged persons, until such time as a disability entitlement scheme is

available for all people with disability regardless of age or level of impairment. For example, wider access schemes include: the disability parking permit scheme, the Companion Card scheme and community transport/taxi subsidy schemes.

Cooperative approaches to service provision do exist in the current system and these should be encouraged under an entitlement scheme. For example, it may be appropriate that certain aspects of the entitlement scheme work in a similar way to how a person with a Veterans' Affairs Gold Card would obtain a guide dog - the service is exactly the same as that received by anyone else with similar need, but the cost of that service is paid by the Department of Veterans' Affairs instead of being funded by charitable donations.

The Australian Blindness Forum recommends that an entitlement system be complementary to the education, health and aged care systems. It should encourage cooperative approaches which improve outcomes for people with blindness or vision impairment and contain deterrents to prevent waste and/or cost-shifting from other sectors.

5.4 Quality Assurance

Providers of services to people with blindness or vision impairment need to have recognized quality assurance systems in place. All therapies and rehabilitative services delivered under an entitlement scheme must be delivered by appropriately qualified and accredited professionals. Quality service provision protects consumers and ensures good value for public expenditure. However, development of a quality system requires resources to be invested. Investment is essential to develop capacity in the not-for-profit sector; in organizations (especially for improved governance and management); and, most importantly, in skills training for the workforce. A quality system also has a simple and effective system for consumers to provide feedback and to enable appropriate resolution of complaints and problems.

The Australian Blindness Forum recommends that services to people with blindness or vision impairment be underpinned by quality assurance processes which required that all therapy and rehabilitative services be delivered by appropriately qualified and accredited professionals.

5.5 Sustainability and Funding

An entitlement scheme is only possible if it is fully funded to provide essential services and is sustainable in the long term. Any new scheme must take into account issues such as capacity, workforce development and infrastructure. It needs to have sufficient resources to enable a forward focus on early intervention and rehabilitation. The Productivity Commission report into the not-for-profit sector

recommended that essential services be explicitly identified and fully funded by government – and it is clear that disability support certainly fits any definition of an essential service.

The Australian Blindness Forum also supports the concept that the scheme should be funded by an equitable measure which is distributed across the whole population. Possible funding sources suggested during the ABF consultation process include: an allocation of 0.5 – 0.7% of GST revenue per annum into a special fund for both the entitlement scheme and to establish a 'future fund' for funding research into social policy and universal/accessible technology development; a small increase in the Medicare levy; or a social insurance payment which funded both disability and aged care (similar to compulsory superannuation). Taxes based on motor vehicle registration, property ownership, stamp duties or levies specifically marked 'disability' were not well-supported by the ABF membership.

The principle of co-payments is already in use for HACC and similar supports, but the Australian Blindness Forum opposes this principle being adopted into an entitlement scheme. There are already significant problems with people who are unable to access the services they need because of gap payments or expectations of co-contributions. People most affected by disability tend to have significantly reduced incomes due to high levels of dependence on government income support and the high costs incurred by meeting the needs of the disability.

The Australian Blindness Forum recommends that an entitlement scheme be fully funded through broad-based measures due to the scheme's potential to provide benefit to all individuals, as well as the wider positive social impacts gained by improving the productivity of the service system and the potential benefit of increased workforce participation of people with disability and carers.

5.6 Transition into a New Scheme

Transition to a new entitlement scheme may need to incorporate a staged approach, to enable funding to be developed to a sustainable level. Existing 'crisis response' funding contracts will need to be phased out as more people benefit from early intervention, rehabilitation and inclusion approaches. It is important that the transition program build to fully funded services at the earliest possible time. It is also important that the transition process avoids 'mission-creep' and keeps support targeted on key principles and priorities until such time that a full system can be established.

The signing of the National Health and Hospitals Network Agreement has established Commonwealth responsibility through the aged care system at age 65. Responsibility for delivery of disability services to people under the age of 65 years

old remains with the states and territories. It is important that a national entitlement scheme provide a structure which fits within the context of Federal/State/Territory funding arrangements, and which is also cohesive, consistent and comprehensive to provide the maximum benefits and deliver improved outcomes for people with disability.

The Australian Blindness Forum recommends that an entitlement scheme be implemented at the earliest possible timeline through a staged approach which is facilitated by cooperation at Federal, State/Territory and local government levels.

6. Benefits of an Entitlement Scheme

6.1 Importance of Economic Participation

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. Research indicates that unemployment and under-employment levels of people with blindness or vision impairment are significantly higher than that experienced by the Australian population^{xiv}.

There are also indirect costs associated with blindness or vision impairment. Typically, a person with blindness or vision impairment needs to live in an accessible home which is close to public transport, shops and other community amenities. Such proximity incurs higher housing costs whether a home is purchased or privately rented. 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 accessing transport. 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. Those people who do use the larger shopping centres often miss out on discounted products as price information is all visually presented.

Improved economic participation would potentially be enabled through an entitlement scheme by providing some of the support needed to engage greater levels of workforce participation, by offsetting some indirect costs of disability through improved support (such as access to transport, home-care services or shopping assistance).

6.2 Importance of Access to Aids and Equipment

Access to required aids and equipment is essential to keep people with blindness or vision impairment connected and participating, especially to enable continued access to information. Cost of accessible technology is a significant barrier for all people with blindness and vision impairment. People with blindness or vision impairment often find that they have no possible means for purchasing or replacing important equipment and are often reliant upon limited charity funds.

Access to information is critical at every stage of the lifespan for all people with blindness or vision impairment. People with a post-school age onset of blindness or vision impairment may particularly need access to training and 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. Introduction of these aids can have immediate positive impacts in enabling participation, improving productivity and reducing need for costly one-to-one support services. Timely access to aids and equipment also helps to keep people with late-onset vision loss socially engaged and participating in the workforce.

6.3 Importance of Access to Information and Education Support

It is currently estimated that only 3 in every 1,000 printed documents are available in an accessible format for people who are blind or vision impaired^{xv}. The introduction of new technologies, such as digital recording and storage systems, and the ability to transmit and reformat digital information electronically offers potential to significantly improve access to information.

Yet, many people with blindness or vision impairment still struggle to access the information needed for their education, training, employment and independent living experience. This generates a profound sense of personal frustration because they cannot achieve their full potential in life. Prolonged frustration leads to social withdrawal, increases risk of depression, and can result in increased levels of dependence on social welfare and disability supports.

It is particularly concerning that children and young people with blindness or vision impairment are still disadvantaged in the existing school system because of the lack of timely access to school texts and other learning materials in alternative formats. Improving literacy and numeracy is critical to reducing dependence on social welfare systems later in life.

6.4 Importance of Social Inclusion

Depression, anxiety and stress are significant, and highly preventable, issue for many people with blindness and vision impairment. Research indicates that mental health problems experienced by people with blindness or vision impairment reflect the prolonged struggle for inclusion and the high levels of social isolation

experienced across the lifespan^{xvi}. Social isolation and enduring poverty are both recognized factors in contributing to depression.

Accessible socialization opportunities can be vital for reducing depressive symptoms in people with blindness or vision impairment, yet service providers and consumers report that most people struggle to obtain access to HACC disability services on the basis of blindness or vision impairment alone. Legal blindness also prohibits access to a driving license, leaving people dependent upon limited public transport options, the assistance of family/friends or community transport services. The struggle to obtain access to transport greatly inhibits social participation and inclusion.

People with blindness or vision impairment may need support to learn communication strategies to enable their successful participation in recreation and leisure activities. Information also needs to be provided to the non-vision impaired people in the group to build appropriate communication skills and establish good strategies to support participation.

Failure to appropriately support people with sensory impairment often makes it impossible for them to maintain adequate levels of workforce 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. Recognizing and managing fatigue is essential for enabling successful participation.

7. Wider Issues

7.1 Supports for People with Mild to Moderate Disability

The Australian Blindness Forum supports the principle that access to appropriate supports for people with lower levels of impairment is an important feature of a just and equitable society. Access to appropriate supports enables greater social inclusion and workforce participation. Access to early intervention and low level rehabilitation can also prevent many people from developing higher levels of disability later in life. For example, people with mild to moderate vision loss benefit significantly from access to low vision clinics, counseling, lighting and a safety review of their home for injury and falls prevention.

While people with severe and profound level of disability must have priority access to an entitlement scheme, the Australian Blindness Forum supports long-term extension of the scheme to all people with disability. In the interim, it is important that people with 'mild to moderate' disability benefit from the development of wider social inclusion, education and employment support schemes. Such schemes need to respond appropriately to wider low-level social disadvantage and should be funded by sources other than a disability entitlement scheme.

Also, people with mild to moderate levels of clinical disability who experience high levels of functional disability due to complex circumstances do need to be eligible for support through an entitlement scheme (as determined by appropriate functional capacity assessment). Similarly, people with low vision and/or with mild hearing impairment can benefit significantly from simple strategies and supports to enable them to remain engaged and productive within the workforce.

The Australian Blindness Forum recommends the earliest possible expansion of the entitlement scheme to benefit all people with disability, regardless of individual level of impairment.

The Australian Blindness Forum further recommends development of the following interim measures for people with mild or moderate levels of disability, until such time that a full entitlement scheme is possible:

- **Development of wider participation/inclusion support schemes to maximize productivity gains and improve outcomes; and,**
- **Low level intervention strategies to inhibit or slow progression to higher level of need.**

7.2 Public Awareness and Prevention Campaigns

Strategies to improve public awareness are an important part of a proposed entitlement scheme. These strategies make good economic sense as promotion helps to improve community support and understanding of people with disability. 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. 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

community, improved understanding of protocols will help to reduce injuries caused by people distracting a guide dog.

Similarly, prevention campaigns strategies help to reduce the long term costs of care by reducing preventable disability. The efficacy of such campaigns is well recognised and has precedents, including falls prevention, skin cancer campaigns and road safety campaigns, which promote safe behaviour and encourage early diagnosis.

The Australian Blindness Forum recommends that an entitlement scheme be supported by appropriate public awareness and prevention campaigns.

7.3 Research and Data Collection

Investing in research and development capacity encourages the development of supports which maximize independence, realize individual potential and reduce demand for higher levels of care. Service development within the disability sector should be informed by research, and is historically a neglected area due to the fact that current funding formulas rarely cover anything beyond basic unit costs of delivery.

Reliance on market forces alone to improve practice is unrealistic in the disability sector, as commercial imperatives have less applicability in limited markets. There is also no existing funding capacity to encourage exploration of new practices or to enable the development of assistive technology. This is especially relevant for the issue of exploratory or 'blue sky' research - which is often needed to make significant leaps forward to improve long-term outcomes for people with disability.

Promotion of universal design is also required across all sectors of society. Universal design principles improve access and reduce need for specialist adaptive support and/or costly retro-fitting. Introduction of universal design is not supported by procurement pathways focused upon achieving the lowest unit price. Industrial designers, too, have little opportunity for getting feedback from the disability sector about what works and what doesn't, and a crisis-focused sector has little time to look to the wider world and make suggestions for improvement.

The Australian Blindness Forum recommends investment in appropriate research and development strategies to improve outcomes for people with blindness or vision impairment, including assistive technology development.

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. It is anticipated that a proposed entitlement scheme should contain appropriate mechanisms for streamlined data collection. Efficient data systems keep compliance costs for service providers to a minimum and also feed information back to the sector to inform the development of good practice.

The Australian Blindness Forum recommends the development of strategies which enable accurate data collection and utilize the sharing of systemic data to promote and develop improved services for people with blindness or vision impairment.

List of Recommendations

1. The Australian Blindness Forum recommends, once deemed eligible, a person should remain eligible to receive support when required, for the rest of their life.
2. The Australian Blindness Forum recommends that a list of recognized disabilities be established to enable fast-track eligibility for an entitlement scheme, and that this list include all people who are legally blind (visual acuity of 6/60 or visual field of <10°) and all people with deafblindness.
3. The Australian Blindness Forum further recommends that the World Health Organization measure for visual impairment (visual acuity of 6/18 or visual field of <20°) be considered as an appropriate measure for eligibility for an entitlement scheme.
4. The Australian Blindness Forum recommends that processes to determine eligibility be based on functional assessment and consider potential capacity. It further recommends that all measures or processes be appropriate, comprehensive, multi-dimensional and respectful of the dignity of people with disabilities.
5. The Australian Blindness Forum recommends that people with disabilities should have access to an independent appeals and review system as part of an entitlement scheme.
6. The Australian Blindness Forum recommends that this Productivity Commission Inquiry take note of the Forum's submission to the *Inquiry into Caring for Older Australians* regarding the benefits to be achieved by providing access to specialist support for older people with blindness or vision impairment..
7. The Australian Blindness Forum recommends that person-centred planning assessments or services for people with blindness or vision impairment be delivered by professionals with specialist training/experience in blindness or vision impairment.
8. The Australian Blindness Forum recommends that services and supports for people with blindness or vision impairment encourage options and choices, be appropriate for individual needs, support access, promote inclusion and enable participation.

9. The Australian Blindness Forum recommends that an entitlement scheme incorporate and promote early-in-age intervention for children and early-in-onset intervention for adults with blindness or vision impairment.
10. The Australian Blindness Forum recommends that an entitlement scheme incorporate systems which support the delivery of rehabilitation services appropriate to the needs of people with blindness or vision impairment.
11. The Australian Blindness Forum recommends that an entitlement scheme enable improved planning and support for transitions, and improve integration between workplace and home supports, to achieve better outcomes for people with blindness or vision impairment.
12. The Australian Blindness Forum recommends that a 'no-fault' entitlement scheme be developed to support all people with disability, regardless of how it was acquired.
13. The Australian Blindness Forum further recommends that an entitlement scheme recognize existing inequities caused by geographic location and seek investment in infrastructure and innovation to deliver improved outcomes and equity of benefit.
14. The Australian Blindness Forum recommends that an entitlement scheme be efficient and effective, incorporating sound accountability and quality systems.
15. The Australian Blindness Forum recommends that an entitlement system be complementary to the education, health and aged care systems. It should encourage cooperative approaches which improve outcomes for people with blindness or vision impairment and contain deterrents to prevent waste and/or cost-shifting from other sectors.
16. The Australian Blindness Forum recommends that services to people with blindness or vision impairment be underpinned by quality assurance processes which required that all therapy and rehabilitative services be delivered by appropriately qualified and accredited professionals.
17. The Australian Blindness Forum recommends that an entitlement scheme be fully funded through broad-based measures due to the scheme's potential to provide benefit to all individuals, as well as the wider positive social impacts gained by improving the productivity of the service system and the potential benefit of increased workforce participation of people with disability and carers.
18. The Australian Blindness Forum recommends that an entitlement scheme be implemented at the earliest possible timeline through a staged approach

which is facilitated by cooperation at Federal, State/Territory and local government levels.

19. The Australian Blindness Forum recommends the earliest possible expansion of the entitlement scheme to benefit all people with disability, regardless of individual level of impairment.
20. The Australian Blindness Forum further recommends development of the following interim measures for people with mild or moderate levels of disability, until such time that a full entitlement scheme is possible:
 - Development of wider participation/inclusion support schemes to maximize productivity gains and improve outcomes; and,
 - Low level intervention strategies to inhibit or slow progression to higher level of need.
21. The Australian Blindness Forum recommends that an entitlement scheme be supported by appropriate public awareness and prevention campaigns.
22. The Australian Blindness Forum recommends investment in appropriate research and development strategies to improve outcomes for people with blindness or vision impairment, including assistive technology development.
23. The Australian Blindness Forum recommends the development of strategies which enable accurate data collection and utilize the sharing of systemic data to promote and develop improved services for people with blindness or vision impairment.

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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 extensive participation of the following members to inform the preparation of this submission: the Australian Deafblind Council, Blind Citizens Australia, Guide Dogs NSW/ACT, Macular Degeneration Foundation, the Royal Institute for Deaf and Blind Children, Royal Guide Dogs Tasmania, the Royal Society for the Blind in South Australia, and Vision Australia. Expert advice during the consultation process was also provided by Carla Anderson, Able Australia; Dr Chyrisse Heine, Healthy Ageing Research Unit, Monash University; and Jan Steen, Executive Director NSW Statewide Ophthalmology Service Agency for Clinical Innovation.

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>.

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