Guide Dogs NSW/ACT and Guide Dogs Australia

This submission to the Productivity Commission in response to the Disability Care and Support inquiry is provided by Guide Dogs NSW/ACT on behalf of Guide Dogs Australia ('GDA'). GDA is the federation of Guide Dog organisations that provide Guide Dogs, cane training and other services that enable people with vision loss to move safely about the community and gain independence.

Vision Loss

Mobility training is one of the two most needed services by blind and vision impaired people (regional presence the other)¹. GDA primarily provides Guide Dogs and mobility (and other) services to about 12,000 people per year.

According to *Clear Focus*², in 2009, 234,000 Australians over the age of 40 had vision loss not caused by refractive error (ie vision loss that cannot be corrected by glasses or contact lenses). The total economic cost of vision loss to Australia was estimated at \$16.6B:

- Productivity costs of \$2.28B
- Carer costs of \$251M
- Indirect costs of \$839M
- Deadweight costs of\$869M
- Loss of well being of \$9.4B
- Direct health costs of \$2.98B.

Clear Focus also demonstrates that vision loss results in:

- Risk of falls doubling
- Risk of depression tripling
- Risk of hip fractures increasing 4-8 times
- Admission to nursing homes occurring 3 years earlier
- People being twice as likely to use health services.

The impact of vision loss on individuals and the Australian community is substantial and can be significantly reduced by providing services to assist people to become more mobile and independent enabling them to be active, productive members of society.

Activity Prior To This Submission

- GDA representatives reviewed the draft report and additional paperwork
- GDA teleconferenced and met to discuss the impact of the scheme on people with impaired vision
- GDA representatives attended the Productivity Commission hearings in Hobart, Brisbane, Melbourne and on Sydney (15th April 2011)
- GDA members consulted in preparing this submission.

GDA Submission

GDA welcomes the development of a National Scheme that reduces inequity in the area of disability services. We are pleased to note the inclusion of sensory impairment and particularly early intervention which will circumvent any exacerbation of the person's disability and help break the cycle of learned

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¹ Vision Australia survey of blind and vision impaired people in NSW, Vic and Qld in 2004 involving 90+ focus group meetings

² Clear Focus – the Access Economics and Vision 2020 study Economic Impact of Vision Loss in Australia in 2009

helplessness. We also applaud the scheme design as it provides the individual with choice, which leads to empowerment and improved standards of service delivery.

We are delighted to have the opportunity to contribute and make the following 3 recommendations to refine the report and deliver an equitable and effective model; review of eligibility criteria, range of services included and standards of guide dogs being included in the scheme.

1 Eligibility Criteria

a. Condition

The vast majority of people with vision impairment or blindness were not born blind. Most lose their sight gradually over a period of years – often decades. Some children are born blind whilst other people lose their sight more quickly or even instantly through injury or accident.

There are many causes of vision impairment, the most common in Australia being:

- Age-related Macular Degeneration
- Cataracts
- Diabetic Retinopathy
- Glaucoma
- Retinitis Pigmentosa
- Neurological Vision Impairment.³

Vision impairment conditions can involve loss of central vision or side vision or indeed the whole field of vision. Sometimes people can see in front and to the sides but their vision is blurry. Other people may see well in daylight but experience great difficulty indoors or at night. There are many combinations of these symptoms. It is important to understand that each person is affected in different ways by their vision, its changing nature and their own circumstances. Vision impairment can have an impact on a person's ability to function effectively in their home, workplace, school and out in the community.

Functional Implications of Low Vision and Blindness

As is recognised in the draft NDIS report, we believe the needs of the individual are of key importance, the particular condition is not. It is the functional impact of the vision impairment, coupled with any other associated disabilities that must be considered. Clinical measurement done under "ideal" rather than real world conditions does not provide a true indication of the functional needs of the person. Two clients with identical clinical vision can function quite differently. Assessment of need should be based on the functional needs of the person not on their clinical vision measurement.

b. Age

We believe the Commission should raise the cut-off age from 65 years to pension age. This would allow coverage of people still working and/or those contributing to society and allow them to continue to contribute rather than rely on welfare and the associated costs to society. We believe there is a strong cost benefit case that supports this recommendation as well as a strong quality of life argument.

With approximately 5% of the population aged 65 to 70 – an age at which many people will experience functional loss as a result of vision impairment for the first time – and productivity and deadweight costs of vision loss totalling \$3.2B raising the eligible age to the retirement age will result in significant savings. In addition to helping older people remain employed or otherwise productive members of society, the

³ Clear Focus

cost saving through reduced falls and injuries and keeping people out of care facilities will amount to hundreds of millions of dollars each year.

In the case of people with degenerative diseases, such as Age Related Macular Degeneration ('AMD'), eligibility for people under retirement age should be based on a needs assessment as it should be for people with any other condition. Eligibility would be based on the age of onset of functional impact, rather than the time of diagnosis. For example, someone diagnosed with AMD at age 60, but who only experiences functional impact at 75 should not be covered under the scheme.

As many vision impairment conditions will develop after retirement age, when people are covered under the aged care system, we urge the Productivity Commission to review the Aged Care system in order to be more equitable in meeting the needs of older Australians living with impaired vision.

c. Needs Assessment

In a needs-based system, determining people's needs is the most important and difficult consideration. Eligibility criteria will vary according to people's age, activities, desires, location and numerous other factors. Significant work will need to be invested in determining eligibility criteria and appropriate assessments tools for identifying a person with impaired vision's need for services to enable them to continue to be valued and contributing members of society.

Any assessment tools will need to address the functional impact of vision loss. GDA offers to assist the Commission in defining the complex needs-based eligibility criteria, in line with the Federal Disability Standards, that will be required to identify a person with vision loss that warrants support by the Scheme.

2 Key Services

Through the provision of appropriate services, people with impaired vision can remain or become to different degrees mobile and independent. With the services listed below, vision impairment need not prevent employment, volunteering, participation in social activities, caring for others, or almost any other form of active participation in productive community life. Following are the key services deemed necessary to maximise the mobility, independence and productivity of a person with vision impairment:

Skill Set	Definition	Functional Examples	Outcome
Orientation	Knowing where you are in the environment	A person commences employment but needs assistance so that they can travel independently to their place of employment. This may include use of public transport, route knowledge and building identification	By the commencement of their employment, the person is able to travel independently and confidently to and from their workplace Person should also be able to move around safely in their workplace and to nearby facilities i.e. café / bank / shops
Mobility	Being able to safely and independently move through an environment	(i) A person with low vision may need to use a small cane (an ID cane) to assist with safely negotiating busy environments and when hailing buses	The person is able to move around safely, confidently and be independent. This enables them to gain or maintain employment, volunteer, assist their

	with, confidence, grace and dignity	(ii) A person with a significant reduction of visual fields and associated night blindness may need to use a long cane to safely detect ground level hazards in the day but to move safely in low light conditions (iii) A person with limited functional vision may require a guide dog	family by caring for grandchildren
Vision Training	Maximising the use of residual vision	A person with early stages of AMD finds it difficult to get out and about. A few hours of training are provided so that the person is able to use their remaining vision.	The person is able to be independent; safely cross roads, negotiate stairs and use public transport to get out into their community.
Neurological vision training	Specific training for people with vision loss associated with acquired brain injury	While individual requirements vary, program teaches the person how to compensate for their vision loss and restores confidence. Also includes scanning strategies or if required, a mobility aid.	Following a stroke related vision loss, the person is able to scan consistently so that they can travel safely and return to work
Children's Services	Specific training for children	Orientation and Mobility Instructors work with children, their parents, families, carers and other professionals to ensure that the children's current and future mobility needs are met	An annual review of O&M skills and needs, in collaboration with the child's family, is conducted for any child with low vision or blindness to help circumvent mobility and conceptual problems later in life. This annual review may or may not lead to intervention.
Technology	Equipment specifically designed to assist people with impaired vision	Current technology includes items such as Miniguide (a hand held sonic device), talking GPS (which provides the person with GPS information in an accessible format for orientation and location information, ie when to get off a bus)	Miniguide reduces injury GPS enables person to easily locate places without having to get professional or family assistance, travel with greater confidence, flexibility and independence

Independent Living Skills	Activities, equipment and training (including occupational therapy) associated with everyday living	Training, skills and equipment to enable a person to be independent with activities of daily living, such as cooking, self care etc	The person is able to care for themselves without assistance or with limited assistance.
Employment Services		Assistance to locate and maintain employment	The person is gainfully employed
Communication	Use of Braille, Large Print and technology	Reading alternatives	The person is able to access information
Low vision services	Low Vision Clinic, low vision aids and equipment, orthoptist assessments and visits	Maximises use of existing vision to assist with visual activities	The person is able to undertake activities which require reading, writing, viewing and detailed vision
Case Management		Ensuring comprehensive suite of services are provided in a timely manner	Person achieves their goals and has confidence to participate ad contribute to society

Provision of these services will enable people with vision loss to be mobile within the community, more independent, have a greater quality of life and be more productive members of the community. Outcome standards and eligibility criteria's for all these services will need to be developed and GDA is well placed and available to assist with their development.

Early Intervention

Early Intervention under Tier 3 of the proposed NDIS is important for both children and adults with vision loss. However the same eligibility criteria can not be applied to children and adults.

For children, even mild low vision can have a severe impact on a child's learning, as it is estimated that at least 70% of learning is done visually and often incidentally. Therefore the eligibility criteria for children must be more flexible and broader to enable better outcomes later in life. The confident young children of today are the independent adults of tomorrow.

Adults experiencing vision loss experience grief and the challenge of adjustment from their previous life to their new circumstances. Early intervention can be pivotal in empowering the person to embrace independence, circumventing the downward spiral into depression and learned helplessness.

Episodic vs. constant need for services

People with vision loss will generally have a need for episodic services rather than require constant lifelong service provision. Adults with progressive vision loss experience recurring need for services as their vision deteriorates, whilst those with non-progressive vision loss will require service as their life changes. Under the current proposed Scheme, there is no mention about the need for episodic service will impact on a person's re-entry into the NDIS.

Examples of when O&M services may be required with progressive vision loss:

6/12 visual acuity Loss of drivers' licence: need to access alternative transports; anxiety about

independence and mobility. The degree to which this is disabling will depend on

person's circumstances.

6/18 visual acuity Low vision: impacts on reading, print access, confidence, glare, fatigue, anxiety,

colour, contrast, lighting sensitivity, mobility.

6/60 visual acuity Legal blindness: need to use alternative strategies and senses other than vision

to perform many tasks, including mobility.

Blind No light perception: need full long cane skill set for independent mobility

GDA recommends that a simplified re-entry system be a part of the NDIS and are happy to work with the Commission to provide guidelines.

3 Guide Dogs and quality standards

GDA welcomes the inclusion of Guide Dogs in the Scheme and the appreciation by the Commission of the extraordinary value of the Guide Dog for certain people with vision loss. Currently there are over 800 Guide Dog users in Australia.

Outcome standards ensure the provision of safe and effective guiding dogs. GDA has prepared an outcome standard that is currently being finalised for Australia and will be offered to the International Guide Dog Federation later this year. This serves as a pass/fail determinant for Guide Dogs covering core competencies. The current standard is provided to the Commission in appendix 1.

With Guide Dogs, as for any other orientation and mobility service, eligibility criteria help determine a cutoff point for inclusion onto the Guide Dog program. GDA offers to assist the Commission in preparing the eligibility criteria for Guide Dog services as with other services.

GDA's Role under the NDIS Tier System

Whilst GDA is best known for the provision of Guide Dogs, it already acts as a Tier 1, Tier 2 and Tier 3 provider for people with vision impairment.

- Tier 1 service is provided via education for the wider community about our services and the needs
 and rights of people with impaired vision, through campaigns such as International Guide Dog
 Day, International White Cane Day, other educational initiatives including 'Working Together' and
 'Don't turn a blind eye' and ongoing community programs.
- Our role as a Tier 2 provider is currently undertake by O&M Instructors who provide referrals to other service providers as part of their individually tailored service to clients.

• Our Tier 3 service is our most visible service, through the training and provision of guide dogs, O&M services and other services to people with impaired vision.

Under the NDIS GDA would continue to operate at all levels including at Tier 2 and Tier 3, building on the expert provision of service in Tier 3, and expanding the referral services offered within Tier 2, whilst continuing and building on its community education role in Tier 1.

Conclusion

In conclusion, Guide Dogs Australia welcomes the inclusion of people with vision loss under the National Disability Insurance Scheme and the inclusion of support via the provision of Guide Dogs and asks that the Commission also include support for provision of all key services. GDA is happy to assist the Commission in any way, including the provision of draft service standards and eligibility criteria for all services for people with vision impairment, several of which are already prepared or in development.

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APPENDIX 1 – OUTCOME STANDARD SAMPLE – GUIDE DOG TEAM

For a Guide Dog Team to graduate, a review of the Team working must demonstrate the following capabilities:

1. Handler

- The Handler is oriented and understands the route that is being travelled. The Handler is making decisions about changing direction, crossing roads, finding objects and accordingly giving commands to the dog; and in this way is demonstrating that he/she is anticipating the route that is being travelled.
- The Handler is not relying on the dog to make decisions about the route to be travelled or relocation of destinations. It should be evident that the Handler is using the dog as a mobility aid and as a safe and effective guide through the environment chosen by the Handler.

2. Walking

- The harness handle is held adjacent to the Handler's hip (or up to 100mm in front of the hip), with a slight forward bend in the elbow. The Handler should not stoop. There should not be excessive or obvious tension.
- The Team travels approximately central to the pathway and as directed by the Handler.

3. Obstacles

The dog recognises an obstacle, including well defined overhead obstacles, and navigates around
it, allowing sufficient room for the Handler to avoid contact. Overhead obstacles may require
specific orientation.

4. Change of direction

• A change in direction of travel should only occur as directed by the Handler.

5. Stopping

The dog should stop within 3 paces of an appropriate command being given by the Handler.

6. Stairs

- The dog should indicate any change in surface levels.
- The dog must stop at the start of stairs (at both the top and bottom of the stairs), ascending or descending and must only proceed when directed to do so by the Handler.
- The Handler may be holding the harness handle or just holding the lead during the travel on the stairs.
- The Handler may allow the dog to travel straight over up kerbs on road crossings.

7. Roads and Crossing

- The dog consistently stops at, or up to 300mm before, the downside of a well defined kerb of a road. An undefined kerb / edge may require specific orientation.
- The dog only proceeds when directed by the Handler.
- The dog takes the shortest and most direct line across road.

• The Handler is responsible for making all safe road crossing decisions.

8. Private and Public Transport

- The dog is capable and sound when travelling on all forms of transport (public or private) required by the Handler and performs in accordance with the above standards.
- The dog approaches, climbs into the vehicle and out of the vehicle as directed by the Handler.
- The dog is controlled, calm and positioned as directed by the Handler whilst on any transport utilised by the Handler.

9. Relieving

- The Handler must provide the dog with appropriate toileting opportunities.
- The dog, if it needs to relieve, should reliably respond to a relieving prompt when given by the Handler.
- The dog should not relieve during walks. If necessary, the dog should indicate a requirement to toilet and should be capable of waiting until given the appropriate prompt by the Handler.

10. Concentration (focus on the guiding task)

- **Distraction.** The dog remains focussed on guiding and / or responds to effective control in order to effectively guide as defined above. This includes when the dog is passing potential distractions such as food, dogs, cats, birds and other animals.
- **Control.** A dog is regarded as effectively controlled if it responds consistently to Handler correction / direction without a requirement for repeated firm corrections or excessive tone or volume (shouting).
- **Startled.** If the dog is startled (eg. a loud noise, sudden unanticipated confrontation), it must recover within 3 seconds and resume guiding.
- **Suspicion.** The dog should not display inappropriate fear reactions to familiar stimuli or stimuli that could readily be assumed to be familiar. The dog must recover within 3 seconds and resume guiding in response to any suspicion that may occur.

11. Control and Commands

- If a command requires an immediate (Direct) response (eg sit, down, no, leave it, etc), the dog must comply within 3 seconds and maintain response until directed otherwise by the Handler.
- If a non-immediate command (eg find left / right, forward, find the door, relieving command, straight on, find the...) is given, then the dog responds as soon as it is able or as the opportunity arises.
- The Handler must be able to control the dog without excessive volume or tone and without resorting to excessive physical correction of the dog.
- The dog should be able to be trained to relocate specific destinations.

12. <u>Public Acceptability</u>

- The dog presents to the public as clean, well groomed and healthy.
- The dog demonstrates no overt signs of aggression or protective behaviour.
- The dog is not excessively or unacceptably vocal.
- The equipment is serviceable and functional.