

AUSTRALIAN BLINDNESS FORUM

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April 2011

Response to the Productivity Disability Care and Support Draft Report

About the Australian Blindness Forum

The Australian Blindness Forum (ABF) 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 blindness organisations providing services to people with blindness or vision impairment and the consumer organisations, Blind Citizens Australia and Blind Citizens WA.

Members of the ABF 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, 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 ABF may be found via the website at:

www.australianblindnessforum.org.au

Disability Care and Support Draft Report Overview

The ABF commends the Productivity Commission on its efforts to reform the disability system and ensure people with disabilities have an entitlement to services and the consequent need to significantly increase funding to achieve this outcome. This is also in accord with Australia's commitment to the United Nations Convention on the Rights of people with a disability (UNCRPD).

In addition the ABF fully endorses the Productivity Commissions initiatives including:

- Client Choice
- National benchmarks, and
- Early Intervention

The ABF however is concerned over a number of recommendations in the Draft Report that are discussed in detail below including:

- Imposition of an arbitrary age barrier for eligibility
- Cost shifting of services for people over retirement age to the Aged Care Sector (for which no provision has been made)
- Focus on a model built around personal care services, and
- The concept of “tradeoffs” and how this will be applied to ration services (indeed the lack of availability of a Braille version of the full report excluded some ABF members from being able to consider the implications of the Draft Report in their format of choice as some one considered this to be a “trade off”)

The ABF’s members share the common goal of enabling people who are Blind or Vision Impaired to realize their potential through the acquisition of skills to provide independence and ability to participate in their community. Whilst a similar stated goal is included in the Draft Report this is then lost on the focus on personal care rather than skill acquisition.

It is also the ABF’s view that the Productivity Commission’s Draft Report has been developed to improve the quality of life for people with or acquiring disabilities in the future. Accordingly it believes that the Productivity Commission needs to either ensure that no person with a disability will be worse off as a result of their recommended changes or alternatively identify who these changes will negatively impact on and the outcome of this for the individual.

Of concern also is the concept that prior to any intervention the Draft Report already limits a person’s eligibility based on “reasonable” as opposed to “aspirational” needs. Whilst the ABF appreciates that this is a method of cost control we are seeking further information on how and who decides this.

Recommendations

The ABF recommends that the Productivity Commission for Disability Support consider the following amendments:

1. Review the Draft Report to ensure that no person will be worse off under the proposed system or if a decision is made to continue to identify who will be negatively impacted.
2. The ABF believes that the Productivity Commission needs to define more clearly what it considers to be a “reasonable” cost and who will decide the application of this.
3. That the Productivity Commission Reports into *Disability Care and Support* and *Caring for Older Australians*, be considered jointly. This is due to the introduction of an arbitrary boundary based solely on age and will assist in ensuring that all people who are blind or vision Impaired have access to their entitlement to specialist services.
4. That if a decision is made to segregate service access and responses based on an arbitrary age, that interfaces be created before any changes are made to ensure that this is not provided in a discriminatory manner and that, irrespective of the funding source, services are identical in terms of quantum, quality, timeliness and payment for all people with vision loss.
5. The Productivity Commission acknowledges the unique needs and nature of services for people who are blind or vision impaired including the episodic nature of responses normally required and the emphasis on skills development, rehabilitation process and client participation which are already in place.
6. That the Productivity Commission review the data relied upon within the Draft Report and in particular review the impact of unmet need and services funded independently by the Not For Profit sector.

The ABF also believes further information is required with regard to how consumers not seeking an individual package of funding will access and receive specialist services.

7. That for specialist services the Productivity Commission review the exclusion of block funding and work with the Vision Loss Sector to create appropriate benchmarks and outcome measures
8. The Productivity Commission define further how the current system of assessment and referral will work in the future and how it will minimize unnecessary assessments, barriers and obstacles created through case management of people requiring episodic interventions.

9. The Productivity Commission develop strategies for ongoing research into not only the efficiency and cost effectiveness of interventions but to investigate and implement new strategies including new technologies.
10. The Productivity Commission develop strategies for the maintenance of specialist staff including for instance Orientation and Mobility Instructors, Guide Dog Instructors etc.

The Two Reports

The ABF notes the release of the two Productivity Commission Draft Reports on “Disability Care and Support” and the “Caring for Older Australians”.

While not a natural part of the ageing process there is a strong correlation between ageing and sensory loss with some ABF members reporting that up to 80% of their client group are over the age of 65 years. Accordingly, people who are blind or vision impaired will rely on both the new “Disability System” and new “Aged Care System” to maintain their independence and quality of life.

In the ABF’s view the Productivity Commission Draft Report on *Caring for Older Australians* makes no acknowledgement, provision or indeed comment on the needs for people over retirement age with a disability and how the system will respond.

As a result it is the ABF’s belief that these two Draft Reports need to be considered together and not in isolation as is currently the case.

It is acknowledged that a “building block” approach is being taken to the work being done by the Productivity Commission and indeed the *Disability Care and Support Draft Report* acknowledges that “drawing the exact boundaries between the responsibilities of the two systems (age care and disability) is not straightforward.”

The ABF believes that the Productivity Commission needs to develop a more detailed explanation of how the continuum of care would operate between the two sectors and, in particular, detail the interface and the role that specialist service providers have within the two systems.

Early Intervention

The ABF supports the emphasis the Productivity Commission places on Early Intervention. The ABF agrees that this is a forward thinking strategy that is both cost effective and enables the avoidance of the crisis that may occur as a result of un supported vision loss including loss of employment, mental health and physical health issues.

To be effective early intervention for people who are Blind or Vision Impaired needs to be available as close to diagnosis as possible and as part of a

continuum of care. Accordingly the proposed system needs to educate referral bodies and provide support at this time, something that already occurs with a number of blindness agencies now.

It would seem that a better use of resources rather than replicate an existing system and add a further layer of management would be to strengthen what currently occurs and embed this in a new system.

Examples of services provided by ABF members that fall into this category include:

- information on the impact of vision loss, strategies and equipment available
- counselling on the adjustment to vision loss
- peer support
- recreation and leisure activities
- home safety assessments
- lighting assessments
- low vision clinics
- adaptive technology
- orientation and mobility
- independent living skills

The ABF's concern is with regard to comments that an agency responsible for budgeting of funds, having no intimate knowledge of the sector is taking carriage of the responsibility of what it considers based on medical or university research to evaluate "the optimal intensity, timing and duration of interventions".

Clearly whilst the ABF believes in appropriate standards and benchmarks individuals recovering from the trauma of vision loss or other changes in their life will do so at different rates and need to be supported accordingly and not up to some artificially determined quantum of service. It would plainly be ridiculous and not cost effective to deliver a mobility package where the funds available enable a person to orientate and navigate to the end of the street but not enable them to cross the road or utilize public transport based on research conducted in another State on another individual.

Therefore the ABF believes it needs to be involved in any work that is done to determine early intervention guidelines.

Unique Needs of people who are Blind or Vision Impaired

People who are Blind or Vision Impaired face unique challenges which are generally overcome with specialist training or equipment and not through the provision of personal care which many blindness agencies view as a dependence model.

For instance an individual whose independence is threatened through an inability to clean their house, the Draft Report's response based on the model of generic assessments would be the provision of an ongoing cleaning service possibly from a person with no prior training or knowledge of the functional impact of vision loss. This may indeed, by default place the person at risk of falls or other injuries or disempower them further, for instance by the person reorganizing their kitchen or furniture.

However the Vision Loss Sector's response would be to retrain the individual to be able to undertake this task themselves, hence both empowering the individual and providing a cost effective long term solution.

For people who are Blind or Vision impaired, whilst there a number of ways of initially entering the Sector, the vast majority are referrals from the primary medical sector with ABF members providing a continuum of care. There is a concern that the proposed system by introducing a further unnecessary tier of case management is not only wasteful but will be also be likely to create delays and barriers to the receipt of services (refer attached case studies).

Services for people with vision loss are also "episodic" as opposed to a personal care model which tends to be whole of life. That is, people will seek rehabilitation support from specialist providers, achieve their goals and move out of the system, coming back typically at times of transition or change.

For instance if a person moves house and requires re orientating to their new environment this may require 4 hours of specialist training but will enable them to independently traverse their environment until there is a further change. Alternatively if this person requires a replacement cane tip, total cost \$10, in either of the above circumstances the most timely, cost effective and logical method of meeting these needs, is direct contact with a specialist agency not having to navigate the NDIA.

Given the specialist and episodic nature of services which are generally not available from a generic provider, the ABF is offering three options to mitigate this namely:

1. The creation of "Trusted intermediaries" being specialist organizations trained in ensuring people are eligible based on National Disability Insurance Agency (NDIA) eligibility criteria for early intervention services. These organizations are able to deliver at a pre agreed rate a package of services to a fixed monetary amount for which they would report and invoice NDIA. Over this amount they would refer onto the NDIA.

2. Creation of a fourth tier which enabled a fast tracking of people meeting a certain criteria to a specialist provider for a specific quantum of services. This is believed to be consistent with comments regarding “warm referral”.
3. Block funding of specialist agencies to deliver services as exists under the current system.

Assessments

Generic disability assessment tools in spite of many attempts to the contrary do not reflect the needs of people with a vision impairment. Indeed, most are designed to assess the personal care services needed by people with an intellectual disability or a brain injury. The ABF does not agree with this “one size fits all” concept and believes that for services to be effective they need to be built around the individual’s aspirations with an appropriate assessor.

In order to assess the specialist needs of a person who is Blind or Vision Impaired, an assessor will require at the very least an understanding of:

- Eligibility criteria
- Functional impact of vision loss
- Strategies to overcome this functional impact
- Services and technology (which changes frequently)
- Environmental barriers e.g. internet or physical access

These skills and knowledge do not exist in the generic disability sector.

Therefore the ABF believes that the Vision Loss Sector is best equipped to conduct specialist assessments, however, if a decision is made to adopt a generic assessment tool, then it is essential that it be tested to ensure it identifies the issues faced specifically by people who are blind or vision impaired and results in a referral for specialist services in a timely manner.

A Case Study is included below demonstrating current protocols.

Age

The Productivity Commission’s Draft Report for Disability Support is recommending that people over retirement age receive access to specialist services from the Aged Care sector, where as the Productivity Commission’s Draft Report, *Caring for Older Australians*, firstly makes no provision for these people and further states that a co-payment for personal support services will be required. Accordingly the ABF is seeking information on whether this co payment applies to specialist disability services.

It is the ABF’s view that if the Productivity Commission supports one group of people with vision loss to an entitlement but not another based solely on age they may be in breach of Commonwealth and State Government Legislation

addressing both Age and Disability Discrimination. In addition it is in breach of the UNCRPD which requires an entitlement for all people with a disability without reference to age.

The ABF also rejects the notion that vision loss is part of the “natural” ageing process and that the needs or specialist services for people with severe vision loss change substantially for people over or under the age of 65.

Indeed, the ABF is querying, other than as a cost shifting mechanism, why an arbitrary boundary is required as the service responses are identical irrespective of age. It also appears from the Draft Report on the Age Care sector that there is no provision for any additional funding to support rehabilitation services to people with a disability. This appears to continue the misconception that the only services that will be required are of a personal care nature which demonstrably is untrue.

Accordingly the ABF believes that irrespective of the funder or the age of the person that there is a right to equitable access to specialist services in a non-discriminatory way.

Cost of Blindness

Whilst being conscious that the Draft Report notes the need to ration and be realistic with regard to what services and supports will be funded there is also a need to realise that for a person who is Blind or Vision Impaired there are costs unique to the disability including:

- Personal costs including increased power charges to accommodate a higher level of lighting,
- Purchasing properties close to public transport and facilities at a premium price,
- Specialist equipment,
- Materials being transcribed into alternative formats,
- Opportunity cost of not being able to identify specials when shopping

For people who are Blind or Vision Impaired access to specialist equipment is a key component of being independent. Unfortunately in many states of Australia people who are Blind or Vision Impaired are excluded from these schemes. A new system needs to ensure the inclusion of people who are Blind or Vision impaired and not accept that cost should be the driver for denying access.

Clearly any assessment needs to be capable of identifying and quantifying the realistic costs of Blindness and Vision Impairment.

Data

At the ABF Forum on the Productivity Commission Report on Disability Care and Support it was acknowledged that the researchers did not have access to meaningful and accurate data. This is exacerbated by the fact that the current data collection by governments on disability is poor and relates primarily to funded services discounted to the Government contribution.

No data on services which are unfunded or unmet need is collected.

Given there are 69,000 currently identified as Legally Blind by Centrelink and another estimated 3-400,000 people that have severe vision loss, the ABF therefore believes that the Productivity Commission has underestimated the true demand for specialist services to people who are Blind or Vision Impaired.

Accordingly, the ABF is concerned given as noted above, other comments already regarding rationing about the impact of this unassessed demand on both the Productivity Commission Reports and ability to provide in a sustainable manner a fair and equitable system. Of greatest concern is that this unassessed demand will cause the system to further ration or not accept new referrals.

Individualised Funding

ABF's members that have researched and observed the overseas experience with Individualised Funding in the Vision Loss Sector report that as it is a rationed system people who are Blind or Vision impaired never reach the required priority level to receive a funded package.

The ABF supports the Productivity Commission in providing consumers choice with regard to accessing services. However, the Draft Report is unclear with regard to the funding options for clients seeking direct access to specialist services rather than a "funded package".

Benchmarks

The ABF membership fully supports National benchmarks and many of its members have led the way for many years in obtaining various quality accreditations. Clearly benchmarks need to be created in consultation with the Sector and represent best practice.

For ABF members the primary concern relates to ensuring that providers are able to deliver appropriate specialist services locally and in a timely manner. This conflicts with the Draft Report in so far as there are no minimum qualifications for providers which may potentially allow sub standard services and indeed compromise the safety and welfare of the client.

For instance a person receiving a Guide Dog from an interstate organisation needs to have access to both regular follow up and immediate problem solving, if not their independence and safety are potentially placed at risk. Therefore in choosing a provider safeguards need to be in place to prevent this occurring.

It is also important that “timeliness” benchmarks are established to ensure the full benefit of early intervention is realised.

Research

The ABF supports the Productivity Commission’s recommendation on the need for research and evaluation processes.

The ABF believes that research is vital both for current interventions and to assess new technologies and service methodologies. However it is concerned over the primary focus being linked to cost effectiveness rather than measures to assess the impact on an individual.

Further in a chronically under funded industry the costs of undertaking clinical research for skills development appear illogical given many of the specialist services provided are to enable an individual to undertake a specific task or activity. For instance:

- Orientation and Mobility services are provided to enable a person who is blind or vision impaired to independently orientate and transverse their environment. The outcome is whether or not the person is able to achieve independent travel, clinical evidence of this is irrelevant.
- Activities of daily living enabling a person to clean their own house is demonstrated by the ability to maintain independently their house.

Accordingly ABF members have significant difficulties with the concept, firstly of a recommended trial whereby people are denied services in order to compare the difference.

Specialist Services for people who are blind or vision impaired are tailored to meet the individual aspirations, environment and life experiences which do not fit within the confines of a control randomised study that requires a large number of people with the same attributes to complete the same program.

Secondly, particularly if external organisations such as hospitals and universities are contracted to provide research as indicated then there needs to be significant discussion on primarily what it is to be researched, is it based on Quality of Life? Outcomes? If not what?

The ABF is also concerned that the cost of research will be shifted to the Sector to satisfy NDIA of a “financial cost benefit” before a service will be funded. This does not recognise that most specialist services for people who

are blind or vision impaired are recognised therapies or interventions such as Orientation and Mobility (and are outcome based).

ABF members believe that as with any intervention there needs to be measurement and justification for its delivery however the research as proposed is both narrow and will not assess the value of intervention. Accordingly the ABF believes that this requires further thought by the Productivity Commission.

The sector has previously demonstrated the benefits of services through Quality of Life surveys in assisting people to maintain their independence however this does not meet the criteria suggested by the Draft Report, noting that this intervention must demonstrate cost effectiveness.

Workforce

The ABF is disappointed and again this can be linked to the focus on personal care that the Draft Report does not consider the need to maintain the specialist skills and workforce required to deliver specialist services to people who are blind or vision impaired. Indeed the ABF rejects the comment that staff only acquire “empathy, practice and good communication skills with on the job training”.

Whilst this may be true for personal care, the ABF would appreciate how this would apply to training of a person with a Guide Dog or white cane.

It is critical that the Gateway systems being recommended for both assessment and early intervention have a workforce which is knowledgeable about the functional impacts of vision loss and the services available from specialist service providers.

Many of the services noted throughout this response are very specialist in nature and require detailed knowledge of vision impairment and the service responses. In many instances the specialist knowledge and experience is obtained through cadetship or on the job training that will not be available in a generic setting. It is highly unlikely a non specialist provider will invest in training people in, for instance, Braille, mobility or training a Guide Dog.

At the current time, ABF members agree that the Industry Skills Council for Community Services is not proactive in assisting current courses to generate a supply of people trained in the provision of specialist services for people with disabilities and at the time of preparing this response consideration of “sensory loss” is not included.

Case Study

Joe is 23 and has recently experienced total vision loss due to glaucoma. He has been referred to the RSB by his treating ophthalmologist for orientation and mobility training. His family is from the Philippines and have no knowledge of services or that people who are blind can be independent. Joe spends his time sleeping or listening to music and is unable to leave the house.

Joe responds well to Orientation and Mobility training. He receives 250 hours of training to develop his travel skills and is able to travel several routes independently.

He decides he would like to live independently from his family and decides to undertake training in a range of independent living skills including banking, cooking, shopping and cleaning. He also learns Braille. He uses volunteer assistance to manage his mail and bills.

Joe decides he would like to work as a masseur and is referred to the RSB's Employment Services to look at his employment options in this field. He decides to undertake study in massage. His text books are transcribed into Braille and tactile diagrams are developed for the anatomy components.

Although he becomes highly qualified in different forms of massage, he is unable to obtain employment for some time. While looking for employment he decides to participate in pottery classes. He again requests further Orientation and Mobility training to learn the route to the class.

Joe also attends church regularly and requires the hymns and prayers transcribed into Braille each week.

Eventually he is successful in obtaining employment and needs to learn the route to his new place of employment within one week. He again requires Orientation and Mobility training.

Outcomes from Specialist Intervention

Joe

- Is in employment and has maintained it for several years
- Is an independent traveler only requiring intervention for new routes
- Is living independently
- Is active in his chosen recreation and leisure activities
- Continues using volunteer assistance for mail
- Continues to have hymns and prayers transcribed into Braille

Service	Current System	Proposed System	Services which are Time Critical
Initial Referral from Ophthalmologist to Vision Loss Agency	√	√	
Vision Loss Agency refers to NDIA and provides information to client and family on all services in alternate format		√	
NDIA Assessment		√	
NDIA refer to Vision Loss Agency for Orientation and Mobility training		√	
VLA Specialist Assessment	√		
Provision of Orientation and Mobility training	√	√	
Completion of service protocols for NDIA		√	
Referral to NDIA for Independent Living Training, Braille training, career counseling, volunteer assistance		√	
NDIA Assessment		√	
VLA Specialist Assessment	√		
NDIA refers to Vision Loss Agency		√	
Provision of Independent Living Training, Braille training, career counseling, volunteer assistance	√	√	
Completion of service protocols for NDIA		√	
Referral to NDIA for Educational assistance, transcription of texts, transcription of hymns and prayers (needed weekly)		√	√
NDIA Assessment		√	√
VLA Specialist Assessment	√		
Provision of services by Vision Loss Agency	√	√	√
Completion of service protocols for NDIA		√	
Referral to NDIA for Employment Assistance, Recreation and Leisure and Orientation and Mobility Training (needed within 1 week for job)		√	√
NDIA Assessment		√	√
VLA Specialist Assessment	√		
Provision of services by Vision Loss Agency	√	√	√
Completion of service protocols for NDIA		√	

Conclusion

The ABF membership has considered the Draft Report and believes there are a number of commendable initiatives, including:

- The recognition of an entitlement for people who have disabilities.
- The introduction of early intervention strategies.
- The injection of funds into a chronically under funded system.

However it believes the architecture created is to meet the needs of people with physical, intellectual disabilities or complex needs and does not assess and provide timely intervention of specialist services for people who are blind or vision impaired.

Accordingly the ABF has provided a number of recommendations for the Productivity Commission's consideration. In the interim if you require any further information regarding the above, please do not hesitate to contact the undersigned.

Yours faithfully

Andrew Daly
Chairperson