



# Australian DeafBlind Council

Australian DeafBlind Council (ADBC)

Submission:     Response to Draft Report  
                      Productivity Commission Inquiry into Long Term Disability Care and  
                      Support Scheme

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## INTRODUCTION

The Australian DeafBlind Council (ADBC) was initiated following the National Deafblind Conference in Melbourne in 1993. It was established to meet the need for a national deafblindness network and representative council working with and for people who are deafblind and their support networks, including professional organisations. At present, ADBC represents the estimated 288,000<sup>1</sup> people, including older people who are deafblind and supports their families, professionals and organisations working in the field.

ADBC seeks to improve conditions and to be an advocate for people who are deafblind across Australia, as well as their families and encourages their self organisation and self determination by:

- Disseminating and being a source of information on deafblindness
- Providing a forum for collaboration and debate, and
- Co-operating with government bodies and organisations
- Taking up issues of concern to people who are deafblind, their families and support networks and organisations

ADBC also seeks to be the hub of a national deafblindness network.

ADBC is committed to educating members of the public about deafblindness since this unique dual sensory disability affects an individual's mobility, their ability to communicate and generally leaves them isolated from the community and information, and significantly affects their education. With adults and children, the dual disability affects an individual's ability to function independently, as well as causing difficulties in developing social networks and independent travel.

ADBC is an unfunded body, despite strenuous efforts to obtain funding, and is Australia's only national information service on and for people who are deafblind, their families and other persons, professionals and organisations requiring information on deafblindness. It is supported financially by its members and major suppliers of services to people who are deafblind. It obtained \$15,000 funding from the Commonwealth Government's Department of Families, Community Services and Indigenous Affairs for a report on deafblindness that was published in 2004-5.

ADBC would like to commend the Productivity Commission on such a comprehensive response to the systemic problem of disability in this country.

### **Eligibility**

We refer to the criteria for people who are eligible for the National Disability Insurance Scheme (“NDIS”). It is with concern we note that people who are considered to have a “severe or profound disability” will be the only applicants eligible for the NDIS. Regardless of degree or level of vision and hearing loss, the dual sensory loss of deafblindness impacts upon all aspects of life, whether the combined hearing and vision loss is mild or profound. People who are deafblind require ongoing support no matter what the extent of their deafblindness. This must be taken into consideration in the eligibility criteria, given that we process 90% of the world around us via our hearing and sight.

When assessing a person who is deafblind the right professionals who are trained and aware of the issues faced by a person who is deafblind is of utmost importance. To clinically measure a person’s sight loss and hearing loss is important however the degree of communication needs must be taken into consideration. Often the clinical diagnosis does not equate to the need for ongoing communication support and 1:1 human support to maximise their social and economic participation in society. One is not relative to the other.

If the NDIS is truly going to be a needs based insurance scheme then the appropriate referral pathways need to be in place so that a person who is deafblind doesn’t need to re-establish their disability once their needs change. As a person’s requirements change, supports and assistance would also need to change as easily and smoothly as possible.

ADBC is greatly concerned that those above the age of 65 years will not be eligible for NDIS. Deafblindness can be a degenerative sensory disability affecting many people over the age of 65 in one form or another. The support of the NDIS should continue and people should not “age out” into an Aged Care sector that is already at breaking point. If they choose to stay under the NDIS people who are deafblind should not be subject to means testing for the scheme.

The current breakdown of numbers of people who are deafblind indicate that there are some 7000 to 9000 people under 65 and 281,000 over the age of 65 years if people with a mild hearing loss are included based on the Access Economics Report<sup>1</sup>. This figure will grow with the ageing of the population.

A front end deductible of \$500 per year is not a realistic amount for a person who is deafblind to pay. Most people who are deafblind are currently on disability support pensions and just surviving each day on this small amount presents more than a challenge. Due to the nature of a dual sensory disability, in many cases they are unable to work and asking them to pay a front end deductible is something that is unattainable.

### **Interpreters**

Provision needs to be made under the NDIS for more funding for interpreters and even go so far as to fund formal qualifications for Tactile Interpreting due to the chronic shortage of qualified tactile interpreters in Australia. Funding family and friends to assist is not ethical or supportive enough. This could potentially lead to miscommunication between family or friends and a person who is deafblind simply due to the complex nature of their communication needs. Professional interpreting services need to be funded for person who is deafblind so they are able to receive all information they require and are entitled to.

### **Adaptive Technology**

Regardless of whether a person who is deafblind is employed, self employed or on a disability support pension a great financial commitment is required to cover any adaptive technology and support for the individual. Currently adaptive technology is not considered an "essential communication tool" even though many people who are deafblind use these technologies to communicate in their everyday lives. Such technologies used are:

1. Adaptive technology to access a computer including a combination of speech output, Braille output and screen magnification.

Access to a computer provides email and internet and these are both an essential communication tool for people who are deafblind, particularly when they cannot rely on the telephone, radio or TV for information and communication. Email is the preferred communication tool to communicate with service providers and government agencies.

2. A mobile phone so that SMS communication can be used to when travelling or as a backup to their regular TTY service at home. Adaptive technology to access a mobile phone also includes combination of Speech output, Braille output and screen magnification software and often an alternative Braille or qwerty input device.

Other adaptive technologies that enable a person with deafblindness to live independently include a Braille embosser to print their information, a Visual alert and vibrator to notify of door, fire or phone, a Braille clock or wrist watch with a vibrating alarm. Even such devices as hearing aides and cochlear implants are not considered “essential” and once a person turns 21 these are no longer funded. This is unacceptable. Many of these adaptive devices are expensive (up to \$10,000) and accessible and affordable technology is essential in the life of a person with deafblindness to participate more fully in the wider community.

Ablelink in Victoria provides support and training for those people who are deafblind who have some access to these adaptive technologies however, it is only currently funded for 2 days per week. This is unacceptable and more funding is needed to provide these services across Australia to allow people who are deafblind the opportunity to gain training on these adaptive technologies. This service also allows them to meet other people who are deafblind and breaks the cycle of isolation. Accessible and affordable technology and supported training has the potential to open the door enabling people who are deafblind to participate more fully in the wider community

It is more feasible to rely on the groups that currently exist and provide them with funding and support to extend their resources and services so that the deafblind community can access their services. Basic computer literacy in terms of the ability to type on a keyboard and learn basic commands has been shown to improve the ability for a person to uptake new technology, because of both confidence and transfer of skills.

ADBC strongly recommends the creation of a well resourced National Equipment Program that will allow people who are deafblind, regardless of age, to live an independent and meaningful life with minimal reliance on personal support services. One possible solution is an expansion of the current Workplace Modifications Scheme, for which infrastructure already exists and could effectively deliver a National Equipment Scheme.

*Affordable access to communications services and information technologies enables economic participation and promotes inclusive communities, as well as assisting people to live independently.<sup>2</sup>*

### **Governing Body**

We note that the proposed structure for overseeing the NDIS is a National Disability Insurance Agency Board. This Board will have an Independent Advisory Council who will report directly to them regarding matters to do with

NDIS. This advisory council must be made up of people with a diverse knowledge of disability issues and the National Disability Agency Board must undertake to use the advice given by the Independent Advisory Council.

AADC are concerned that if the Independent Advisory Council is not made up of people who are diverse in their knowledge of disability and the Board then doesn't take the advice given, the approach to running an "insurance" scheme may be to take the cheapest service or devices required by a person who is deafblind rather than looking at the right service or device for that individual.

The Board must ensure that they have the right people in the right places for what fits each person's stage in life. It must be a fit for purpose scenario not just the cheapest and easiest option.

A national clear and transparent complaints and disputes system must also be established.

### **Service Providers**

There needs to be an across the board approach to service providers and agencies being accredited under the proposed NDIS. One concern of AADC is that not all service providers or agencies have, or effectively deliver the services and expertise they claim to have, particularly in the area of deafblindness which is such a highly specialised area. Some service providers and agencies will claim to have 'deafblind specialists' when in fact they are simply therapists or others who happen to work for the service provider or agency and have no training or expertise specific to deafblindness. AADC recognises that finding and retaining people with these skills is a challenge, not just in Australia, but internationally; however, there needs to be a more transparent way for people who are deafblind, their families and carers to access information about what kind of expertise each service provider or agency actually does provide and not just what they claim to do.

With a greater access to funding, demand will increase across the disability sector. Given the current shortages in qualified and skilled people working with people who are deafblind consideration needs to be made into how to increase and financially support an already under staffed specialist workforce.

### **Interfacing with Other Health Care Sectors**

The NDIS proposed to work closely with the Age Care sector in assessing the needs of older people under its scheme however, the need for younger people who are deafblind has been overlooked. Currently there are no recognised

facilities for people who are deafblind who also suffer from other disabilities and many of these younger Australians end up in aged care facilities.

The Productivity Commission has released a further draft report on *Disability Support* which, while acknowledging that people with a severe and profound disability have a right to an entitlement to specialist services, then introduces an arbitrary restriction allowing only access to those acquiring their disability before the age of 65 years. The inference being that the Aged Care Sector will assume responsibility for the costs of supporting these people. This is a significant issue for people who are deafblind since many acquire their vision and/or hearing loss later in life.

This cost shifting from disability to aged care services could result in no genuine provision being made within the aged care sector for support of people who are deafblind. In fact the services required would not differ, for example, for those acquiring their vision loss at 64 years of age and someone acquiring their vision loss at 66. The restriction appears duplicative, with new bureaucratic machinery necessitated on both sides of the new age barrier.

Under the current draft report the NDIS is proposing to “put in place a memoranda of understanding with the health, mental health, aged and palliative care sectors” (recommendation 3.4). Currently the waiting time for a person who is deafblind on the Disability Support Register is 7-8 years. This is unacceptable and much more needs to be done to ensure “the respective schemes have effective protocols for timely and smooth referrals”.

### **Assessing Care and Support Needs**

Support from family and friends or community supports for a person who is deafblind is very minimal due to the complex nature of their communication needs. Therefore people who are deafblind will be unable to utilise these “unpaid” services that will be recognised under the proposed NDIS. People who are deafblind require experienced and trained 1:1 human support in the form of tactile interpreters and guides.

ADBC understands the complexities of running an NDIS however we are concerned by who will be “monitoring” on an ongoing basis the needs of people who are deafblind. When assessing a person who is deafblind the right professionals who are trained and aware of the issues faced by a person who is deafblind is of utmost importance if they are considered to be a “trained assessor”. A timeframe of 2 years should be placed on “periodically” re-assessing a person who is deafblind needs under their funded support package.

### **Mental Health**

People who are deafblind face many issues in their everyday life that hearing and sighted people often take for granted. The central issue in a deafblind person's life is communication and 1:1 human support.

The communication problems and breakdowns occur almost anywhere. The degrees of deafblindness varies so much from person to person that even when a group of deafblind people gather to socialise, there are often major communication problems that at times lead to tension and conflict. Support workers are often needed to set up and assist with the communication processes, to limit the potential communication problems.

With the combination of communication breakdowns, isolation and loneliness, that a person who is deafblind faces, feelings of grief, anger and dissatisfaction is felt at an intense level. Such feelings can manifest into more serious mental health issues like low self esteem, pessimism, mood swings, panic attacks, and even suicidal thoughts and insomnia. Anxiety and nervousness when in the community is also a commonly reported experience. A person who is deafblind feels anxious about the future, and about getting out in the community for reasons of safety and orientation. The risk factors for depression are many for a person who is deafblind.

The main problem faced by a person who is deafblind who is feeling one or more issues related to mental illness is the inadequate training of mental health professionals in understanding the deafblind world and experiences.

Deafblindness is a specific and specialised area and most mental health professionals have not heard about deafblindness let alone worked with a deafblind person. As a result people who are deafblind have reported feeling unheard, misunderstood and experience communication difficulties and breakdowns with many mental health professionals.

ADBC recommends that accredited service providers under the NDIS who provide services for people who are deafblind should work closely with mental health professionals to raise their awareness and train them in the specifics of deafblindness. Additional supports and programs to assist in area of mental health need to be included and funded properly in the relevant accredited service providers that support people who are deafblind. More comprehensive research must be funded to continue to explore additional mental health experiences and issues in the deafblind population.

Again, ADBC reiterates that interfacing with other health care sectors such as the mental health sector is the most important first step supporting a person who is deafblind and is experiencing mental health issues. These referrals must



ensure “the respective schemes have effective protocols for timely and smooth referrals” and the mental health professional is fully trained and aware of the issues faced by a person who is deafblind.

### **Funding the NDIS**

The proposed funding models for the NDIS must take into consideration:

1. Adequacy for the scheme to work;
2. Not politicised so that there are significant variations from Budget to Budget or government to government;
3. Able to increase with increases in CPI relatively easily;
4. Flexible enough to meet the changing needs of people with disability and to be increased overall (as opposed to only for CPI) with relative ease.

Funding the NDIS from general revenue makes it more flexible, and gives more accountability to government in terms of making sure the scheme is adequate. A tax means it's not politicised and should increase with CPI (because wages generally do, so taxes would).

ADBC recommends that the Productivity Commission be mindful that both scenarios could potentially encounter problems. We think it's more important to make sure there is protections in place whatever happens.

ADBC recommends that if the funding comes out of general revenue we recommend the Productivity Commission needs to propose that the legislation for the National Disability Insurance Agency sets aside the money and that CPI increases are legislated for.

Likewise, if the Productivity Commission recommends a tax or levy we suggest a legislated review of the adequacy of funding and regular consideration of whether the National Disability Insurance Agency needs more funding.

### **SUMMARY**

In current day Australia, it is not longer acceptable that people who are deafblind find themselves isolated from life and interaction with the world around them. Australia has taken significant steps forward in changing this situation by ratifying the United Nations Convention on the Rights of Persons with Disabilities in 2008. However this is a small first step in what will be a long journey to ensure that the rights preserved under this convention become a reality for people who are deafblind. Upholding these rights is largely dependent on having access to adequate specialists and resources in the area of deafblindness.

People who are deafblind in Australia want to have direct access to people and the community as a whole and want to be able to express what they are thinking and feeling. The only way a person who is deafblind can do this is to have fair access to both human and technical resources that allows them to enjoy life and to participate in the community.

The NDIS is an approach to disability funding that is an important and individual part of what must be seen as a broader reform of the disability care and support system. A new scheme such as this must be seen as a fundamental part in the National Disability Strategy currently being undertaken by the Council of Australian Governments. The focus of this strategy is to address the systemic reform that is required to ensure that Australia has a national system in place that will make certain that people who are deafblind have the same rights and opportunities as all other members of the community irrespective of the state jurisdiction in which they live.

The current system of disability is fragmented across all states in Australia. ADBC commends the Productivity Commission for recognising this, proposing more consumer choice which allows a more holistic approach to disability and, in turn, empowering a person who is deafblind to make decisions for themselves.

## **REFERENCES**

<sup>1</sup>Access Economics. (2007). *Making sense, A report into dual sensory loss and multiple disabilities in Australia*. Retrieved 27 May 2010 from <http://www.ableaustralia.org.au/content-files/Penny%20Taylor%20Presentation.pdf>

<sup>2</sup>Australian Communications Consumer Action Network ( 2011) *Connecting Us All: The Role of the National Disability Strategy*