

Australian DeafBlind Council

**Submission for the proposed National Disability Insurance Scheme (NDIS) Quality and Safeguarding framework**

Australian Deafblind Council (ADBC) is a peak national organisation for deafblind. ADBC welcomes the opportunity to comment on the policies and Government’s efforts to engage with deafblind participants and their services for the roll out of National Disability Insurance Scheme.

**ABOUT THE AUSTRALIAN DEAFBLIND COUNCIL (ADBC)**

The Australian Deafblind Council (ADBC) was developed in 1993 at the National Deafblind Conference in Melbourne. This council was established to provide security; sense of belonging, freedom of speech and represent the Australian deafblind community and their supporting networks. At present, ADBC represents an estimated 288,000 people, including elderly populations who are deafblind, their families and organisations working in the field.

ADBC seeks to increase access to their communities and provide advocacy support for people with deafblindness across Australia. ADBC provides the skills to deafblind people by encouraging self-organisation and self-determination.

ADBC’s objectives:

* Information resource on deafblindness.
* Platform for discussions and share the challenges of being deafblind.
* Provide guidance and support to government agencies and other organisations.
* Identify issues on deafblindness and provide advocacy support.
* Information and referral centre for families, supporters, deafblind service providers and other organisations.

ADBC understands the importance of providing quality and safeguarding practices for individuals who are deafblind. In Australia, there are two service providers that specialises in providing quality support to people who are deafblind. Able Australia and Senses Australia are currently providing specialist support to accommodate people living with deafblindiness.

**ABLE AUSTRALIA Deafblind Services**

For nearly 50 years, Able Australia has specialised in the provision of comprehensive support services for people with deafblindness.

From its humble beginnings in 1967 as an association for people with deafblindness and rubella, Able Australia has grown into a diverse and dynamic organisation that supports people throughout the Australian Capital Territory, New South Wales, South Australia, Tasmania, Queensland and Victoria.

Able Australia assists people with deafblindness to direct their own support because we understand that everyone has right to exercise choice and control over their own life goals and dreams. Able’s flexible support services are customised to meet the needs of every individual, as they are the most qualified to determine what they need to live a valued life.
Able Australia’s holistic service is built on listening and learning, which is why Able Australia’s team of experienced deafblind service professionals take the time to sit with each individual and their support network to assess every need before connecting them with the right services.

The support each person receives depends entirely on their needs. Able Australia’s experienced staff have expertise in the provision of a wide range of specialist services, including:

* Able living – a series of group homes, supported living, outreach and in home support programs which provide individuals with everyday life experiences and a personal approach to home living
* Deafblind services – a range of best practice, self-directed support services for people in the community living with deafblindness
* Ablelink – a unique e-communications centre for people with deafblindness incorporating a drop-in centre, training and access to state-of-the- art adaptive communication technologies
* Recreation programs – a diverse selection of recreation activities and camps that assist people with deafblindness to interact with others, develop social skills and have fun
* Lifestyle choices - a community-based service providing a range of high quality, individually designed day activities for people with physical, intellectual and sensory disabilities
* Respite – tailored activities for people with a disability, including deafblind and in need of respite care for their family
* Music therapy – a community-based service that encourages communication, participation, socialisation and self-expression through music
* Arts therapy – a special program that helps people with a disability including deafblind to find a new way to express their emotions, explore their creativity and increase their self-esteem.

**SENSES AUSTRALIA** **Deafblind Services**

Currently Senses Australia provides the only specialised service for individuals who are deafblind in Western Australia. They provide a consultation service related to deafblindness to individuals, families, groups, health professionals, organisations and other service providers. The Deafblind Services Team encourages the development of communication and independence for people who are deafblind throughout Western Australia. The aim of the service is to enable people living with this unique disability to gain or maintain their independence, quality of life and reduce the isolation that deafblindness creates.This targeted service is currently partly funded via the Disability Services Commission and partly through charitable fund raising by Senses Australia.

People with deafblindness form a very diverse group due to the varying degrees of their vision and hearing impairments plus possible additional disabilities. This leads to a wide range of communication methods including but not limited to speech, lip reading, various forms of sign language including: Auslan, tactile, visual frame, deafblind manual alphabet, block alphabet, haptic and Key Word Sign, alternative and augmentative communication, symbols of reference, pictorial communication systems, braille, note taking, electronic communication, technology, large print, low vision aids and a combination of any of the above preferred by the individual. Use of appropriate and preferred communication modes ensures that deafblind people are as fully engaged as possible in assessment, planning and provision and are able to have choice, access and control over their lives.

**Providing information for participants and building natural safeguards through individual capacity building**

The NDIS aims to position participants as active consumers with choice and control over the supports they need to live the lifeas members of the community. This means participants need access to high-quality information that can give them the tools to choose the best providers of their supports.

An important safeguard for this important first developmental step is to provide capacity building so that deafblind participants can access an online environment to gather information. Information is to be provided in an accessible format and on a variety of platforms, however, deafblind participants will need skills to read information in Braille or use assistive technology so that they have access to this information.

Information and communications technology is an area that will constantly change, not only to businesses and governments, who need to be nimble and innovative to keep up with the rapid pace of change, but it is also equally essential that the deafblind community have the support to also keep up with this rapid pace of technological change**.**

NDIS information should be available on a range of platforms and in text, audio, video and Australian sign language. The only way to ensure accessibility with emerging technology is to provide the necessary supports to ensure they have access to emerging technology and can be engaged to provide feedback as new systems are developed.

The benefits of feedback are clearly established, however, participation rates of the deafblind community participating in online forums and consumer ratings is extremely low. Safeguards include providing support for individuals to participate and support for building skills in digital literacy.

**Able Australia**

Building capacity through plan development, through Local Area Coordinators and in the community and targeted funding of community can only be achieved for the deafblind community through support for digital literacy and e communication.

The Mentor Project in New South Wales and Tasmania has established the success of five people with disabilities who are currently undergoing training to work as ‘Assistive Technology Mentors’. To be engaged by the NDIA and provide individual support to participants enables better choices about equipment and technologies with a view to establishing a nationally recognised training programme at the Certifiate IV level.

This model of individualised peer support is used extensively and successfully in mental health services. Able Australia’s Ablelink, in Victoria has established a successful Peer Mentoring program to provide Assistive technology support across the deafblind community with 80 deafblind participants involved nationally.

Ablelink has been involved in building capacity through education by supporting deafblind students in their studies by providing additional support to access the Education online platform or provide access to braille printers or one to one support to work through issues of accessibility. Ablelink has been involved in building capacity through employment through developing volunteer roles in peer mentoring, advocacy, braille training and technical support at Ablelink for 12 deafblind participants over the past 15 years.

Without the support for digital literacy, specifically provided as capacity building for the deafblind community there is a risk that people with disability could receive poor quality supports that do not help them achieve their goals. Ablelink, in conjuction with Sensewide in WA provide a national service for the deafblind community in capacity building in digital literacy skills. Ablelink provides support and training for the deafblind community in digital Literacy skills throughout Australia.

In 2011, Able Australia in conjunction with Australian Communication Consumer Action Network (ACCAN) published a report “Telecommunications and Deafblind Australians” whereby it was established that across Australia people who are deafblind have significant difficulty accessing telecommunication devices.

The deafblind community is a small and isolated group of people and their communication needs are complex and diverse. Specialist deafblind technology consultants are essential to provide the necessary supports to ensure individuals have access to the internet and electronic communication. Without specialised support, due to their complex communication needs, access to electronic communication is a barrier they cannot overcome.

NIDS is to be applauded for their initiative in funding individuals to make choices about their supports. For an individual to make choices they need to be aware of the range of services in their local community and to be able to articulate their personal goals. Digital literacy skills provides the key to access to their local community and make informed choices. Promote market supports for people with disabilities offering greater choice will focus on generic solutions for the biggest number of participants. Market forces do not take care of small and complex groups. This seems to be ongoing trend with not recognising the needs of people who are deafblind.

**Recommendation:**

* Block funding be provided to ensure the deafblind community have access to adaptive technology, training and equipment specific to their complex disability
* Digital Literacy skills are an ongoing life learning and Ablelink has established a Peer training model to facilitate the sharing of skills within the deafblind community. Skill development is a safeguard to making informed choices
* A safeguard is required for the provision of services for the deafblind community, to ensure specialist technology services and equipment can be provided to promote digital literacy and independent electronic communication
* Digital literacy and the ability to communicate electronically is a necessary support for people with deafblindness to enable them to engage with the NDIS , access mainstream services and participate in their local community

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In 2010, the Australian Deafblind Council (ADBC) examined the specific services available for people who are deafblind in Australia. In their findings it is argued that single sensory disability service provider organisations are not effective in meeting the needs of people with a dual sensory loss, deafblindness. This is supported in the UK, Canada and Denmark where it is also recognized that there is a need to acknowledge the importance of providing appropriate services/supports for deafblind people. This means commissioning services that are specifically designed for deafblind people. It was found that those with deafblindness may not benefit from mainstream services, (services aimed primarily at blind people or deaf people who are able to rely on their other sense).

The Australian Deafblind Council report also compared services to people with deafblindness in Australia and concluded that the services were inadequate. Only Able Australia in Victoria and Senses Australia in Western Australia currently offer deafblind specific services. The ADBC commented that in the five years since the initial report, little has changed, the barrier to progress is attributed to a lack of government and community awareness of deafblindness, lack of funding of support services and lack of available resources.

Other major client group – people with profound intellectual and multiple disabilities, often do not have impartial advocates and are not able to advocate for themselves, therefore a circle of support model should be employed to optimise the likelihood that their needs and preferences are adequately represented. It is hoped that the NDIS will help address the gaps for people living with deafblindness in Australia.

Other key factors that have been identified as barriers to the deafblind population accessing services include: availability of Deafblind Consultants, suitably trained staff and support (Communication Guides/Support workers) lack of communication in the preferred communication mode, miscommunications, information not available in accessible formats, consumer lack of understanding about deafblindness and available service supports, lack of knowledge about deafblindness and how to work with people who are deafblind by generic health professionals and the community, issues with accessibility of interpreters and knowledge of how to work with interpreters , accessibility to community and services, access to and appropriate training for adaptive technology, access to the deafblind community and the lack of appropriate employment and education support. Senses Australia’s Deafblind Consultants skills are vital in coordinating the specialist care, support and ongoing advocacy to break down these barriers.

**Senses Australia - Deafblind Consultants**

Senses Australia’s Deafblind Services Team is staffed by experienced allied health professionals with specific training and expertise relating to people living with deafblindness (congenital and acquired). Senses Australia is considered a centre for excellence in deafblindness and the Deafblind Consultants deliver conference presentations both locally, nationally and internationally, provide training, conduct ongoing research and coordinate specialized projects for this unique population. Deafblind Consultants assess, plan and develop programs relevant to the needs and aspirations of the person that is deafblind. In the UK and Denmark it is recommended that as soon as an initial assessment identifies that a person is deafblind, Local Government Authorities should arrange a specialist assessment to identify their communication abilities, need for one to one human contact, level of social interaction, any support required with mobility, assistive technology that may be beneficial and the need for any rehabilitation services. They also recommend that the assessment be conducted by a Deafblind Specialist/Consultant and the assessment should take into account the current and future needs of that person as it is easier for a person to learn alternative forms of communication before their deafblindness has deteriorated to the point where they are no longer able to use their preferred method of communication. Senses Australia Deafblind Services Team wishes to continue to emulate these models and international best practice.

The Deafblind Consultants act as specialist advisors to other health professionals, support staff, caregivers, external agencies and local community as required, to ensure the communication, behavioural, psychosocial, equipment and mobility needs are meet for clients who are deafblind. The Deafblind Consultants facilitate informal and formal groups where appropriate to better meet client outcomes; this is frequently in a group/peer situation and may include peer support, mentoring and information exchange. Deafblind Consultants participate in client individual service plans, case conferences and therapy meetings. They also develop resources necessary to meet the client specific communication needs, along with providing individually tailored training to family and support works in these communication needs/modes to deliver the plans. Deafblind Consultants also provide specialised training to family, direct care workers, teaching staff and to therapy staff working with people who are deafblind. The team and the service they provide play an integral part in the lives of people living with deafblindness in Western Australia.

**Communication Guides**

Internationally specialised deafblind support is available in a number of countries to maintain independence in decision making, and provide opportunity for socialisation and community involvement. In these countries, individuals who are deafblind are assessed by a Deafblind consultant and are entitled to a level of individual support. In some countries this is enshrined in legislation. In Denmark these support workers are referred to as Contact Persons, in the UK they are Communicator Guides (and for children Intervenors), in Canada they are Intervenors and in the US they are Support Service Providers. The roles of these positions are similar between countries with variations related predominately to where they work. They are all specifically skilled to be aware of the issues related to deafblindness and to work with the person to be the link between them and their community. They are they ‘ears and the eyes’ for the person they are supporting, thus minimizing the severe isolation associated with deafblindness. In Australia the role is titled Communication Guide/Support worker. Internationally Danish deafblind people can access contact person/communication guide support regularly with most individuals in Denmark receiving between 10 and 25hours of support a week. In Canada, deafblind people can access approximately 21 hours per week Communication Guide support. Studies have demonstrated the use of services by those who are deafblind differ significantly from those of the general population. The supports required by the deafblind person are in the form of one to one communication, environmental information and sighted guide. Communication Guides provide practical help with everyday tasks and access to community services. The role of this specialised support is very complex, requiring constant observation and interpretation of behaviour of individuals who they support to determine what information is needed, the best way to convey it, and if it has been clearly received.

Supporting communication, access to information and mobility, the Communication Guide is the deafblind person’s link to the world, providing one-to-one support in the preferred communication mode of the deafblind person they are supporting, along with information and resources to enable the person to be fully informed about their environment and their circumstances, have choices and make decisions. Communication Guides need to be trained to work specifically with people who are deafblind and have a clear understanding and knowledge of dual sensory impairment, how to work with that population along with the impacts of deafblindness. The Communication Guides provides practical support with everyday tasks such as: facilitating communication in the preferred communication mode, sighted guide, facilitating access to information, facilitating inclusion/access to recreational/social/community activities, facilitating access to public transport, providing vital visual and auditory information, providing environmental information, assistance with shopping, attending appointments, practical help with everyday tasks along with social support. The Deafblind Services Team has developed training modules and delivers training for communication guides along with the provision of supervision and ongoing training.

Recommendations from Australian, Canadian and UK reports for improving services for people who are deafblind include:

* Increasing the number of Communication Guides to provide services
* Increasing funding for quality intervention (Communication Guide) services and for communication guide training programs
* Provision of appropriate and accessible social care services and more appropriate services for people who are deafblind
* The provision of Deafblind Consultants to assist their organisation and individuals working with people who are deafblind in relation to communication, orientations and mobility, assistive devices and employment was also strongly recommended

 These reports identified the need to improve the identification and improved assessment of people who are deafblind to ensure that appropriate services and supports can be established.

Recommendations to best support deafblind people for the NDIS rollout:

* The provision of Deafblind Consultants within the therapeutic support cluster to assess, assist and coordinate services and support for people who are deafblind in relation to communication, orientation and mobility, access issues, assistive devices, social inclusion, psychosocial support, connection to the deafblind community, advocacy, peer support, future planning, employment and education (Note: Deafblind Consultants are included in the Better Start program)
* Increased support for people who are deafblind to assist with practical tasks and access to the community
* The provision for funding for a 4 day Communication Guide training course, delivered by Deafblind Consultants, incorporated into all NDIS plans which have support to access community, recreation etc as a goal.
* Fund Tier 2 to support Deafblind Consultants to provide ongoing deafblind awareness training to health professionals and the community
* Increased access to Interpreters with skills in the preferred communication mode of the deafblind person
* Information available in the preferred communication mode of the deafblind person
* Training for NDIS planners and staff in regard to Deafblind Awareness, how to work with deafblind people and Interpreters
* Funding stream to support participation in Deafblind Support group and Deafblind camp in individual plans

Australian Deafblind Council (ADBC) works in collaboration with Deafblind service providers to uphold the values of supporting/assisting people living with deafblindness to have full access into mainstream community.

“Deafblindness is described as a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation mobility and daily living” (Australian Deafblind Council).

The needs of people with deafblindness are poorly understood by generic disability services or even single sensory services, thus NDIA planners are unlikely to have the knowledge required.  Suggestions to adopt a similar policy/standard, to that which they have in the UK, whereby when anyone referred to NDIA who is deafblind, they automatically get allocated a senior planner who should have awareness of deafblindness.

ADBC challenges NDIS to integrate and consider specialist service providers like Able Australia’s and Senses Australia’s support systems with the following recommendations are highly regarded. NDIS has the capacity to demonstrate quality and safeguarding frameworks in cooperation with Australian DeafBlind Council, Deafblind service providers and Deafblind supporters by adhering to the laws of the rights of people with disabilities, including deafblindness. The following articles provide foundations of providing opportunities for deafblind participants of the NDIS quality and safeguarding framework.

United Nations Human for people with Disabilities

Article 21 - Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;

Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;

Recognizing and promoting the use of sign languages.

Article 26 - Habilitation and rehabilitation

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

**References:**

Australian DeafBlind Council. (2010). *Submission: Productivity Commission Inquiry into Long Term Disability Care and Support Scheme*. Retrieved from <http://www.deafblind.org.au/reports.asp>

Sense. (2010). A Sense of Urgency. Retrieved from <http://www.sense.org.uk/sites/default/files/A_Sense_of_Urgency_Summary_report_CEDR_Research.pdf>

United Nations. (2006). Convention on the Rights of People with Disabilities. Retrieved from http://www.un.org/disabilities/convention/conventionfull.shtml

Watters, C., Owen, M. & Munroe, S. (2004). A study of deaf-blind demographics and services in Canada. Retrieved from [http://www.cdbanational.com/PDFs/Demographic%20Study%20(English).pdf](http://www.cdbanational.com/PDFs/Demographic%20Study%20%28English%29.pdf)