



Submission to the parliamentary inquiry into NDIS planning

Joint Standing Committee on the NDIS – NDIS planning

September 2019

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SUMMARY OF RECOMMENDATIONS

Recommendation 1. Due to the invariably complex nature of support needs of people with deafblindness it is recommended that only senior NDIA staff are involved in the planning process with people who identify as having deafblindness.

Recommendation 2. That the NDIA funds Deafblind Consultants in each State of Australia to provide information and support to both Australians with deafblindness, and NDIA planners, to optimise relevance and effective implementation of the NDIS plans of Australians with deafblindness.

Recommendation 3. That all planners are made aware that deafblindness is a disability in its own right, and should be listed as the primary disability if this is requested by the person with deafblindness.

Recommendation 4. To ensure the planning needs of people with deafblindness are appropriately and adequately addressed, make available online, self-paced training packages to NDIS planners.

This training should include:

- information about Auslan interpreters, including 2 hr minimum booking
- role of a communication guide and that due to skill level these staff are paid at higher rates than disability support workers
- role of deafblind consultant
- need for specialist support coordination due to complexity of deafblindness
- role of assistance dogs with people with deafblindness
- technologies required by people with deafblindness

Recommendation 5. Advanced notice is generally required for people with deafblindness in order to book communication support to attend the planning meeting.

Recommendation 6. Employ more NDIS planners whose first language is Auslan, and prioritise that these planners work with NDIS participants with deafblindness whose first language is Auslan.

Recommendation 7. All NDIS participants with deafblindness should have access to NDIS planning information, and other NDIS information in their preferred format which may include:

- electronic in word format with no formatting
- print, including large print
- braille
- Auslan

Recommendation 8. That any person with deafblindness who requires an Auslan interpreter can have their choice of interpreter or other communication support. The NDIS planner should book the preferred interpreter and the planning meeting should not proceed until a preferred Auslan interpreter can be booked.

Recommendation 9. That draft plans are provided to NDIS participants with deafblindness, to allow time for them to access the information in the plan.

Recommendation 10: There needs to be consideration of whether the purpose a device is going to be used is for mainstream or not, rather than whether the device is mainstream or disability specific. Mainstream technologies and equipment which enables a person with deafblindness to communicate and to develop and maintain social networks, or increase independence, by using the device in a way which a person without deafblindness would not, should be accepted as reasonable and necessary if consistent with the client's goals.

Recommendation 11. That people born deaf, blind or deafblind are not required to provide a current assessment report or undertake repeat assessments.

Recommendation 12. Core supports should not be reduced from one plan to the next, unless the person with deafblindness requests this as they have developed natural supports or capacity to undertake the activity independently.

Recommendation 13. Work force development is needed to train more interpreters and communication guides to work with people with deafblindness, and to upskill allied health professionals in the area of deafblindness.

Recommendation 14. For deafblindness to be included as a category which indicates complexity of need and qualifies NDIS participants for higher levels of Typical Support Package funding.

EXECUTIVE SUMMARY

People with deafblindness remain some of the most marginalised in Australia, with their complex needs being poorly understood and inadequately addressed. While it is envisaged that the National Disability Insurance Scheme will to some extent address current issues experienced by people with deafblindness, unless systemic changes are made to approaches to service delivery to this group, it is likely their needs will not only not be fully addressed, but in some instances current services may diminish.

People with deafblindness require some specific supports to meet even basic daily needs which differ considerably from other disability groups. These supports include use of Auslan interpreters with an understanding of the communication needs of people with deafblindness, including tactile sign language, use of communication guides trained specifically to work with people with deafblindness, and deafblindness consultants to provide input to service providers and community facilities to ensure the access needs of the person with deafblindness are fully understood and addressed. Without these supports people with deafblindness often cannot access medical and therapy services and education and employment settings as well as community services and facilities.

The current disability workforce is poorly equipped to meet the needs of people with deafblindness. Even if funding is available, there are inadequate numbers of qualified experienced and trained staff to meet the demands. Workforce development needs to be addressed by the National Disability Insurance Agency if the needs of people with deafblindness are to be addressed effectively.

Access to information and services remains problematic for people with deafblindness due to issues accessing standard print and audiovisual media. These barriers to accessing information go both ways, as it is currently extremely difficult for people with deafblindness to have their needs and perspectives understood by service providers and government agencies due to the complexity of communication needs.

All of these issues directly impact on the NDIS planning process. Issues are experienced by Australians with deafblindness in accessing information about NDIS planning, having NDIS staff understand their needs, and participating fully in the planning process.

BACKGROUND

Introduction

This is a joint submission from Able Australia, Senses Australia and Deafblind Australia into the parliamentary inquiry into NDIS planning. Able Australia and Senses Australia are the two lead agencies providing services to Australians with deafblindness, Able Australia in Victoria, South Australia and Queensland, and Senses Australia in Western Australia. Deafblind Australia is the peak body for people with deafblindness and those that support them in Australia.

Introduction to deafblindness

Throughout this submission, the terms deafblind, combined vision and hearing impairment and dual sensory impairment will be used interchangeably as all three are used to describe people with deafblindness. Deafblindness is described by Deafblind Australia 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.

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 speech, oral/aural communication, various forms of sign language including tactile, Deafblind fingerspelling, alternative and augmentative communication and print / braille”

“Representing between 0.2% to 2% of the population, persons with deafblindness are a very diverse yet hidden group and are, overall, more likely to be poor and unemployed, and with lower educational outcomes. Because deafblindness is less well-known and often misunderstood, people struggle to obtain the right support, and are often excluded from both development and disability programmes.”

World Federation of the Deafblind (2018)

People with deafblindness will ALL require the provision of hearing services at some stage in their lives, though services for those with the single sensory impairment often do not fully address the needs of, or remain inaccessible to people with deafblindness.

Causes of deafblindness and prevalence

The below background information is given regarding prevalence and causes of deafblindness to support recommendations made throughout this submission. While exact prevalence of deafblindness is not known, it was estimated that in 2013, there were 13,700 Australian's with deafblindness under 60 years old (Dyke, 2013).

There are a number of syndromes and other causes which result in hearing impairment combined with vision impairment (deafblindness). Usher syndrome results in the combination of a hearing impairment and retinitis pigmentosa (a vision condition causing tunnel vision and night blindness). There are multiple types of Usher syndrome and those born with Usher syndrome type 1 have associated balance problems. Kimberling et al (2010) found 11% of all children diagnosed with a hearing impairment carried a gene for Usher syndrome and estimate the prevalence may be as high as one in 6,000. All individuals with Usher syndrome will fulfil the criteria for acceptance into the National Disability Insurance Scheme given they are born with a hearing impairment and have a progressive vision condition which will significantly impact on their functioning well before the age of 65 years.

CHARGE Association also results in combined vision and hearing impairment. The true incidence of CHARGE syndrome is not known, with estimates ranging from 0.1 to 1.2 in 10,000. The highest incidence of CHARGE syndrome in Canada was estimated at 1 in 8,500 in provinces with a research interest in CHARGE syndrome, so the true incidence of CHARGE

syndrome reported internationally may therefore be underestimated. (Blake and Prasad, 2006)

Research has shown that prevalence of deafblindness in adults with an intellectual disability is 5% which is considerably higher than the rest of the population (MeuweseJongejeugd et al., 2008). It is important to note this figure does not include children so the number will be higher across the whole population of individuals with a developmental or intellectual disability who are eligible to participate in the National Disability Insurance Scheme. The prevalence of hearing impairment is at least 40 times higher in people with intellectual disability compared with the general population (Carvill, 2001). However, vision and hearing impairments are frequently inadequately diagnosed and poorly addressed in people with intellectual disabilities (Kiani and Miller, 2010).

The prevalence of deaf-blindness is about 1 in 10000 school-age children in the UK (Kiana and Miller, 2010).

Availability of and access to Auslan interpreters

Sign language is seen as the main feature that defines any Deaf community. The use of sign language covers a wide range of areas in the everyday life of the Deaf person. It impacts areas where language is an essential tool in the life of a person, ranging from family life through to media and telecommunications, entertainment and including education, employment, community access and inclusion. Auslan is the recognised language of the Australian Deaf Community, it is a visual spatial language represented through hand movements known as “signs”, facial expression and body language. Auslan has its own syntax, grammatical structure and word order which is different to that of English and fulfils all the criteria of natural language, Auslan is not a universal language. It is unique to Australia, though it does share similarities to some other signed languages around the world.

Auslan was recognised by the Australian Government as a ‘community language other than English’ and as the preferred language of the Deaf community over 20 years ago. The Australian Government has also recognised that access to interpreters is a fundamental need for Deaf people to be able to participate in society and avoid the negative impacts and costs of isolation from community life (Access Economics Report, 2008). Access to Auslan interpreting is fundamental to the ongoing participation and inclusion in community for users of this language. Without access to a NAATI (National Accreditation Authority for Translators and Interpreters Ltd) accredited, professional interpreting services Deaf people will experience isolation and marginalisation as they are unable to take part or benefit from opportunities that are routinely afforded to other members of the community. Without access to interpreters the experiences of Deaf people are commensurate with the wheelchair user who faces a flight of stairs and no ramp.

“Deaf people should not be limited to the settings that they can access interpreting services for. They should be able to watch their son’s soccer presentation and have access to the information being spoken, or see their daughter in a play and understand what the audience is laughing about....”

Victorian Council of Deaf People Report Pg. 7, 2008.

Deaf people's right to use Auslan in their everyday lives is reflected in a range of national and international laws and conventions. This includes the Australian ratified Convention on the Rights of People with Disabilities (United Nations 2008). The UN convention affirms the right for Deaf people to access Auslan interpreting under the following general principles: non-discrimination; full and effective participation and inclusion in society; respect for difference; equal opportunity; and accessibility. The Convention also requires that all parties "take appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion.....on an equal; basis with others through all forms of communication of their choice.....including by.....accepting and facilitating the use of sign languages (United Nations, 2008). The Disability Discrimination Act states that providing an interpreting service to a Deaf person is not the only consideration but also that the provision of an inappropriately qualified interpreter can ultimately inhibit the communication process and decrease the level of participation for the Deaf person.

Access to provision of interpreting services in Australia is historically limited to workplace, education and health. But there are significant changes in this area currently with the introduction by the Federal Government of the NDIS. All medical interpreting costs need to be included in an individual's NDIS plan. Medical Interpreting will no longer be funded under NABS the National Auslan Interpreter Booking Payment Service. These costs (medical and therapy appointments) will need to be predicted and included in each individuals NDIS plan. The lack of provisions of medical/community interpreting is identified as a barrier, a major hurdle which does not enable Auslan users' access to everyday needs nor allow them to play significant, socially valued roles in community participation. Without access to qualified interpreters Deaf/Deafblind people will not be able to fully access medical, therapy and community services putting their own health and goal attainment at risk.

What is interpreting?

Interpreting is the act of transferring a message from one language to another, in this case from Auslan to English and vice versa utilizing ones linguistic and cultural knowledge in both languages.

However, simply knowing both Auslan and English does not qualify a person as an interpreter. Interpreters are professional qualified in a highly specialized field. Interpreters work in a variety of settings and situations, many of whom have additional skills and qualifications in specialized areas (i.e. Deafblind interpreting)

Auslan Interpreters accredited by the National Accreditation Authority for Translators and Interpreters (NAATI), as are all language interpreters in Australia. The West Australian Health Language Services Policy, 2008 defines competent translators and interpreters as: those who adhere to a professional Code of Ethics for Practitioners incorporating the principles of impartiality and confidentiality and performance that is accurate and faithful and who meet at least one of the following criteria:

1. National Accreditation Authority for Translators and Interpreters (NAATI) accredited, which can be achieved by passing a NAATI test; or by successfully completing a course of

studies at an Australian Institution approved by NAATI; or by providing evidence of specialised qualification in translating and or interpreting obtained from a recognised training institution outside Australia.

2. Obtained a formal qualification in interpreting or translating from an accredited tertiary institution

The role of the interpreter is to: facilitate communication between two parties who do not share the same language. The interpreter will sign what is spoken and speak what is signed conveying meaning and intent. The interpreter will not add, embellish or delete information. The only time the interpreter should be involved in the discussion is when a word or phrase needs to be clarified from either the Deaf or hearing persons. Interpreters are bound by a code of ethics that, among other things, stipulates that all content of an assignment is confidential.

RESPONSE TO TERMS OF REFERENCE

a. the experience, expertise and qualifications of planners;

Deafblindness is a low incidence disability, estimated to effect 0.2 – 2% of the population (World Federation of the Deafblind, 2018). For this reason, it is likely that most planners will not have met a person with deafblindness before. As sensory impairment is less common than physical and intellectual disability, people with deafblindness can appear to planners as “high functioning” if they do not have physical or intellectual disabilities, and thus perceived by planners to be less in need of supports. The complex interaction of dual sensory impairment however invariably results in complex and high needs for human communication supports, skill development and assistive technologies.

Recommendation 1. Due to the invariably complex nature of support needs of people with deafblindness it is recommended that only senior NDIA staff are involved in the planning process with people who identify as having deafblindness.

b. the ability of planners to understand and address complex needs

As stated above, all people with deafblindness due to the complex interaction between both vision and hearing impairments, have complex needs. People with deafblindness who communicate using Auslan have the additional need for services which are culturally and linguistically sensitive to their needs.

People with deafblindness report that they are the first person with deafblindness that the planner has ever met, and that they need to spend a long time explaining to the planner, the nature of their disability. Due to the nature of deafblindness, many people with deafblindness are not able to clearly express their abilities and needs, and require support from someone who understands deafblindness as well as how the individual’s combined vision and hearing impairment impact on them specifically.

Western Australia is the only State where Deafblind Consultants are employed, and are available to support people with deafblindness through the NDIS planning process. Because of this, people with deafblindness are more likely to receive plans which appropriately reflect their needs than in others States.

Senses Australia has been funded to the end of June 2020 to provide a National – Ask a Deafblind Consultant service. People with deafblindness service providers and NDIA staff have been taking advantage of this service to gain information and appropriate referral to relevant services.

A similar service exists in Sweden. See www.nkcdb.se Funding State based Deafblind Consultants who would work for a centralised service like the model in Sweden and that established by Senses Australia would be a cost effective way to better meet the information needs of Australians with deafblindness and service provides including NDIA staff.

Recommendation 2. That the NDIA funds Deafblind Consultants in each State of Australia to provide information and support to both Australians with deafblindness, and NDIA planners, to optimise relevance and effective implementation of the NDIS plans of Australians with deafblindness.

- c. the ongoing training and professional development of planners;

It is recognised that it is unrealistic for all planners to develop the skills and experience required to adequately meet the needs of NDIS participants, so a three pronged approach is recommended; see recommendations 1, 2, 3 and 4.

For people with deafblindness, NDIS planners are still listing single sensory impairments as primary and secondary disabilities, whereas in most instances deafblindness is the primary disability, rather than vision or hearing loss. It is the combination of the two which creates the complex disability of deafblindness. So, as an absolute minimum, all planners should be aware that the disability of deafblindness exists and can be listed as the person's primary disability.

Recommendation 3. That all planners are made aware that deafblindness is a disability in it's own right, and should be listed as the primary disability if this is requested by the person with deafblindness.

Recommendation 4. To ensure the planning needs of people with deafblindness are appropriately and adequately addressed, make available online, self-paced training packages to NDIS planners.

This training should include:

- information about Auslan interpreters, including 2 hr minimum booking
- role of a communication guide and that due to skill level these staff are paid at higher rates than disability support workers
- role of deafblind consultant
- need for specialist support coordination due to complexity of deafblindness

- role of assistance dogs with people with deafblindness
 - technologies required by people with deafblindness
 -
- d. the overall number of planners relative to the demand for plans;

Long wait times for planning meetings are compounded by the need of people with deafblindness to book communication support, which may include a skilled qualified Auslan interpreter.

The better way to address this issue would be to employ more NDIS planners whose first language is Auslan, which would reduce communication breakdowns and improve the overall quality of the communication in planning meetings.

Recommendation 5. Advanced notice is generally required for people with deafblindness in order to book communication support to attend the planning meeting.

Recommendation 6. Employ more NDIS planners whose first language is Auslan, and prioritise that these planners work with NDIS participants with deafblindness whose first language is Auslan.

- e. participant involvement in planning processes and the efficacy of introducing draft plans;

On numerous occasions people with deafblindness have nearly missed the opportunity to be involved in the planning process due to inaccessible information being provided. E.g. people with deafblindness who are profoundly deaf being called on the phone, when they can only respond to text message, or people with deafblindness who are blind being sent printed letters.

As outlined in the introduction, many people with deafblindness have reduced educational opportunities and so have considerable difficulty understanding the complex language involved in the NDIS planning process. Therefore, the provision of a draft plan would enable the opportunity for more time to be taken with communication support to understand the contents of the plan before agreeing to it.

To fully participate in the planning process people with deafblindness need to have access to their preferred communication supports which may include preferred Auslan interpreters. There have been numerous instances in which a preferred interpreter has been denied, as the NDIS staff member has reported that only one Auslan interpreter booking agency can be used. Using an unfamiliar or non-preferred interpreter compromises the ability of the person with deafblindness to fully access or participate in the planning process.

Recommendation 7. All NDIS participants with deafblindness should have access to NDIS planning information, and other NDIS information in their preferred format which may include:

- electronic in word format with no formatting
- print, including large print

- braille
- Auslan

Recommendation 8. That draft plans are provided to NDIS participants with deafblindness, to allow time for them to access the information in the plan.

Recommendation 9. That any person with deafblindness who requires an Auslan interpreter can have their choice of interpreter or other communication support. The NDIS planner should book the preferred interpreter and the planning meeting should not proceed until a preferred Auslan interpreter can be booked.

- f. the incidence, severity and impact of plan gaps;

There are examples of people with deafblindness receiving insufficient Auslan interpreting hours in their plans, including having interpreting hours reduced from one plan to the next, which has resulted in involvement in preferred activities being restricted for the person with deafblindness.

Technologies which are relied on for safety, and access to information and social connection have not been approved. Some main stream devices which are used by people with deafblindness for communication purposes, where others could rely on speech and hearing have also not been approved due to them being mainstream.

These technologies are necessary in today's context to ensure equal participation and inclusion and to ensure person can function to their full potential. Yet people with deafblindness who are unemployed and have little hope of gaining employment are unable to afford these devices. To maximise chances of employment, it is necessary to have access to mainstream devices which are critical for people with deafblindness to be included equally. These devices are often the only way that someone who does not know Auslan can communicate with an Auslan user.

Recommendation 10 There needs to be consideration of whether the purpose a device is going to be used for is mainstream or not, rather than whether the device is mainstream or disability specific. Mainstream technologies and equipment which enables a person with deafblindness to communicate and to develop and maintain social networks, or increase independence, by using the device in a way which a person without deafblindness would not, should be accepted as reasonable and necessary if consistent with the client's goals.

- g. the reassessment process, including the incidence and impact of funding changes;

People who were born deaf, or blind or deafblind should be exempt from having to prove, through assessment, their disability, as there are currently no medical procedures which can restore vision and hearing to the degree that the person no longer has a disability.

Recommendation 11. That people born deaf, blind or deafblind are not required to provide a current assessment report or undertake repeat assessments.

- h. the review process and means to streamline it;

People with deafblindness are in some instances receiving fewer hours of support in subsequent NDIS plans, or previously State funded individual support packages. In many instances, supports are not used, not because of a lack of desire, but because of a lack of understanding the system involved in booking and using the supports, or a lack of available supports to book.

Recommendation 12. Core supports should not be reduced from one plan to the next, unless the person with deafblindness requests this as they have developed natural supports or capacity to undertake the activity independently.

- i. the incidence of appeals to the AAT and possible measures to reduce the number;

Incidence of appeals would be lower if plans of people with deafblindness were adequate and appropriate in the first instance. By taking up the recommendations outlined in this submission, there will be a reduction of appeals from NDIS participants with deafblindness.

- j. the circumstances in which plans could be automatically rolled-over

If a person with deafblindness is managing their daily, weekly and annual needs well with the core supports they have in place, and have no current needs for capacity building or equipment, it would be reasonable that they could roll their plan over from one year to the next. The goal of “maintaining current status” is a reasonable and valid goal.

- k. the circumstances in which longer plans could be introduced;

If an NDIS participant rolls their plan over three years in a row, it would be reasonable to lengthen the plan duration to 2 – 3 years.

- l. the adequacy of the planning process for rural and regional participants;

NDIS participants with deafblindness who use Auslan are significantly disadvantaged if they live in rural and remote areas due to lack of skilled Auslan interpreters. Due to their vision impairment, use of video relay interpreters may not be an option, or if they do have sufficient vision to use video conference, the infrastructure in rural and remote areas cannot always support features required for video conferencing. See recommendation 12 regarding workforce development to address this issue.

- m. any other related matters.

There are currently significant work force issues associated with adequate provision of services to NDIS participants with deafblindness. These include:

- insufficient staff to meet demand – particularly Auslan interpreters, communication guides and allied health staff. These issues are pronounced in regional and rural areas.
- lack of skill and experience of service providers to adequately meet needs. The staff who are available, often have little or no training, skill or experience in working with people with deafblindness, and so provide a substandard service.

The needs of NDIS participants with deafblindness are under-represented in the Typical Support Package (TSP) calculations. The complexity of deafblindness is not considered and the TSPs of deafblind participants are often funded at the lowest level. No provision has been made to acknowledge the complexity of deafblindness in the process so deafblind participants don't qualify for higher funding levels within TSP's.

Recommendation 13. Work force development is needed to train more interpreters and communication guides to work with people with deafblindness, and to upskill allied health professionals in the area of deafblindness.

Recommendation 14. For deafblindness to be included as a category which indicates complexity of need and qualifies NDIS participants for higher levels of Typical Support Package funding.

REFERENCES

Access Economics, Penny Taylor, Presentation National DeafBlind Conference April 2010, Making sense: A report into dual sensory loss and multiple disabilities in Australia, 2007, <http://www.deafblind.org.au/content-files/Penny%20Taylor%20->

ASLIA (Australian Sign Language Interpreters Association) Victoria: Access for Deaf People in Victoria: Why Auslan interpreting matters <http://www.asliavic.com.au/>

Australian Deafblind Council (ADBC), (2010) Submission: Submission: Productivity Commission Inquiry into Long Term Disability Care and Support Scheme

Australian Federation of Deaf Societies (AFDS), (2005) Response to inquiry into the provision of mental health in Australia

Australian Government (2011): National Disability Strategy 2010- 2020

Blake, K. D. and Prasad, C (2006) CHARGE Syndrome, Orphanet J Rare Dis. 1: 34. Accessed 25 November, 2016 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1586184/>

Carvill S (2001) Sensory impairment, intellectual disability and psychiatry. Journal of Intellectual Disability Research 45: 467–83.

Deaf Australia (2010): Auslan Policy, www.deafau.org.au/info/policy_auslan.php

Deafblind Australia (n.d) What is deafblindness? Retrieved from <https://www.deafblind.org.au/deafblind-information/what-is-deafblindness/> 2nd September, 2019

Disability Discrimination Act, 1992 (Cth)

George Brown College. (n.d.). Intervenor for Deafblind Persons Program. Retrieved from <http://www.georgebrown.ca/C108-2011-2012/>

Hammer, E. & Carlson, R. (1996). Using the intervener model with adults who are deaf-blind. *Journal of Vocational Rehabilitation*, 7, 125-128.

Kiani, R. and Miller, H. (2010) Sensory impairment and intellectual disability. *Advances in psychiatric treatment* 16, 228–235

Kimberling W. J., Hildebrand M. S., Shearer A. E., Jensen M. L., Halder J. A., Trzuppek K., Cohn E. S., Weleber R. G., Stone E. M., Smith R. J. (2010) Frequency of Usher syndrome in two pediatric populations: Implications for genetic screening of deaf and hard of hearing children. *Genetics in Medicine* 12, 512–516.

World Federation of the deafblind (2018) At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness- Initial global report on the situation and rights of persons with deafblindness