Joint Standing Committee on the National Disability Insurance Scheme
Capability and Culture of the NDIA
Organisation Submission
October 2022

Contents

ABOUT US

Established in 1903 (Deaf Services Limited) and 1913 (The Deaf Society) respectively, Deaf Connect, is a not-for-profit, social impact organisation supporting Deaf, Deafblind, and hard of hearing communities across the country, with offices across Queensland and New South Wales, as well in Adelaide, Melbourne and Darwin. Deaf Connect. Our mission is standing with the Deaf community, building capacity, and influencing social change. Deaf Connect offers a whole life range of services to support the community including early intervention and therapy services, accredited Auslan courses and community classes, Auslan translation and interpreting services, lifestyle support services, engagement, information, and referral services, including plan management and support coordination, aged care support and socialisation services. Deaf Connect are the largest Deaf, Deafblind, and hard of hearing specialist service provider in Australia with over 225 years of collective experience delivering quality services to the community across Australia in Auslan. Deaf Connect are also the largest employer of Deaf and hard of hearing people in Australia.

FACTS

- Auslan (Australian Sign Language) is the sign language of the Australian Deaf community.
- Auslan (Australian Sign Language) is an accepted communication method recognised by the National Accreditation Authority for Translators and Interpreters.
- Auslan is recognised as a community language (Dawkins, 1991).
- One in six Australian have some form of hearing loss, with that number projected to increase to one in four by 2050. Hearing loss is the second most prevalent national health issue yet remains the 8th national funding priority (Access Economics, 2006).
- According to the 2021 Census, which is at the conservative end, there are 16,242 Auslan users in Australia.

DEFINITIONS

Deaf
The term "Deaf" refers to those who use a sign language as their primary language. Deaf people are more likely to have been born deaf or to have acquired a hearing loss early in life. This group is relatively small, but not insignificant; and our analysis of data suggests there is approximately 30,000 Deaf Auslan users in Australia. Deaf people typically tend to acquire sign language as their primary means of communication in addition to the written or spoken language of the wider community. They are not necessarily fluent in written English and proficiency should not be assumed.

Deafblind
Deafblindness is 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. There are two distinct cultural groups within the deafblind community. The first group are born blind and lose their hearing as adults. They tend to continue to use speech as their main communication and have a variety of hearing devices to help them to communicate. The second group are born deaf and lose their sight as adults. This group are culturally deaf and use sign

language to communicate[1].

Hard of hearing

The term "hard of hearing" is usually used to refer to those who use English rather than a signed language as their primary means of communication. Most people with a hearing loss (estimated at one in six Australians), belong to this group. People with acquired hearing loss will usually continue accessing information and interacting with those around them in English, whether spoken or written, and are well served by assistive technologies such as hearing aids, hearing loops, and captions.

Auslan

Auslan (Australian Sign Language) is the signed language used by the Deaf Community in Australia and is the primary and preferred language of those who identify with the Deaf community. It is historically related to British Sign Language, as is New Zealand Sign Language, and has been influenced, to a lesser extent, by Irish Sign Language and American Sign Language. It is not a signed form of English, rather, it is a language in its own right with its own unique grammatical structures, which are different to that of English. As with any foreign language, it generally takes at least 2-3 years to acquire proficiency through a number of avenues including formal study and community immersion.

EXECUTIVE SUMMARY

Deaf Connect welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Capability and Culture. For the purposes of this submission, we will be using 'deaf' when referring to all individuals with varying degrees of deafness. This includes members of the community who identify as Deaf, deaf, deafblind, hard of hearing and members of the Deaf community who identify as culturally Deaf and primarily use Auslan to communicate. As a national, deaf-led service provider and social impact organisation, Deaf Connect has held a strong interest in the rollout of the NDIS. Since the implementation of the Scheme, we have observed significant challenges in its implementation for deaf participants including:

- inequitable plan variations, particularly in the provision of Auslan appropriate supports;
- lack of awareness of deafness and Auslan amongst the NDIA, delegates and access partners; and
- overall lack of culturally and linguistically appropriate resources.

Planners and delegates from the NDIA are not fully equipped to support deaf participants. This is due to high turnover and inconsistent training. Ongoing deaf awareness training is crucial to the culture and capability of the NDIA as any existing knowledge is generally lost when staff depart the Agency. This lack of awareness has many enduring consequences beginning at plan development through to implementation and review. Deaf advocacy organisations and service providers spend countless hours providing unfunded supports assisting deaf individuals with pre-planning and review paperwork. This ultimately reduces the time and capacity on already strained resources within the community where funding is low or has been decreased over time. The NDIS is comprised of many complicated and bureaucratic operational processes which defy the very nature of the Scheme's

---

[1] https://www.deafblind.org.au/deafblind-information/deafblindness-in-depth/

intent; this is further compounded for the Deaf community due to language barriers, lack of understanding and deaf awareness and Auslan workforce shortages.

Deaf Connect recommends the following:

Recommendation 1: The NDIA website and all relevant materials must be updated to remove "hearing impaired" and replace with "deaf and hard of hearing". "Hearing impaired" is considered offensive by deaf people.

Recommendation 2: The NDIA must cease using "sloping loss of 65dB or greater in the better ear" to determine eligibility. Speech occurs between 20dB to 60dB, consider capacity or reduction in capacity rather than a dB level.

Recommendation 3: The NDIA must cease using the Australian Census to determine what is an everyday household item to determine 'reasonable and necessary'. Research indicates that deaf people experience unemployment rates three times higher than the general population, are employed in low skilled occupations and are underemployed (Willoughby, 2011).

Recommendation 4: The NDIA must support the provision of communication devices with a minimum of 4G capability for deaf participants requiring standalone devices where Wi-Fi is not available to access Auslan interpreters virtually in settings such as banks, tax consultants and GPs etc.

Recommendation 5: National Disability Insurance Agency (NDIA) and LAC Partners in the Community (PITC) staff must receive mandatory deaf awareness training annually, at minimum.

Recommendation 6: The NDIA must investigate alternative options other than emails to notify of key events, decisions and milestones including automatic plan extensions.

Recommendation 7: If written communication is used, the language needs to be accessible and in plain, clear and visual English.

Recommendation 8: The NDIA must communicate with deaf participants virtually using accessible applications such as Zoom, FaceTime, WhatsApp, or other platforms, not solely Teams which is not accessible to deaf participants.

Recommendation 9: The NDIA must employ deaf staff or staff with a background and understanding of deafness to build plans for deaf participants. This enables staff to link deaf participants to deaf led and deaf friendly, culturally appropriate community supports who can suggest more effective and appropriate solutions, as opposed to referring to generalist staff with no knowledge of the deaf community or the communication needs of deaf individuals. Furthermore, the NDIA must consider having staff with the necessary language and cultural skills in their call centre to manage enquiries and issues by deaf participants.

Recommendation 10: The NDIA must stop reducing deaf people's plans because of underutilisation; this is due to the known significant workforce shortage impacting deaf people's ability to secure interpreters and professionals with Auslan skills.

Recommendation 11: The NDIA must ensure service providers with hearing staff that are supporting deaf participants:

      a.   have completed accredited Auslan training and/or have demonstrated proficiency in Auslan, or

      b.   take appropriate steps to employ more deaf staff members.

Recommendation 12: NDIA staff and partners must cease making "either or" decisions relating to language acquisition for deaf children and adopt a holistic, transdisciplinary approach to early intervention.

Recommendation 13: The NDIA must use additional deaf specific assessment tools based on literacy and digital literacy to determine if support coordination for deaf participants is required.

Recommendation 14: The NDIA must continue making resources and information accessible in Auslan and consider a deaf-led engagement strategy regarding the NDIS and system navigation.

STAFF CULTURE AND CAPABILITY

The NDIS is an invaluable support system for deaf people and their families. Deaf Connect have been heavily involved in the implementation and rollout of the NDIS since its inception and have a deep understanding of the barriers experienced by the deaf community.

Cultural and Linguistic Minority

Interestingly, the NDIA have not afforded the deaf community similar considerations as indigenous and CALD communities, despite identifying as a cultural linguistic minority. Having this understanding of the deaf community as a cultural and linguistic group would equip NDIA staff to better address barriers

Auslan for All

Inconsistencies are common amongst plans for deaf people, particularly children. Some planners provide access to cochlear implants and Auslan tutoring without question, while other planners view this as "double dipping," stating a child who has a cochlear implant does not need access to Auslan. Deaf connect staff have witnessed instances where NDIA staff have stated that Auslan is not an effective language at all. This inconsistent approach to plans means that if the auditory pathway is unsuccessful, and Auslan tutoring is not included in the plan as requested, deaf children are at risk of linguistic deprivation. Furthermore, it is not up to the planner to determine the best pathway for the deaf child which should be the choice of the deaf individual or their parents. The Agency's role is to provide reasonable and necessary supports for people with disability.

Language development for deaf children

The developing brain is negatively affected by a lack of necessary stimuli early in life. Such deprivation of required sensory experiences can alter brain organisation (Nelson, 2000; Twardosz & Lutzker, 2010). One such necessary stimulus is language input, which is critical during the early years because it builds neural connections that aid in overall neurocognitive growth. As Toe et al. (2019) asserts, language input, regardless of modality, is vital for cognitive development. Language

acquisition occurs most readily in the first few years of life due to elevated levels of neuroplasticity (Friedmann & Rusou, 2015; Kuhl, 2010), and early language exposure is essential for the development of language processing circuitry in the brain.

A holistic, transdisciplinary approach ensures language acquisition occurs at the same rate as hearing children, whether this be in Auslan or spoken English. Auslan can be accessed before speech, and therefore provides foundational knowledge for deaf children. For example, using one language to support the learning of another provides context for the deaf child; a deaf child can learn the sign for *"eat"* and then learn to say the word through speech therapy. The speech pathologist is not then left with the additional task of instructing the child, conceptually, what the term *"eat"* means because the child has already learnt the meaning through Auslan.

Parents of deaf children should have access to Auslan tutoring and/or accredited Auslan training as soon as possible. It is imperative that parent's Auslan fluency is ahead of their deaf child's. This allows parents to provide positive role modelling and supports healthy language development, in line with appropriate milestones. Parents whose Auslan is not ahead of their child's are at risk of being taught Auslan by their deaf child rather than modelling and educating their child, resulting in the deaf child experiencing language deprivation and isolation. The NDIS ECEI approach recognises that every child, regardless of their needs, has the right to participate fully in their family and community life and to have the same choices, opportunities, and experiences as other children. The funded supports in a NDIS plan should not inadvertently reduce their community or mainstream participation.

Auslan Interpreters

The NDIA needs to understand that deaf children's access to Auslan is crucial for their linguistic and social development. As such, the need to understand how communication aids and supports such as interpreters are used is also crucial information for planners.

Additional inconsistencies have been cited amongst plans where some deaf children have been denied access to Auslan interpreters by the Agency whilst others have not. Some families reported the NDIA expects the parents to interpret for their child.

Deaf children who use Auslan require access to professionally trained, credentialled interpreters who adhere to the ASLIA Code of Ethics and Guidelines for Professional Conduct. This is to ensure communication can be appropriately facilitated between English and Auslan. It is inappropriate for parents to assume the position of interpreter for their child, particularly if the parents learning Auslan do not have the proficiency, speed, and vocabulary of a credentialled interpreter. Deaf children benefit greatly by having access to Auslan interpreters as they provide incidental learning, familiarising deaf children with the role of a professional interpreter. Auslan interpreters also provide access to additional vocabulary, educate the child on how to articulate themselves and conduct interactions with hearing people; interpreters empower deaf children from hearing families to advocate for themselves and socialise in the community.

With the cashing in of the National Auslan Booking Service (NABS) to the NDIA, any child who does not have allocated funding in their plan for Auslan interpreters is unable to access an interpreter when consulting with their GP. Whilst a young child may not understand all the vocabulary associated with a GP consultation via an interpreter, provision of an interpreter allows the child to see how such interactions are held and provides access to new vocabulary otherwise missed, in the same way hearing children do when attending appointments with their parents.

7

Auslan workforce challenges

It is important that the NDIA and its staff understand the workforce issues impacting deaf participants. Currently there is a national shortage of Auslan interpreters, which restricts access to communication for Deaf, Deafblind, and hard of hearing people. Whilst the NDIA is approving and funding plans that include interpreting services, the current supply of trained Auslan interpreters cannot meet rising demand. This continues to present a threat to the effectiveness of the NDIS and access to civic and social services for deaf people, and carries risks around service utilisation, quality, timeliness, cost and work health and safety.

This makes the workforce situation for deaf supports unique. Workers can be trained in other adaptive communication techniques within short timeframes, however, the acquisition of Auslan, like any other language, takes at least 2-3 years; the acquisition of interpreting skills takes longer still. This is very problematic for addressing supply issues because the timeframe for training the Auslan workforce is necessarily longer, and the investment needs to be sustained.

As a result, Australia as a whole has not produced enough Auslan interpreter graduates to keep pace with sharply rising demand, and graduates are moving into other sectors and not staying within the interpreting field. This has detrimental impacts on the quality and timely access to interpreters, placing further pressure on already thin markets and lean workforce. Plan utilisation is therefore impacted as demand outweighs supply.

There is also a reluctance by the NDIA to provide access to data and appropriately sized tablets with 4G to deaf participants as this is seen as an everyday item. As 45% of people with a disability live close to the poverty line[2] and are therefore unable to afford what some may deem as an everyday item, appropriate assistive technology devices, such as tablets and laptops, are often overlooked as reasonable and necessary in NDIS plans. Provision of such communication devices would allow Deaf and hard of hearing participants to book an interpreter via Video Remote Interpreting (VRI) for a minimum of one hour, rather than the two-hour minimum which is required when booking an interpreter for face to face. Using VRI and removing travel time frees up an already limited resource and allows participants to access interpreters in regions where there are none or very few available. Denial of communication devices and data is counterintuitive. Continued, significant investment to develop, attract and retain the Auslan workforce is required, as well as provision of appropriate devices and data.

Deaf Awareness

Staff turnover is another major issue impacting deaf NDIS participants. Due to high staff turnover, a lack of awareness and understanding of deafness, and other systemic barriers, deaf people's access and utilisation of the NDIS is severely limited. The NDIA must understand that:

- Auslan is an effective language, and the preferred language for many deaf Australians.
- by the age of 19 months, a hearing child will have been exposed to approximately 4,380 waking hours of oral language. Deaf children do not have access to this level of incidental learning.

---

[2] https://inclusionmelbourne.org.au/disability-and-poverty/

- any delay to language acquisition during early intervention either in Auslan or spoken English may result in permanent and irreversible language deprivation.
- the crucial window of language development is 0 to 3.
- speech is not a language but a modality of expressing a language.
- hearing parent's acquisition of Auslan needs to be ahead of their deaf signing children's. A community class will not give parents the specific vocabulary required to love, support, honour, educate, praise, or discipline their deaf child. One on one Auslan tuition in the family home and other natural settings that can use visual cues to prompt language development is crucial.
- tablets and iPads of a medium to large size with at least 4G capability and data are essential and are at times the only option for deaf participants to receive supports in regional and remote areas.

ACCESSIBILITY OF RESOURCES

Accessing the Access Request Form (ARF) requires digital literacy and literacy in written English, however literacy is varied across the deaf community. Deaf people do not have phonics to aid with the spelling of written English and do not hear English spoken daily to reinforce English grammar. It is our experience that deaf individuals also do not receive an adequate explanation regarding their care needs unless an active deaf organisation has provided such information or if the delegate or planner, they are communicating with is familiar with Auslan, and/or deaf culture, which is rarely the case. This has significant impacts on plans and is evident for deaf participants accessing support coordination. Of the 17 specialist cohorts listed by the NDIA, deaf participants are listed 15th to receive support coordination in their plans[3]. On average across all cohorts, 40% of NDIS participants receive support coordination, however for deaf participants, the average is only 14%. In certain regions, there is a direct correlation between a lack of support coordination for deaf participants and plan underutilisation and delay. For example, Partners in the Community (PITC) have made comment that in Far North Queensland, deaf participants are not using their plans at the rate of other cohorts.

Without support coordination in their plans, it is impossible for some deaf people to execute delivery of supports due to low digital literacy and written English literacy. This then leaves some deaf participants relying on informal supports which are often hearing family members or acquaintances who lack Auslan proficiency. Without at least proficiency in Auslan, informal supports are unable to articulate processes and system navigation, therefore managing plans and supports for deaf people rather than enabling them to navigate it themselves. This behaviour repeats an ongoing, paternalistic cycle whereby the deaf participant remains disempowered because they cannot execute their NDIS independently. This contradicts the philosophy of the NDIS whereby participants can use their packages to live fulfilling lives, build capacity and self-advocacy skills and participate and engage with the broader community. Instead, deaf participants without appropriate supports are faced with a system that is inaccessible, legalistic, and inconsistent in its operational functions.

Most concerningly, the NDIA does not use "deaf" in any of its terminology. In fact, strategies and terminology used by the NDIA include the category *"Hearing Impairment," "Hearing Pathway"* and *"Hearing Tool Kit."* These terms are counterintuitive, audist[4] and are deeply rooted in pathology and

---

[3] See page 15 of https://www.ndis.gov.au/community/we-listened/improving-support-coordination-participants
[4] See Eckert, Richard & Rowley, Amy. (2013). Audism A Theory and Practice of Audiocentric Privilege. Humanity & Society. 37. 101-130 for a thorough summary of audism.

negative stigma, which centres hearing over deafness. The term *"Hearing Impaired"* itself is considered by many deaf people to be derogatory, as it implies deafness is lesser or incomplete. Dotted throughout all NDIA materials, deaf people are referred to as *"Hearing Impaired"* and at no point is the term "deaf" used by the NDIA. Given the name of these toolkits and strategies, culturally deaf people understand them to be intended for hearing people as they do not identify with the term *"hearing"* or the hearing community, rather as a cultural and linguistic minority group and members of the signing deaf community. The NDIA must change their use of language to better engage and reflect the communities they serve.

RECOMMENDATIONS

Recommendation 1: The NDIA website and all relevant materials must be updated to remove "hearing impaired" and replace with "deaf and hard of hearing". "Hearing impaired" is considered offensive by deaf people.

Recommendation 2: The NDIA must cease using "sloping loss of 65dB or greater in the better ear" to determine eligibility. Speech occurs between 20dB to 60dB, consider capacity or reduction in capacity rather than a dB level.

Recommendation 3: The NDIA must cease using the Australian Census to determine what is an everyday household item to determine 'reasonable and necessary'. Research indicates that deaf people experience unemployment rates three times higher than the general population, are employed in low skilled occupations and are underemployed (Willoughby, 2011).

Recommendation 4: The NDIA must support the provision of communication devices with a minimum of 4G capability for deaf participants requiring standalone devices where Wi-Fi is not available to access Auslan interpreters virtually in settings such as banks, tax consultants and GPs etc.

Recommendation 5: National Disability Insurance Agency (NDIA) and LAC Partners in the Community (PITC) staff must receive mandatory deaf awareness training annually, at minimum.

Recommendation 6: The NDIA must investigate alternative options other than emails to notify of key events, decisions and milestones including automatic plan extensions.

Recommendation 7: If written communication is used, the language needs to be accessible and in plain, clear and visual English.

Recommendation 8: The NDIA must communicate with deaf participants virtually using accessible applications such as Zoom, FaceTime, WhatsApp, or other platforms, not solely Teams which is not accessible to deaf participants.

Recommendation 9: The NDIA must employ deaf staff or staff with a background and understanding of deafness to build plans for deaf participants. This enables staff to link deaf participants to deaf led and deaf friendly, culturally appropriate community supports who can suggest more effective and appropriate solutions, as opposed to referring to generalist staff with no knowledge of the deaf

community or the communication needs of deaf individuals. Furthermore, the NDIA must consider having staff with the necessary language and cultural skills in their call centre to manage enquiries and issues by deaf participants.

Recommendation 10: The NDIA must stop reducing deaf people's plans because of underutilisation; this is due to the known significant workforce shortage impacting deaf people's ability to secure interpreters and professionals with Auslan skills.

Recommendation 11: The NDIA must ensure service providers with hearing staff that are supporting deaf participants:

       a. have completed accredited Auslan training and/or have demonstrated proficiency in Auslan, or

       b. take appropriate steps to employ more deaf staff members.

Recommendation 12: NDIA staff and partners must cease making "either or" decisions relating to language acquisition for deaf children and adopt a holistic, transdisciplinary approach to early intervention.

Recommendation 13: The NDIA must use additional deaf specific assessment tools based on literacy and digital literacy to determine if support coordination for deaf participants is required.

Recommendation 14: The NDIA must continue making resources and information accessible in Auslan and consider a deaf-led engagement strategy regarding the NDIS and system navigation.

CONCLUSION

Deaf Connect welcomes the Committee's efforts to review the operations, capability and culture of the NDIS. The deaf community would benefit greatly from a robust review to ensure the Scheme, and its processes, are accessible and equitable, and increase self-advocacy, self-determination, and greater participation in society. In doing so, we believe the only way forward would be to ensure that this process engages experts with a lived experience being deaf, and also drawn from key stakeholders in the Deaf sector and community.

We would like to thank the Joint Standing Committee for the opportunity to participate in this submission. Deaf Connect welcomes and encourages the opportunity to participate in the upcoming public hearing in late 2022.

Contact

Brett Casey
Chief Executive Officer

Brent Phillips
Chief Impact Officer

REFERENCES

Access Economics (2006). *Listen hear: the economic impact and cost of hearing loss in Australia.* Melbourne: CRC Hear and the Victorian Deaf Society.

Dawkins, J (1991). *Australia's Language: The Australian Language and Literacy Policy.* Australian Government Printing Service: Canberra

Kuhl, P. K. (2010). Brain mechanisms in early language acquisition. *Neuron Review, 67*(5), 713-727.

Ladd, P. (2003). *Understanding Deaf Culture: In Search of Deafhood*. Bristol, Blue Ridge Summit: Multilingual Matters.

Friedmann, N., & Rusou, D. (2015). Critical period for first language: the crucial role of language input during the first year of life. *Current opinion in neurobiology*, 35, 27-34.

Nelson, C. A. (2000). Neural plasticity and human development: The role of early experience in sculpting memory systems. *Developmental Science*, 3(2), 115-136.

Toe, D., Paatsch, L., & Szarkowski, A. (2019). Assessing Pragmatic Skills Using Checklists with Children who are Deaf and Hard of Hearing: A Systematic Review. *Journal of Deaf Studies and Deaf Education,* 24, 189-200.

Twardosz, S., & Lutzker, J. R. (2010). Child maltreatment and the developing brain: A review of neuroscience perspectives. *Aggression and Violent Behavior*, 15(1), 59-68

Willoughby, L. (2011). Sign Language Users' Education and Employment Levels: Keeping Pace with Changes in the General Australian Population? *Journal Of Deaf Studies and Deaf Education*, *16*(3), 401-413.