

Deaf Services Queensland Position Statement on:

- 1. NDIS Eligibility Criteria for adults over 25yrs
- 2. NDIS Eligibility Criteria for Early Intervention (0-25yrs)
- 3. Australian Hearing as the referral pathway for Early Intervention

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Background

Enquiry Submissions

The Joint Standing Committee on the NDIS as part of their inquiry into the implementation, performance and governance of the NDIS has undertaken two enquiries:

- The Provision of services under the NDIS Early Childhood Early Intervention Approach
- The Provision of Hearing services under the NDIS for the Joint Standing Committee on the NDIS

Deaf Services QLD has made submission to both those inquires and also submitted a response to the Inquiry into the Hearing Health and Wellbeing of Australians.

Response to Recommendations and recent NDIA changes

There is some alignment across these reports in terms of their recommendations as they relate to the NDIS. Further, it would appear that NDIA has ignored one key recommendation around eligibility (from Hearing services enquiry) which has raised significant concerns. Deaf Service QLD has prepared three position statements in relation to

- 1. NDIS Eligibility Criteria for adults over 25yrs
- 2. NDIS Eligibility Criteria for Early Intervention (0-25yrs)
- 3. Australian Hearing as Access Partner for Early Intervention

Deaf Services Queensland

Deaf Services Queensland is a not for profit organisation working with the community to enhance services and programs that benefit Deaf or hard-of-hearing adults and children across Queensland. Supports and services cover the entire lifespan from:

- Early intervention
- Lifestyle support service (in people's homes and communities)
- Community Engagement and Development
- Education service accredited as an RTO provider and unaccredited community courses
- Language services including Auslan interpreting (online and onsite), CALD interpreting and Translating, and
- Ageing well service.



Deaf Services Queensland is the prominent end-to-end service provider, advocate and leader for Deaf or hard-of-hearing community members across all ages with a vision of our cohort of participants being empowered, connecting and achieving their goals.

We are a provider of NDIS services across Queensland and also deliver State funded participant readiness including the ECEI approach to parents of children who are deaf or hard of hearing. We have received feedback and questions that have assisted us in deepening our understanding of the approach and emerging issues for families through our participant readiness work.

Terminology

Deaf Australia operates a terminology policy that was adopted by members in 2010¹. For the purposes of this paper Deaf Services Queensland adopts these definitions also:

- **deaf:** all Deaf and hard of hearing groups at once
- Deaf: culturally Deaf people who use Auslan and identify with the Deaf community
- hard of hearing: people whose primary communication mode is speech

An additional concept discussed in this paper is **deafhood** which is the process of actualising deaf identity.² **Auslan** is Australian Sign Language which is the language of the Deaf community in Australia¹.

Auslan Language Acquisition

Within the context of the framework of the NDIS in which supports are deemed reasonable and necessary, there will be a highly individualised approach with a high degree of personal choice and control over language acquisition for Deaf children. The NDIS as we have seen now provides a clear Language pathway (Auslan and Speech) early thereby with the intent of reducing the long term needs (cost of the scheme) of some children³.

With the phasing out of various State and Commonwealth schemes in response to the NDIS there are several gaps that have emerged for the Deaf and hard-of-hearing community. In particular an emerging concern has been the structural changes and reforms to the mainstream setting that have previously provided specialist and transdisciplinary responses (recognised as best practice by the NDIS) to children who are Deaf or hard of hearing. This has proved to be a best practice early intervention approach in a transdisciplinary⁴ family centred team and a very cost efficient model.

In response to the NDIS, language immersion environments through various education settings have announced closures (including ECDP's (Early Childhood Development Programs) in QLD and Centre For Hearing Impaired (CHI) children situated at the Elizabeth Park Primary School grounds in South

¹ Deaf Australia Inc. (2016). Terminology. Accessed from: http://www.deafau.org.au/info/terminology.php

² Ladd, P. (2003). Understanding deaf culture: In search of deafhood. Multilingual Matters.

³ Note — until the implementation of the NDIS, there has been no clear pathway for learning Auslan for Deaf children and their parents. The Better Start program only aligns to allied health — covering speech therapy and not that of Auslan although it is noted that following direct representation by Deaf Services Queensland to the Better Start program, Auslan learning was since approved as a service outcome and is able to be utilised through the resource funding of the Better Start program — amounting to only \$2000 per child.

⁴ "Transdisciplinary teamwork involves a team of professionals who work collaboratively, and share the responsibilities of evaluating, planning and implementing services to children

⁴ "Transdisciplinary teamwork involves a team of professionals who work collaboratively, and share the responsibilities of evaluating, planning and implementing services to children and their families. Families are valued members of the team, and are involved in all aspects of intervention. One professional is chosen as the primary service provider for the family, and acts as the conduit for the expertise of the team" (Early childhood intervention – transdisciplinary approach to service provision fact sheet, NDIS, 6 May 2014)



Australia) which would move Deaf children into expensive, non-Deaf-inclusive settings and where the key provisions of Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁵ in which Australia is a signatory to and has ratified into domestic law are not affected and disregarded. Best practice recommends that Deaf Children learn best when instructed by an Auslan speaking teacher and supported by Auslan speaking staff and peers (direct instruction) rather than through an interpreter (mediated instruction) which they would require in a mainstream setting⁶. Learning in first language is always easier and provides positive role models, particularly for those in primary school.

The recent announcement of Auslan as a LOTE inclusion in the national curriculum although a pleasing development, does not address the language acquisition needs of Deaf children. Further it will be many years before we see the results of the Auslan as a LOTE as language acquisitions takes several years and not a semester to acquire. Article 24 (UNCRPD) references the rights of people who are Deaf or hard-of-hearing to learn sign language early, develop linguistic identity as a deaf person and ensure that education of children who are deaf or deafblind are delivered in the languages and models of communication that matter to that individual. For these rights to occur, this article also recognises that teachers with the appropriate qualifications (such as Auslan) are employed and trained to support children learning Auslan.

Recent changes to NDIS eligibility criteria and recommendations through various inquiries have raised some concerns for Deaf Services Queensland.

1. NDIS Eligibility Criteria for adults aged over 25 years

The current eligibility criteria for adults aged over 25 years are as follows:

8.3.3 Additional guidance for hearing impairments

"Hearing impairments may result in reduced functional capacity to undertake communication, social interaction, learning and self-management activities."

Generally, the NDIA will be satisfied that hearing impairments of \geq 65 decibels in the better ear (pure tone average of 500Hz, 1000Hz, 2000Hz and 4000Hz) may result in substantially reduced functional capacity to perform one or more activities. This audiometric criteria reflects the lower limit of what is likely to constitute a substantially reduced functional capacity to undertake relevant activities.

Hearing impairments < 65dB decibels in the better ear (pure tone average of 500Hz, 1000Hz, 2000Hz and 4000Hz) in conjunction with other permanent impairments (for example vision or cognitive impairments), or where there is evidence of significantly poorer than expected

Queensland Forum for Young Children with Hearing Loss (2013), the Parent Professional Charter (http://www.health.qld.gov.au/healthyhearing/docs/parentcharter.pdf)

⁵ United Nations. Convention on the Rights of Persons with Disabilities. Accessed from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

⁶ Yoshinaga-Itano, C. (2013). Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. Journal of Deaf Studies and Deaf Education, 19(2),



speech detection and discrimination outcomes, may also be considered to result in substantially reduced functional capacity to undertake relevant activities"

To further complicate this new criteria, NDIS has also changed the requirements under List A.

List A: Conditions which are likely to meet the disability requirements in section 24 of the NDIS Act

Permanent bilateral hearing loss > 90 decibels in the better ear (pure tone average of 500Hz, 1000Hz, 2000Hz and 4000Hz) https://www.ndis.gov.au/operational-guideline/access/list-a.html

As , List A refers to those conditions that will automatically be included and not necessarily as an exclusion criteria, however Deaf Services Queensland has some key concerns relating to this new criteria, which was previously defined in List D as "45 decibels or greater hearing impairment in the better ear, based on a 4 frequency pure tone average (using 500, 1000, 2000 and 4000 Hz)". Having two different lists with different recommendations is bureaucratic and confusing. Either way a loss over 65 or over 90 in the better ear will require additional evidence. It is an unnecessarily confusing to have both listed.

1. Medicalising Deafness

The assumption in the updated criteria is that a decibel loss of over 65 (and 90) is likely to result in a reduced functional capacity. It would appear from this erroneous conclusion that the agency is taking a medical approach to Deafness. To contextualise hearing loss, Australian Hearing identifies that a moderately severe hearing loss (60-75dB) means you can't hear crickets or a vacuum cleaner, a severe hearing loss (75-90dB) you can't hear a motor bike or personal stereo at maximum volume let alone conversations⁸. The relationship between level of hearing loss and functional impairment is not linear or consistent across people. For example, children who have one "good" ear with loss in the other still have significant impacts on their learning. The International Classification of Functioning Disability and Health (ICF) as developed by the World Health Organisation⁹ and an assessment approach for the NDIS takes a much a broader view of disability. It considers: the condition, body functions and structures (impairments), activities (limitations), participation (restriction), environmental factors and personal factors.

The medical approach as defined by the agency fails to consider how important other aspects are in terms of disability function. If you have a lower decibel loss, acquired limited English as a child, can't or don't want to use hearing aids for a range of reasons, are fluent in Auslan and identify as culturally Deaf - the decibel reading has no meaning. NDIS is about equity in access, not necessarily equity in what you access and receive – it is based on individual circumstances and need. This eligibility criteria will automatically preclude people from the scheme without consideration of their individual

⁷ https://www.ndis.gov.au/operational-guideline/access/disability-requirements.html

⁸ Australian Hearing. Frequency and intensity of familiar sounds. http://www.soundgearaustralia.com.au/_literature_72679/Frequency_and_Intensity_of_Familiar_Sounds



circumstances in the first instance, thereby resulting in participants having to go through appeal or review. Planners will no doubt appreciate such a cut and dry approach and it is inconsistent with the intention and purpose of the NDIS. It does not seem to be that reasonable and necessary supports allocated will be based on the individual's goals rather based on the proposed functional hearing capacity as defined above.

The other issue related to this is, what happens to those who are already in the scheme and have a lower than 65 decibel or in fact lower than 90 level. What is the process that will be taken to support them? In addition, how with the scheme transition young adults who are 25 with a decibel reading of greater than 25 when the scheme will reject them unless they are suddenly 90 decibels or they can prove their functional limitation (e.g. that they are culturally Deaf and use Auslan thereby require an interpreter).

2. Costly Burden of proof on people already marginalised

To be accepted into the scheme, participants will be required to have the appropriate audiology reports indicating decibel reading. Many Deaf people have not had this done since childhood and so this becomes a new expense burden. On top of this, they will also need "information in writing regarding how their impairment substantially affects their functional capacity in one or more of the activities is required" (from an email from NDIS 31/10 regarding this eligibility criteria). This will mean they require expensive speech therapy, psychology/social worker and occupational therapy assessments and reports to even be considered eligible. According to NDIS to "meet section 24 disability access a person must demonstrate they have an impairment that results in substantially reduced functional capacity to undertake one or more of the following activities: communication, social interaction, learning, mobility, self-care or self-management" (from an email from NDIS 31/10 regarding this eligibility criteria). We feel that being Deaf and needing an interpreter meets this requirement (in one or more areas e.g. communication). Literacy levels are highly variable amongst Deaf community members. It should never be assumed that written English is a reliable method of sharing information, although this assumption appears to be what is driving many of the NDIA's decisions regarding Deafness. Many Deaf people are already significantly marginalised, employment can be difficult to obtain and maintain and they are excluded from the mainstream on a regular basis due to lack of communication access. Some of the participants we support in our walk in services are at risk of homelessness and have problems with the justice system due to misunderstanding written legal documents. The expense of proving disability just to get into the scheme continues to be a source of distress and concern for the community, increasing the gap to inclusion and participation.

3. Hard of Hearing Community

List A would also indicate that the Hard of Hearing community has been completely overlooked, although many with a lower decibel reading would consider themselves culturally Deaf and have Auslan as their first language. In our recent experiences with the NDIS (where eligibility was 45db) people who are Hard of Hearing often only require hearing aids and some other technical aids (e.g. visual deaf alarms for baby cry monitors, smoke alarms, door bells etc.). These are either one off costs or devices with low level replacement. An investment of \$10 -12,000 in the first year of a participants plan may mean they require no further input for 5-10 years depending on their needs.



Hard of hearing community members have missed out on aids in the past unless they were Centrelink recipients. If they are over 25 and have a job they have to pay for aids themselves unless they are receive a Centrelink pension. The NDIS offered them the opportunity to finally have equitable access to resources for their own participation and inclusion, the scheme has placed the burden and expense back on people. For example, to stay in employment all a person may need is hearing aids and this is currently not funded anywhere, making unemployment a viable solution to getting hearing aid needs met (when a Centrelink recipient).

Recommendations

- Provide a more flexible approach to decibel levels is taken where wording includes a focus and
 explanation of functionality as an assessment criteria for eligibility. We suggest utilising World
 bodies such as the world Federation of the Deaf and the International committee on Deaf sports
 and model their idea of deaf and hard of hearing people hearing levels to participants in world
 deaf sports as a starting point.
- 2. Explanation of how existing Deaf people on the scheme who don't meet eligibility will be supported, including those who transition from age 25 (see below early intervention requirement).
- 3. List A requirements be taken down or at least to match 8.8.3 to avoid ongoing confusion and concern and reduce the burden of proof.
- 4. Hard of hearing community be given equitable access to a scheme that will require minimal input for significant outcomes in the areas of participation and inclusion in employment and the community.

2. NDIS Eligibility Criteria for Early Childhood Early Intervention

The current operating guidelines for Deafness and Early intervention are defined as follows:

9.5.2 Early intervention for hearing impairment for people aged 0-25

"The NDIA will be satisfied that a person meets the <u>early intervention requirements</u> without further assessment when the person:

- is aged between birth and 25 years of age; and
- has confirmed results from a specialist audiological assessment (including electrophysiological testing when required) consistent with auditory neuropathy OR hearing loss ≥ 25 decibels in either ear at 2 or more adjacent frequencies, which is likely to be permanent or long term; and
- the hearing loss of the person necessitates the use of personal amplification. This streamlined access approach for early intervention acknowledges a rich body of evidence that recognises that early intervention support up to and including the age of 25 is critical for people with hearing impairment as the developing brain requires consistent and quality sound input and other support over that period to develop normally and ameliorate the risk of lifelong disability.



This same body of evidence suggests that brain development and language capability have been achieved by the age of 26. Therefore, adults aged 26 years and over are not immediately accepted to be likely to benefit from the same early intervention approach because there is no requirement to support the development of the auditory pathways. Adults aged 26 years and over with hearing impairment will therefore be assessed normally, on a case by case basis, having regard to the availability of all relevant evidence"¹⁰.

Deaf Services Queensland welcomes the lower decibel threshold and acknowledgement of early intervention being useful for language acquisition beyond 6 years of age. There are however several points of concern for the Deaf community in relation to this eligibility criteria.

1. Regression to a Auralism Approach to Deafness:

In the past, one approach to Deafness was to ban the use of sign language. This was the result of the Milan Conference in 1880 and influenced education of Deaf Australian students. The statement on the eligibility criteria: "the hearing loss of the person necessitates the use of personal amplification" would appear to be an unconscious return to this Auralistic thinking – mandating the use of aids rather than making it a choice. This statement by its very nature precludes the Deaf community who embrace Deaf culture and Auslan (Australian Sign language) acquisition as their preferred approach to language development as a matter of individual choice and control. This also has implications with the decibel criteria for over 25years. What if a person has a lower decibel reading than 65 and has acquired Auslan as a first language and then is precluded by the scheme for interpreters etc. once they turn 26? This statement suggests a clear medical approach to Deafness at exclusion to the legitimacy of an Auslan pathway.

Language regarding Early Intervention that is available to 25 year olds is also of concern. Potentially reinforcing ancient stereotypes and infantilising young deaf adults to be child like.

2. Medicalised approach to Deafness and Language acquisition

Further, comments such as "developing brain requires consistent and quality sound input and other support over that period to develop normally and ameliorate the risk of lifelong disability" undermine and ignore an Auslan pathway as a valued and legitimate pathway to language and life. The focus on only the auditory pathway for eligibility is, non-inclusive and offensive to the Deaf community and suggests that the scheme will focus on 'cure' medicalized approach (e.g "ameliorate the risk of lifelong disability") thereby not recognising their permanent disability as a deaf individual and enforcing deaf people to aim and aspire to live as a hearing person over individual choice of being a deaf person.

Language acquisition for deaf children needs to consider ALL of the pathways including aural and Auslan. Sound is not a language. The same brain areas for processing meaning are activated if a person speaks English or signs. If the NDIS is about choice the alternative pathway needs to be clear and available from the start of intervention. There is enough research available that indicates early

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 $^{^{10}\} https://www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html$



language acquisition is important and that learning Auslan as well as an auditory approach does not impact or impair the development of speech for those deaf individuals that choose both signing and speech acquisition. Other disability types (e.g. Autism) will in fact use Auslan or key signs as a way to engage communication and develop speech over time.

Recommendations

- 1. Change the wording from "the hearing loss of the person necessitates the use of personal amplification" to "the hearing loss of the person may be aid-able". Consider the use of other language and wording in the eligibility criteria that remove the emphasis on a medical and auralistic approach.
- 2. Clarity and explanation of Auslan as a legitimate and often preferred pathway of language acquisition with or without Aural focus.

3. Australian Hearing as the referral pathway for Early Intervention

It is recommended in both the Provision of Hearing Services under the NDIS inquiry interim report ¹¹ and Inquiry into the Hearing Health and Wellbeing of Australians ¹² that Australian Hearing take on a greater role in in the scheme with regards to operating as the independent referral pathway.

"Recommendation 4: The committee recommends Australian Hearing be formally appointed as the independent referral pathway for access to early intervention services under the NDIS and funded appropriately to take on this new role".

"Recommendation 15: The Committee recommends that the Office of Hearing Services fund the creation of a national 'guided pathway' system, based in Australian Hearing, to assist parents in choosing expert early intervention services for their children".

Deaf Services Queensland has a number of concerns and questions regarding these recommendations:

- Appointing one organisation as the one referral pathway for Deafness is not competitive or open and not in the spirit of the NDIS in terms of open market or individual choice and control (e.g. Access Partners and Local Area Coordinators need to apply through competitive open tender to provide referral pathways and support).
- 2. How will Australia Hearing separate functions of their referral pathway with their service delivery? For example, there is an alignment of early intervention age group (0-25) with currently free hearing aid scheme as provided by Australian Hearing. Additionally current access partners do not provide early intervention services thereby reducing the potential of conflict of interest.

12 https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/HearingHealth/Report_1

¹¹ https://www.aph.gov.au/Parliamentary Business/Committees/Joint/National Disability Insurance Scheme/HearingServices/Interim Report



- 3. How will children with **multiple needs** be served by Australian Hearing, will they have expertise and knowledge in other disabilities that may be presenting as the primary need? What will be the interface with other sectors and section of the NDIS? Will their needs associated with their physical disability be through an LAC or AP or will Australian Hearing manage this entire pathway.
- 4. What is Australian Hearings expertise and knowledge of other pathways, including an **Auslan** pathway for language acquisition? Auditory services as provided by Australian Hearing traditionally aligned with the auditory aural approach to deafness and speech acquisition. Parents dealing with their newly diagnosed deaf baby are influenced by the professionals who are seen as experts in this field however their expertise is limited to one methodology of language acquisition, thereby the range of choices for parents to consider are not provided.
- 5. How will **young adults** be empowered to take charge of their own pathway when 18, the language in recommendation 15 is clearly focused on parents and their needs not in keeping with the spirit of the NDIS around individual choice and control.

Recommendation: one organisation should not be appointed directly to manage the "referral pathway for access to early intervention services under the NDIS". Competitive open tender with multiple options for access and provision across Australia is required to ensure that the Deaf community has their needs met more broadly without a singular focus (e.g. aural/auditory). Appointing Australian Hearing as the pathway for access to early intervention services under the NDIS is not in keeping with the spirit of choice and control for families.