# ECEI Reset Consultation

## Deaf Services Ltd.
## February 2021

## EXECUTIVE SUMMARY

Deaf and hard of hearing children have unique needs. We are grateful for the opportunity to share our expertise on early intervention and make the following recommendations particularly in relation to children who are deaf and hard of hearing and their families.

## RECOMMENDATIONS

### 1.1 General

- That the age range be extended to 9 years.
- That STEI involve appropriately qualified clinicians, AND people with lived experience of the disability in early contact with the family.
- That the NDIA consider possible overlap of STEI services with existing specialised services.
- That the NDIA avoids jargon as much as possible in communication with families and encourages partners and providers to do the same.

### 1.2 Goals

- That the NDIA introduce a requirement for the person connecting DHH children and their families with services to have specialist knowledge in DHH services. If there is no specialist early childhood partner for DHH children available, then support coordination should be provided.
- That the NDIA redouble its efforts to support peer networking for families, including plan budget allocations for access to parent-to-parent mentoring.
- That the NDIA ensure that children receive the supports they need to achieve their full potential.

### 1.3 Targeted support

- That the NDIA review its approach to thin markets and adjust pricing structures to enable specialist supports to be provided in regional, rural and remote communities.
- That the NDIA encourage and fund proactive strategies such as schools outreach and peer mentoring to ensure that families, especially those who may be at higher risk of disengagement because of language barriers, unemployment, domestic and family violence or other challenges, are able to engage effectively with services and peer networks.

### 1.4 IAs

- That the IA process adopt appropriate assessments for DHH children for the IA. See Appendix A for a list of speech and language assessments in use at Deaf Services.
- That the NDIA work with specialists in the field of signed language linguistics and Auslan service providers to develop an assessment tool for Auslan language proficiency in children.
- That the service provider does the cohort-specific assessments and provides a recommendation in their end of plan reports as they are already assessing this anyway. This would save enormous costs for the NDIA and would lead to more accurate assessment of needs and children would perform better with their familiar clinician.

### 1.5 Transparency

- That the NDIA continue to monitor quality through existing mechanisms and trust families to navigate the market appropriately.
- That the NDIA continue to support choice and control by allowing the use of unregistered providers who have lived experience.
- That the NDIA support peer-to-peer networks as these are excellent as a quality control mechanism.

# BACKGROUND

Being deaf is not as simple as not being able to hear. When deafness occurs early in life, it can mean missing out on education, literacy and knowledge which invariably impacts on a deaf individual's ability to engage in the social, civic and economic life of the community.

## TERMINOLOGY

The term "hard of hearing" is usually used to refer to those with those who use English rather than a signed language as their primary means of communication. The term "deaf" refers to those who use a sign language as their primary language. As it is not always possible to predict which language/s a child with hearing loss will use as their primary language as an adult, it is usual to refer to children with a hearing loss as "deaf or hard of hearing" (DHH).

## AUSLAN

Auslan (Australian Sign Language) is the signed language used by the Deaf Community in Australia. 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 a grammar and lexicon quite different to those of English. As for any foreign language, many years of study are needed to acquire fluency.

Auslan is the preferred language of those who identify with the Deaf community. Fewer than 5% of deaf people acquire Auslan as a first language from deaf parents.[1] Others typically acquire it from participation and socialisation within the school environment, from interacting with the Deaf Community as a teenager or young adult, or in some cases from hearing parents who have learned the language themselves. Auslan is also acquired as a first language by the hearing children of deaf parents.

# RESPONSE TO QUESTIONS

## 1.1 GENERAL QUESTIONS

We agree that the proposed increase in age range for the EC Approach to under 9 years of age is likely to facilitate a more effective transition to primary school.

STEI delivery outside of access to the scheme may be helpful if it is conducted by appropriately qualified professionals and people with lived experience of deafness. We would emphasise the importance of timely access to supports, regardless of which program or scheme facilitates that access. Hearing loss is typically diagnosed within the first days of a child's life at a time when families are very vulnerable. A family whose child has been recently diagnosed with hearing loss usually needs prompt access to both good clinical advice and to adults with lived experience of the disability, including deaf and hard of hearing adults and other families.

The development of STEI programs should take into account existing specialised programs which offer a range of these services. It should be noted that the number of different services can be confusing for families in the early stages.

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[1] 10% is often quoted as the proportion of deaf children with deaf parents, but Johnston (2004) found that 3% of deaf students enrolled at a particular institution had any deaf relatives and Mitchell and Karchmer (2004) argue that the figure is under 5%.

As far as possible, we would encourage planners, partners and other professionals to avoid unnecessary jargon when communicating with families. This is especially helpful when communicating with parents and carers who have English as a second language.

Recommendations:

- That the age range be extended to 9 years.
- That STEI involve appropriately qualified clinicians, AND people with lived experience of the disability in early contact with the family.
- That the NDIA consider possible overlap of STEI services with existing specialised services.
- That the NDIA avoids jargon as much as possible in communication with families and encourages partners and providers to do the same.

## 1.2 SUPPORT WITH ACHIEVING GOALS

Our service provides reports prior to each plan review meeting. Detailed periodic assessment is an essential part of good clinical practice in any case. We would encourage the NDIA and other decision makers to rely more heavily on this natural part of the clinical practice in tracking the goals of children and families. Certainly the NDIA could make this mandatory, as good clinicians should be providing such reports anyway.

In our experience, some early childhood partners who are responsible for linking families with services do not have specialist knowledge of DHH services. Families have reported that they are simply given a list and sent on their way. The early childhood partners tend to have high staff turnover so as a provider we are constantly developing relationships with staff who learn about our services and then move on. Specialist knowledge is thus lost very quickly.

We find that those families who are allocated support coordination in their plans are much better connected with services.

If a child ceases to need supports, the family will naturally know to celebrate this without assistance from providers, partners, or the NDIA. The cessation of supports which are necessary to the child developing to his or her full potential is no cause for celebration. It is essential that the NDIA develop systems and processes which accurately distinguish between these two situations. In the case of DHH children, the disability is permanent and the child is likely to require ongoing supports throughout different stages of life and transitions. Artificial attempts to cut off supports which are working effectively may create greater need later in life, thus undermining the early intervention principles of the scheme.

To better support families of DHH children to connect with services, funded or mainstream, two approaches are critical:

- The person connecting the families MUST have specialist knowledge in the area of deafness and hearing loss. If the early childhood partner does not have this knowledge, then support coordination by a specialist provider is essential.
- Families must be connected with other families who also have DHH children. Peer-to-peer networks are often the most effective and they are more cost effective as well.

Recommendations:

- That the NDIA introduce a requirement for the person connecting DHH children and their families with services to have specialist knowledge in DHH services. If there is no specialist early childhood partner for DHH children available, then support coordination should be provided.
- That the NDIA redouble its efforts to support peer networking for families, including plan budget allocations for access to parent-to-parent mentoring.
- That the NDIA ensure that children receive the supports they need to achieve their full potential.

## 1.3 TARGETED SUPPORT

As a provider in a “thin market” (DHH services), we are acutely aware that there is much unmet need in regional, rural and remote areas. Unfortunately the pricing structures for NDIA supports are not adequate to cover the costs of provision. For example, Cairns and Mackay are not deemed to be remote, and do not attract a loading under the Modified Monash Model. However, they do not have specialist services for DHH children. Where there is good internet and the service is appropriate for remote provision, this can be of some use. Where this is not possible, we send staff from Townsville at our own expense.

To support peer-to-peer connections, early childhood partners could run their own playgroups or partner with mainstream services to do so. We have also found our Parent-to-Parent Mentor Program highly effective over many years. We also know that the Benevolent Society in Queensland did some schools outreach work which we believe was highly effective in engaging children in the scheme.

Recommendations:

- That the NDIA review its approach to thin markets and adjust pricing structures to enable specialist supports to be provided in regional, rural and remote communities.
- That the NDIA encourage and fund proactive strategies such as schools outreach and peer mentoring to ensure that families, especially those who may be at higher risk of disengagement because of language barriers, unemployment, domestic and family violence or other challenges, are able to engage effectively with services and peer networks.

## 1.4 TAILORED INDEPENDENT ASSESSMENTS (IAS) APPROACH

### *Functional Capacity Assessment*

Assessing the need for intervention based on current functional capacity is not an adequate basis to determine the needs of DHH children and their families. Long-term communication, literacy and socio-economic outcomes are put at risk if current functional capacity is the basis of assessing need. We intervene now to prevent problems in the future. Research has established the risk and the intervention that is needed, and it is irresponsible to ‘wait to fail’ before we apply what we know.

Waiting for a delay in functional capacity is against the principals of good early intervention for DHH children. Delays should be minimal or not present if intervention is effective and no other disabilities or environmental factors are present. Intervention should prevent delays developing. A child demonstrating age-appropriate skills is a sign that appropriate intervention is occurring and needs to continue. It is not an indication that the child and family need less intervention.

Communication growth is rapid in the early years. Children and families need ongoing support that responds quickly to changes in development. Short delays in accessing appropriate intervention can result in long-lasting delays in development.

Functional capacity needs to be considered together with the individual’s potential. Some DHH children are able to achieve language outcomes that are well above average: intervention should aim to help a child reach his/her potential, and not be halted by achievement at a pre-determined standard.

### *Assessment Tools*

Broad based measures such as the Pedi-Cat (Speedy) and Vineland 3 are not sensitive to the specific needs of DHH children. The Ages & Stage Questionnaire 3 may be a better indicator that functional delays are developing in the critically at-risk domains for DHH children, and will identify those for whom intervention is inadequate or other factors are at play. However, these tests do not identify the on-going intervention needs of DHH children who are responding well to intervention. These children have a recognised need for early detection of delay through ongoing monitoring of a specialised nature by professionals experienced in this field. This is for the following reasons:

- The child may be too young for a deficit to show but the risk has been established;
- The measure may not be fine enough to identify early signs of deficit. For example, all babies vocalise but specialised tests are used to identify delays in the amount and nature of the vocalization of DHH babies and toddlers;
- Measures may be insensitive to DHH children with mild and moderate needs. These children require intervention to reach their potential;
- The measure may be too broad to identify subtle signs of deficit which could be addressed with intervention. For example, a child with a mild hearing loss may perform adequately on a measure such as the ASQ 3 but later experience difficulties acquiring literacy at school because specific functional listening deficits were not identified;
- Tests which total scores across a domain or set of domains may underestimate the needs of a DHH child who scores well in one area but poorly in another;
- Scores on tests do not show what the family’s needs are. Parents have reported that they want help in identifying the things they need to know, as well as knowledgeable responses to their ‘known unknowns’.

In addition, the proposed tools will not adequately address the need to assess a child’s Auslan proficiency if the family is using Auslan as part of their approach to communication. There have been tools developed overseas and it would probably be possible to adapt these.

### ***Workforce Issues***

We are pleased that the NDIA is considering not having a separate IA workforce, as the workforce is already stretched. Although we understand that the assessments are supposed to be independent, there are good reasons to rely more heavily on service providers in determining the need for supports. These are:

- Children do not generally perform so well with strangers as with those known to them. Relying more on the reports of regular clinicians is likely to produce reports that show a higher capacity and give a more accurate picture of actual support needs, thus reducing overall cost.
- Good service providers are already doing this reporting so it saves duplication of work to rely more on these reports, thus reducing strain on the workforce.

Recommendations in relation to IAs:

- That the IA process adopt appropriate assessments for DHH children for the IA. See Appendix A for a list of speech and language assessments in use at Deaf Services.
- That the NDIA work with specialists in the field of signed language linguistics and Auslan service providers to develop an assessment tool for Auslan language proficiency in children.
- That the service provider does the cohort-specific assessments and provides a recommendation in their end of plan reports as they are already assessing this anyway. This would save enormous costs for the NDIA and would lead to more accurate assessment of needs, and children would perform better with their familiar clinician.

### 1.5 GREATER TRANSPARENCY ON PROVIDERS OF BEST PRACTICE

In addition to complying with the NDIS Practice Standards we provide services according to the *Queensland Minimum Standards of Practice - Early intervention for children who are deaf or hard of hearing and their families.* It is important to take into account existing cohort-specific best practice standards. Groups such as the Queensland Early Intervention Working Group which link providers, not-for-profits, Health, Education, university sector, and parent groups are ideally placed to work on complementary mechanisms.

The use of registered providers only limits family choice and control, which is against the principles of the NDIS. For example, families wishing to organise additional Auslan language modelling or mentoring for their children have the flexibility to approach Deaf community members and gain exposure to the Deaf community and Deaf culture. By reducing choice and control, the NDIA would limit competition, especially in more specialised areas such as the DHH sector. This could have the unintended consequence of reducing accountability and thus reducing quality of services.

In our experience, peer-to-peer networks and competition need to be fostered in order to drive quality. Once families are in contact with each other, they will provide informal ratings of services to each other and exercise their collective power as consumers to keep their service providers accountable. They do this at no cost to anyone, and more effectively than an artificial ratings system which can be “gamed” by providers (e.g. by refusing services to clients likely to pull their rating down).

Recommendations:

- That the NDIA continue to monitor quality through existing mechanisms and trust families to navigate the market appropriately.
- That the NDIA continue to support choice and control by allowing the use of unregistered providers who have lived experience.
- That the NDIA support peer-to-peer networks as these are excellent as a quality control mechanism.

## REFERENCES

Johnston, Trevor A. “W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign Language” *American Annals of the Deaf* 148(5), Spring 2004, pp. 358-375.

Mitchell, Ross and Karchmer, Michael. “Chasing the Mythical Ten Percent: Parental Hearing Status of Deaf and Hard of Hearing Students in the United States” *Sign Language Studies* 4(2):138-163, December 2004, pp. 138-163.

## ABOUT US

Deaf Services Ltd. is a specialist service provider for deaf, deafblind and hard of hearing people. We work with the Deaf Community towards equity for deaf people.

## CONTACT

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# APPENDIX A

Hear for Kids

Speech Language Assessments for children aged 0 – 6

- Rossetti Infant-Toddler Language Scale/ Cottage Acquisition Scales for Listening, Language and Speech
- Vocal Development - Infant Monitor of Vocal Production eIMP https://www.eimponline.org/
- Functional Listening – FLIP 2/PEACH
- MacArthur-Bates CDI Words & Gestures/Words & Sentences
- LENA vocal productivity measure
- Toddler Phonology Test
- SIR (speech intelligibility rating) or Intelligibility in Context Scale
- CELF-P2
- Vocabulary - PPVT-5 and EVT3
- DEAP
- Phonological Awareness - 4 and 5 years- CTOPPs
- The Pragmatic Profile or the Pragmatics subtest from the CELF-P2
- Narrative assessment (4 and 5 years) CUBED, or Bus Story, or Snap Dragons
- PLS-5, MacArthur (no norms), The Communication Matrix, , Monitoring protocol (British)