



# The provision of services under the NDIS Early Childhood Early Intervention approach

August 2017

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## Background

### Joint Standing Committee

The Joint Standing Committee on the NDIS as part of their inquiry into the implementation, performance and governance of the NDIS is seeking submissions on NDIS ECEI (Early Childhood Early Intervention) approach. Terms of Reference<sup>1</sup> for the inquiry are as follows:

- a) the eligibility criteria for determining access to the ECEI pathway;
- b) the service needs of NDIS participants receiving support under the ECEI pathway;
- c) the timeframe in receiving services under the ECEI pathway;
- d) the adequacy of funding for services under the ECEI pathway;
- e) the costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants;
- f) the evidence of the effectiveness of the ECEI Approach;
- g) the robustness of the data required to identify and deliver services to participants under the ECEI;
- h) the adequacy of information for potential ECEI participants and other stakeholders;
- i) the accessibility of the ECEI Approach, including in rural and remote areas;
- j) the principle of choice of ECEI providers;
- k) the application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services; and
- l) any other related matters.

### 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)

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<sup>1</sup> [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/EarlyChildhood](http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/EarlyChildhood)



- Community Engagement and Development
- Education service operating both accredited as an RTO provider and unaccredited community courses
- Language services including Auslan interpreting (online and onsite), CALD interpreting and Translating, and
- An 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 customers being empowered, connecting and achieving their goals.

We are a provider of ECEI in Brisbane, Townsville, Mackay, Ipswich, Toowoomba and surrounds. Our early intervention services are funded by a mixture of State based and Commonwealth programs (Better Start and NDIS). With our remit and service offerings, Deaf Services Queensland is well placed to make observations and share experiences relating to the NDIS and ECEI implementation under the terms of reference in this inquiry.

Further, as a State funded provider of participant readiness on the ECEI approach to parents of children who are deaf or hard of hearing, we have received feedback and questions that has assisted us in deepening our understanding of the approach and emerging issues for families. This paper is informed by these observations with a focus on Queensland roll out. Our submission to the Joint Standing Committee seeks to address each area of the inquiry.

### **Terminology**

Deaf Australia operates a terminology policy that was adopted by members in 2010<sup>i</sup>. 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.<sup>ii</sup> **Auslan** is Australian Sign Language which is the language of the Deaf community in Australia<sup>i</sup>.

### **Auslan**

Willoughby (2013)<sup>iii</sup> reported from 2011 ABS census data that there were 9723 Auslan users. This figure represents a 124% increase from the 2001 census which was explained by several factors including, growing Auslan pride in the community and a census awareness campaign by Australian Deaf Societies. Queensland had a population of Auslan signers (n= 2221) which was only a few hundred less than NSW, thought to be explained by increase in children using Auslan at home due to QLD government policy implementation of transition to Auslan in Deaf education.



Other studies have estimated that there are around 15,000 people using Auslan<sup>iv</sup>. The census cannot be solely relied on as many deaf people with English as their second language may not have completed the census due to lower English literacy (English is a second language) and many may have missed the question about “speaking” a language other than English at home as it would have been perceived as not being relevant. Indeed, people may “speak” English at home but in reality it is not their preferred language.

### **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 children<sup>2</sup>.

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 transdisciplinary<sup>3</sup> family centred team and a very cost efficient model.

In response to the NDIS, language emersion environments through various education settings have announced closures (including ECDP (Early Childhood Development Program) in QLD and Centre For Hearing Impaired (CHI) children situated at the Elizabeth Park Primary School grounds in South Australia) which would move Deaf children into expensive, non-Deaf-inclusive settings and where the key aspects of Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>v</sup> are ignored. Many studies have consistently concluded that Deaf Children learn best when instructed by an Auslan speaking teacher and supported by Auslan speaking staff and peers rather than through an interpreter which they would require in a mainstream setting.

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 take many years to come into any effective practice or process for Deaf students, let alone their peers. 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.

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<sup>2</sup> 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 over the last few years Auslan learning can be utilised through the resource funding of the Better Start program – amounting to only \$2000 per child.

<sup>3</sup> “ 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*)



## Addressing the Terms of Reference

### a) Eligibility criteria

Eligibility criteria for determining access to the ECEI pathway are as follows:

- 0-6 years
- Live in Australia and are an Australian citizen, or have paperwork that gives permission to live in Australia permanently
- Meet four early intervention requirements
  1. Identified disability or impairment that is likely to be permanent or a developmental delay
  2. ECEI will reduce future needs for supports in relation to disability
  3. ECEI will benefit the person through reducing impact of disability, preventing deterioration, improving functional capacity and strengthening supports
  4. Is NOT most appropriately funded through external systems

The operational guidelines for access to early intervention provide a list of permanent impairments that mean no further assessment is required. The relevant definitions to Deaf and hard of hearing in the guide are:

- **Deafblindness** confirmed by ophthalmologist and audiologist and assessed as resulting in permanent and severe to total impairment of visual function and hearing
- **Deafness/hearing loss** – a 45 decibels or greater hearing impairment in the better ear, based on a 4 frequency pure tone average (using 500, 1000, 2000 and 4000Hz)

It is our understanding that this does not exclude children with higher decibel readings from the ECEI approach and that their developmental capacities are taken into consideration when making these eligibility decisions.

#### Issues arising from ECEI eligibility criteria

- The automatic inclusion (no further assessment required if your child is under a certain decibel reading) is useful; however, this has led to a misunderstanding among parents that if their child's loss was not in this decibel range then they would not be eligible for ECEI. If developmental delay is taken into consideration then this would not be the only criteria on which children are assessed against, however sometimes planners don't consider this. Children with less hearing loss benefit from early intervention in terms of speech and language development to prevent delays later. Further, many parents report that their child started with hearing loss in one ear and then later lost hearing in both or hearing was completely lost in one or both ears over time. Delaying their opportunities for language access creates a bigger cost burden long term. This criteria has also led to confusion over the eligibility of children with unilateral hearing losses (one ear).
- Parents have also addressed concern over assessment criteria/process of development delay. In terms of language acquisition this delay is not always apparent early and it is not until they reach certain ages that language milestones become obvious. However, early access to language acquisition increases the child's opportunities for participation, inclusion and capacity building.



Developmental delay diagnosis for hearing loss if under the automatic threshold is hard to pick up until later and by then some key windows of language acquisition have been missed.

- Children born in Australia with New Zealand citizen parents are NOT eligible for the scheme unless their NZ citizen parent holds an Australian permanent visa, was a dual Australian-NZ citizen or was covered by the transitional arrangements for the 26 February 2001 changes. Anyone who holds a Protect Special Category Visa is eligible. At the age of 10 these children become eligible for the scheme through automatic citizenship if they have been residing in Australia since birth. This means they have missed a critical window of opportunity for early intervention to assist with language acquisition (whether by signing, speech or both) and other interventions related to their disability. One of the intentions of early intervention approach is to reduce the long term cost on the scheme, excluding this group of children until the age of 10 does not adhere to that intention.

#### **b) Service needs**

Deaf Services Queensland has been providing ECEI supports to Deaf and hard of hearing children via the NDIS ECEI approach since its launch in Townsville. DSQ's service provision differs in the different regions of Queensland due to the concentration of deaf and hard of hearing children in the south-east corner and the existence of historical early intervention programs. Future supports will include transdisciplinary early childhood intervention and multidisciplinary team models.

Service needs of NDIS participants receiving support under the ECEI pathway who are Deaf and Hard of Hearing based on the best practice principles of family centred early intervention and are:

- **Auslan at home:** a flexible program teaching Auslan to participants and/or their supporters, family and friends. The program can be delivered at a time and location that suits the participant and the content can be customised to suit the language needs of those involved in terms of developing language, understanding grammatical structure, attending the communication of other people and so on.
- **Auslan Community classes** for parents to learn Auslan to enable them to communicate with their child's emerging language.
- Access to **aids and equipment** has meant guidance on best technological options and specialised equipment (e.g., hearing aids).
- **Speech therapy** includes supporting children in:
  - Attending to the communication of other people
  - Developing listening skills
  - Understanding the meaning of spoken language
  - Using words and then sentences to express themselves and participate in their community
  - Improving the clarity of the speech sounds they produce, progressing from 'baby talk' to speech that is easily understood
  - Learning to read and write
  - Using augmentative and alternative communication when this is the most appropriate way for the child to communicate
  - Developing safe and mature eating patterns, when this is problematic
  - Guidance on alternative communication options



- Teacher of the Deaf expertise includes:
  - Auslan tutoring
  - Hearing aid management
  - Creating good listening environments
  - Strategies for supporting communication, including listening, speech, language and play.
  - Recommending age appropriate resources to support language and communication development, including Auslan resources
  - Tips for talking with a deaf or hard of hearing child
  - Hearing technology and audiology
  - Information on Deaf culture
- **Early intervention group program:** provides opportunities for children to meet and play with other Deaf or hard of hearing children. This happens in a guided play situation where activities are provided to match the language needs of the participants. The group program is also a valuable way for parents to provide support to each other.

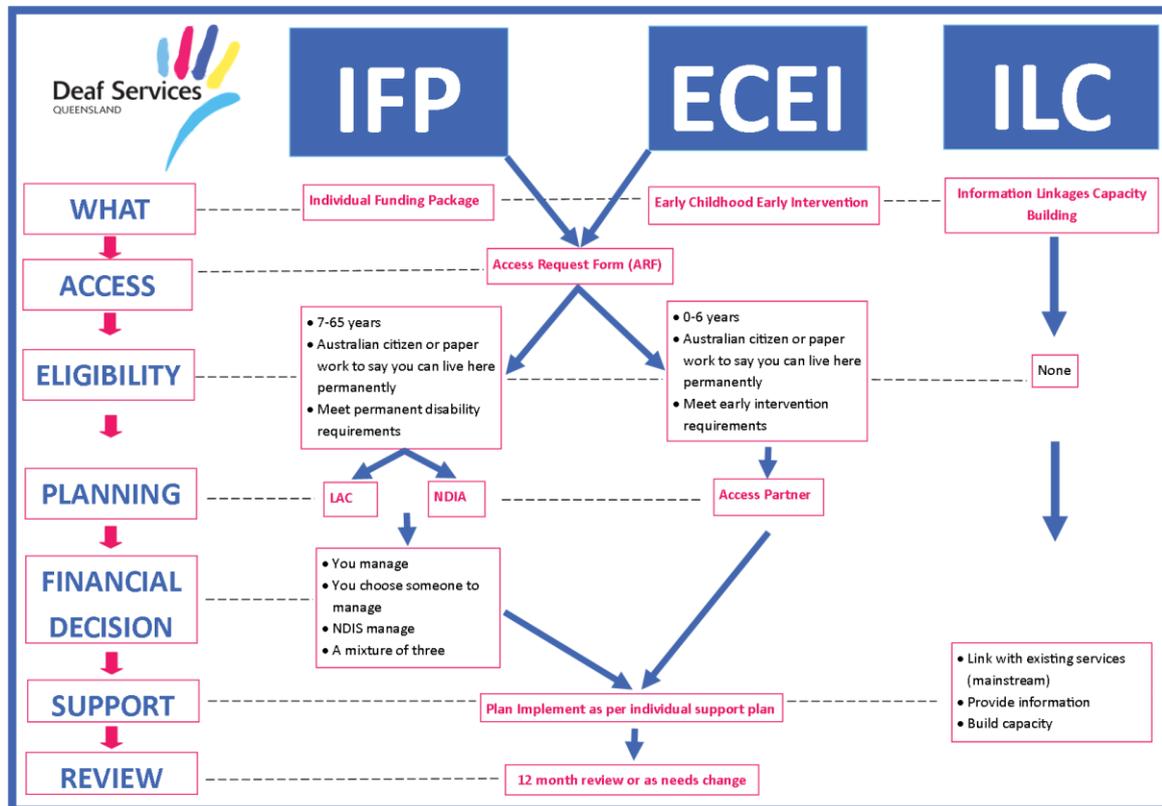
In terms of responding to the service needs of children who are Deaf or hard of hearing it is apparent that the Auslan referral pathways for Deaf children has not been well understood by the Access Partners and NDIA planners. There is little understanding that even if a medical intervention such as cochlear is taken, parents may still choose an Auslan pathway to work in conjunction with this or parents may prefer an Auslan only pathway. Creating an Auslan pathway provides language acquisition to deaf and hard of hearing children and thereby providing a means of communication for the child in a natural environment and creating the same opportunities as their hearing peers gain when learning the language of speech.

Language acquisition through speech is mostly viewed as an allied health pathway. Language acquisition through signing is not seen as an allied health pathway and we have seen consistently less emphasis has been placed on the acquisition of Auslan as it is not an allied health service although it is an integral pathway for deaf children.

Mapped Auslan pathway early intervention approach education is needed for planners, Access Partners and supports coordinators to assist families to make informed decisions for their children. Families should not be provided with an “either” “or” approach for early intervention of deafness, rather a range of options that suit them and their child’s needs. Planners failing to understand that hearing aids and other devices such as cochlear implants are not a quick fix and that further ‘work’ is required for language development has resulted in some unfair plan decisions (e.g. no Auslan at home funded for carers after cochlear implants were supplied).

### **c) Service implementation time frame**

The timeframe in receiving services under the ECEI pathway has raised several issues. The ECEI pathway is different from IFP (individual funding program) and has been identified by Deaf Services QLD as visualised over the page. The key point of difference from IFP is all support is determined via Access partners and that families do not get financial decision making opportunities.



In our experience, delays in service are related to provider availability and limited awareness from relevant Access Partner on possible pathways of support for a Deaf child. Planners in particular have been unaware of the range of ways support can be provided to Deaf children and failure to recognise Auslan as an important aspect of a child’s development for long term independence. This results in a failure to refer to a range of options for service provision in the early intervention space.

Issues of service delay are obviously exacerbated through the tyranny of distance and limited options of specialist<sup>4</sup> providers within certain locations.

**d) Adequacy of funding**

Funding tablets and data under the NDIS

It has been difficult to get a firm position from the NDIA on the funding of tablets however our experience of supporting parents through this process is that tablets have been mainly rejected in plans. It appears that the NDIA want services to provide and or develop innovative service solutions. Whilst we are in agreement one aspect of service delivery for rural and remote areas sees the use of

<sup>4</sup> In discussing specialist services, we are referring to providers who provide information and support through the method of communication required by the person and having staff who understand Deafhood. For example, Auslan communicating staff for drop in support, in home and community support workers. This is a unique point of difference from other non-specialist Deaf service providers.



learning language (Auslan and speech) through video conferencing rather than expecting those Participants in regional and remote areas to travel many hours to borrow a tablet to undertake the said NDIS activity/service.

There is reluctance by the NDIA to fund a participant in being able to access innovative technological devices, despite these strategies reducing expenses to the NDIA over the short and long term. Additionally, access to tablets will allow Deaf participants to seek other services such as securing Auslan interpreters remotely through the tablet, particularly in regional and remote areas where no physical Auslan interpreter is available and some tele-practice therapy and auslan at home thereby meeting their goals. It will also enable children to participate in therapy or Teacher of the Deaf services via tele-practice, thereby increasing efficiencies and decreasing the impact of travel distances.

Tablets were previously funded under Commonwealth schemes such as Better Start and Helping Children with Autism. Tablets can have impact beyond being a device for service access but also as access to programs and tools that can assist in skills development, such as language acquisition.

Some regional NDIA offices are requesting Access partners add clinical reporting to a Participants Plan so as to justify the need for Assistive Technology i.e. Commercial Tablets. We have concerns that most traditional clinicians do not have sufficient understanding of the Deaf community and the benefits of the delivery of services such as interpreting, Auslan at Home and some telepractice. The cost of the clinical reporting becomes farcical when it is greater or equivalent to the purchase of an iPad in the first place.

Additionally there is little understanding by the NDIA that many regional areas in Queensland do not have Auslan interpreters or Teachers of the Deaf physically located there and that under current plans there is no allowance for travel.

There is also comment from the NDIA in some regions of Queensland that existing services could be used to eliminate the need to have Assistive Technology added to Deaf Participants plans. However, in our experience existing services may be Video Conferencing (VC) equipment based in Queensland Health Facilities or some Centrelink Offices. This is problematic in terms of a Deaf person arranging to loan the equipment for community participation, as well as leading to questions around funding and payment for use.

#### Deaf Awareness

90% of deaf children are born into hearing families, meaning most families are new to the world of Deafness and require information about Deaf culture and experiences so they can better support their child integrate and prepare for life. Although Auslan at home may touch on aspects of this it has not traditionally been funded and seen as useful for families and their communities to understand issues of Deafhood. There are significant gaps in planner's knowledge which impacts on



what is recommend for service provision for the child – leaving a gap and needs. In the interests of representing our Deaf community, DSQ at minimum would recommend all planners and eventually LAC's and Access Partners have some grounding in Deaf awareness. Without adequate understanding of the unique issues that Deaf people face they will continue to be at a disadvantage in the new system.

#### **e) Costs associated with ECEI services**

##### Costs in relation to initial diagnosis and testing

In Queensland, children identified with hearing loss as part of the Newborn Hearing Screening program are tested and diagnosed via hospitals. Families then access hearing aids through Australian Hearing, and cochlear implants through hospitals. Children who are diagnosed later are also able to access these services, although some families may engage with private audiologists at their own cost.

In terms of access to the NDIS ECEI funding, we recommend that parents/carers can provide existing allied health and audiological reports as evidence of their child's developmental delay (whether that be language acquisitive or other developmental milestone delays). Where these reports are already available it is both time consuming and costly to seek further assessment for allied health providers to undertake testing and reporting. This is especially so in early childhood and with complex cases.

In Queensland children are part of the Healthy Hearing monitoring program and speech language assessments are available via hospital speech language pathologists up until the child is five, leaving a gap of a year with the ECEI approach. Hospital-provided occupational therapy and physiotherapy assessments are not routine and wait lists can be high. In practice many families have their children assessed through other services, such as private providers, Hear for Kids or via Better Start providers. Hear for Kids provides comprehensive assessment services to families for in all facets of speech language pathology, occupational therapy and physiotherapy. The inability of the State to respond to diagnosis and testing of Deafness will continue to create strains for families wanting timely acceptance into the NDIS to commence their early intervention program as promptly as possible.

##### Service provider transport costs

Travel has been the single most complex issue in terms of adequate funding to provide support, particularly in locations where the participant does not live closely to services. The \$1000 a year limit of travel for therapists (across all therapy support delivered) does not provide fair and equitable access to supports and services for clients living in more regional areas or clients who are financially challenged and don't have access to transport to attend sessions. Travel is paid at the normal therapy rate of \$175.57/ hr (SLP or Teacher of the deaf). This equates to 5.7 hours. For children in remote areas such as Emerald (610 km away from Townsville) or Bowen (200 km away from



Townsville) the travel allowance does not equate to a fair service. For families engaging in telepractice services it is still best practice to have face-to-face contact with a therapist or Teacher of the Deaf at different time intervals. This is especially important when developing a relationship with the child and family. The NDIS suggests that you group your clients but in the area of deafness there is often only one participant in a regional area.

#### Additional costs not covered by NDIS hourly rate

NDIS only covers time with the client, with high needs or complex clients and multidisciplinary in nature, it is best practice to meet, communicate and collaborate with a range of other stakeholders (e.g. physiotherapists, ECDP teacher, autism specialist etc.). Report writing time is also not covered unless it is for an NDIA requested assessment. Further the costs associated with rural and remote delivery (namely transport, flights, accommodation) are not adequately covered.

#### **f) Evidence of the effectiveness of the ECEI Approach**

There is sufficient evidence and research available on the benefits of early language acquisition for children who are Deaf and hard of hearing and this does not appear to be accessible to the NDIS planners. If ECEI is designed to be best practice then it should be accessing contemporary research and information on best practice for specific populations.

#### Best practice ECEI Models

The NDIS acknowledges that evidence-based family-centred transdisciplinary approaches are best practice for early intervention services. For early intervention for Deaf and hard of hearing children the highlights of this model include allied health professionals (speech therapist, occupational therapist) and Teachers of the Deaf working collaboratively with parents to provide the best program to suit the individual needs of each child and family. Recognition that children's communication needs vary and that children learn using various approaches mean that programs are tailored to meet the individual needs of each child and family.

A best-practice model for ECEI for Deaf and hard of hearing children ensures:

- Children receive co-ordinated services that are planned, reliable and meet their ongoing individual needs
- Respect for each child's age, culture, personality, learning style and ability
- Each child develops their ability to communicate in a way that is right for them, both as an individual and as a member of their family
- Children and families are part of a community with other Deaf and hard of hearing children and adults
- Families are recognised as the experts on their child, and the best judges of how they can manage the strengths and the unique needs of their family to give their child the best possible

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start in life. Interventions are provided according to the families' preferences, informed choices, and in consideration of cultural and social practices

- Families are informed about the program and consulted about any changes required
- Families' rights to privacy and confidentiality are respected, and they have access to the personal information held by the provider
- Families have access to fair and equitable procedures for dealing with complaints and disputes

The 2012 international convention on family centred interventions agreed that family centred early intervention practices optimise outcomes for deaf and hard of hearing children and their families. The international expert panel defines ten best practice principles guiding the implementation of family centred early interventions for Deaf and hard of hearing children. The principles were published in the Journal of Deaf Studies and Deaf Education (June 2013)<sup>vi</sup>.

- **Principle 1 - Early, Timely and Equitable Access to Services:** Screening and confirmation that a child is deaf or hard of hearing will be effective to the degree that they are linked with immediate, timely, and equitable access to appropriate interventions.
- **Principle 2 - Family/Provider Partnerships:** A goal of family centred early intervention is the development of balanced partnerships between families and the professionals supporting them. Family-provider partnerships are characterized by: reciprocity, mutual trust, respect, honesty, shared tasks and open communication.
- **Principle 3 - Informed Choice and Decision Making:** Professionals promote the process wherein families gain necessary knowledge, information and experiences to make fully informed decisions about the therapy needs for their children. This includes educating families regarding their rights, accessing specialized therapies and educational services and how to respond to the changing needs of the child.
- **Principle 4 - Family Social and Emotional Support:** Families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their deaf or hard of hearing child.
- **Principle 5 - Family Infant Interaction:** Families and therapists work together to create optimal environments for language and learning through the use of everyday routines, play and typical interactions to promote the child's communicative development.
- **Principle 6 - Use of Assistive Technology and Supporting Means of Communication:** Therapists must be skilled in the tools, assistive devices and mechanisms necessary to optimally support the child's language and communication development. Therapists must also be able to share this knowledge to support families in its application in the promotion of language and communication interactions.
- **Principle 7 - Qualified Providers:** Therapists must be well trained and have specialised knowledge and skills related to working with children who are deaf or hard of hearing and their



families. Providers possess the core competencies to support families in optimizing the child's development and child-family wellbeing.

- **Principle 8 - Collaborative Team Work:** An optimal family-centred early intervention team focuses on the family and includes professionals with experiences in promoting early development of children who are deaf or hard of hearing. Ongoing support is provided to families and children through multi-disciplinary teamwork, whereby professionals with the requisite skills are matched to the needs of the child and family.
- **Principle 9 - Progress Monitoring:** Family-centred early intervention is guided by regular monitoring/assessment of the child and family outcomes by routinely and authentically evaluating the individual child's development as well as the family satisfaction, self-efficacy and wellbeing.
- **Principle 10 - Family centred:** Early intervention programs evaluate provider adherence to best practice and include quality assurance monitors for all program elements.

Hear for Kids also adheres to *the Queensland Minimum Standards of Practice – Early intervention for children who are deaf or hard of hearing and their families*, and is guided by the *Parent Professional Charter – Queensland forum for Young Children with a Hearing Loss*.

An initiative of the Queensland Forum for Young Children with Hearing Loss (2013), the Parent Professional Charter<sup>vii</sup> describes the things which are important to parents of children with hearing loss when working with professionals. It is essential that professionals are aware of these needs, as working alongside parents in a way that fulfils these needs will lead to better relationships and enhanced outcomes for their child.

1. **Professionalism:** Be sensitive, organised and consistent
2. **Information:** Provide accurate, unbiased, and comprehensive information early and make it accessible to all
3. **Support:** Pitch it to where parents are at, and be supportive of the decisions parents make
4. **Respect:** Acknowledge that parents know their child best
5. **Communication:** Listen to parents, be clear, check that they have understood the messages, and work as a team
6. **Being Positive:** Be optimistic and constructive with parents about the future
7. **Choice:** Acknowledge that choice is a parent's right
8. **Sensitivity:** Be tactful in how you speak to us and deliver information
9. **Responsiveness:** React appropriately to parents' request and understand that they become anxious when a child's needs aren't being met
10. **Knowledge:** Maintain professional knowledge so that parents can benefit from your expertise
11. **Direction:** Provide guidance so that parents know what they have to do and what is ahead.

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**g) robustness of data required to identify and deliver services to participants under the ECEI**

This has been addressed to some degree in the terms of reference f) and c). In short, the expertise and knowledge about Deafness and the support needs of Deaf people from planners is limited and extremely important. Instead of taking information on board with due respect from Deaf specialists and therapist, this is often rejected, for example, one planner felt it was appropriate for a Hearing parent (with insufficient Auslan) to teach her child Auslan once she had received cochlear implants. The planner was convinced that cochlear removed the need for language acquisition (although the child would always be Deaf and it was this families preference to learn Auslan). The inconsistency between regions, planners and outcomes in funding for participants is frustrating and often alarming.

**h) the adequacy of information for potential ECEI participants and other stakeholders**

Deaf Services QLD has been funded by State disability services to deliver participant readiness information to parents of the ECEI approach. The inadequacy of information from the NDIA just to prepare for these session was challenging at the beginning of roll out. By in depth reading of operational guides and the early information about the ECEI approach meant most questions were able to be addressed. Many of the early fact sheets and resources that were on the NDIS website relating to ECEI approach are currently not available on line. Further the basic search function on the website is inadequate and rarely results in locating the document you require even if you know it by name.

Misinformation and rumour spread quickly among parents and it is often hard to get to the bottom of the facts in the situation. The most obviously example is in relation to decibel reading. This is about automatic inclusion and not necessarily exclusion from the scheme. However, parents, planners and service providers frequently misunderstand this and fail to consider the developmental needs of the child as intended by the ECEI approach.

Other information that parents and other stakeholders require and is not readily accessible is in relation to:

- eligibility for children born in Australia of NZ citizen parents
- decision making regarding development delay (how is this measured for a child with mild hearing loss and no or little language acquisition)
- where to go in complex family situations for planning, e.g. one child may be under ECEI approach and one in IFP approach, these situations need to be explored as a collective family experience and not just the individual children
- where to go for service providers with specialist knowledge on their Deaf child's needs now and into the future (i.e. an Auslan pathway in conjunction with implants, speech therapy and a range of interventions).



**i) the accessibility of the ECEI Approach, including in rural and remote areas**

*Accessibility of services for deaf and hard of hearing children, including in rural and remote areas* is a significant area of concern for our community as the NDIS rolls out. Accessibility pertains to the area of communication for a Deaf child. Specialised models of providing workforces that use Auslan are overlooked in rural areas and this is compounded in indigenous and other CALD communities where people are also Deaf. Key issues are described below.

Workforce accessibility issues

There are limited Auslan communicating staff available to support Deaf and hard of hearing children in rural and remote areas. However, the high cost of delivery for the provider will increase inaccessibility, for example travel.

In most places in Queensland there are NO locally available teachers of the Deaf, Deaf specialist speech therapist or occupational therapist. Access to Vide Conferencing (VC) can overcome this to some degree, however as noted earlier, by not funding tablets and data VC also becomes inaccessible instead of being the most cost effective and accessible method for providing interpreting. Further, in areas where we have arranged VC for families to have Auslan at home there is no internet access due to the NBN roll out.

Definitions of rural and remote

Given the specialist nature of support required by Deaf people, issues of support overlap with issues of rural and remote delivery. For example, under the Modified Monash Model<sup>viii</sup> where areas are not considered remote by geography from our experience we would consider them remote due to the fact that no specialist services exist to provide support, creating an issue of remoteness. For example, where a teacher of the Deaf (TOD) does not live in a town, even if the town is not defined as remote the lack of TOD's makes it more remote.

**j) the principle of choice of ECEI providers**

The principle of choice for Deaf service provision is closely associated with the principle of inclusion. A fully inclusive community and society is an applauded principle and area of policy action in the National Disability Strategy 2010-2020 and one that Deaf Services Queensland supports. However, failure to recognise Deaf people have a "bona fide" culture<sup>ii</sup> presents an ongoing failure to honour Deafhood and Deaf identity. The NDIS and associated system changes for many deaf people fails to recognise that deaf people view inclusion as being and living as a part of their own community. Whilst mainstream services and access to these services are equally important, many Deaf people prefer to mix with other Deaf people and attend deaf related events, in the same way people from



different CALD groups often prefer to mix with those with similar cultural experiences and language. This is due to the barrier free communication environment that they participate in and the inherent cultural understanding of one another. This notion is complex for the required NDIS paradigm shift that is aimed at inclusion. Therefore, in discussing the principle of choice there needs to be a deep understanding of Deafhood and the Deaf community as a linguistic minority group issue, particularly for children acquiring language and the need of emersion.

Deaf Services Queensland staff have noticed two key issues relating to choice of provider. Firstly, families and parents need to be offered a range of pathways and merging of pathways between a medicalised response (cochlear and speech acquisition) and a Deaf culture response (Auslan acquisition). With 90% of children born deaf have hearing parents, many parents are influenced by the medical approach to deafness and will select a cochlear response with Auslan acquisition as secondary choice however this is misrepresented and the cochlear does not cure Deafness and when the processors are removed or damaged the person is still Deaf. Secondly, it is our observation that people tend to stay with their existing service provider, however, if planners or support coordinators have insufficient knowledge of what services may be available to a deaf or hard of hearing child and their families, then they may not be offered the full range of options (for example, an Auslan pathway).

**k) the application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services**

We have also seen little evidence if any of innovation in early intervention services for Deaf children. Failure to understand and use technology has meant decision around equipment purchase like iPads and tablets has been overlooked as crucial for a Deaf person to access affordable and accessible interpreting, therapy and auslan at home. It is unclear how existing research on Deaf culture and language development has been utilised in making planning decisions.

The NDIS offers a real opportunity to change the previously limited opportunities for deaf people to be included based on their needs rather than the dominate cultures needs. Accessing existing research and information and building on research relating to the NDIS individualised funding approach is an important way forward.

**l) any other related matters**

Other matters relating the NDIS that have been overlooked and are of importance include:

- **Transition from ECEI to IFP approach:** There is no information on the transition between the two different aspects of the scheme. At participant readiness workshops with parents, where they accept that their child MAY receive NDIS support for developmental delay they become



concerned about the transition to IFP. Will they be eligible? What if they need a little more time than the cut off of 7 years? How will the transition be supported?

- **Deaf Culture and Awareness Training (DAT)** for planners, LAC's, community partners, ECEI access partners, supports coordinators, and eventually ILC funded programs is crucial if the needs of Deaf people are to be met.
- Concepts of **inclusion** as they relate to the broader community do not relate to Deaf people and are more in line with CALD experiences of service inaccessibility.

#### Additional NDIS concerns: interfacing with NDIA and understanding Deafness

There are a number of additional concerns of the deaf community in regards to the interface with the NDIA. Deaf resources and support requires deaf awareness and knowledge to ensure people have their needs meet. Several key issues have already emerged that relate in varying degrees to both the IFP and ECEI approach (if we consider ECEI the first relationship and plan):

- There is an assumption that cochlear implant is the solution to deafness as a medical deficit, once again this fails to recognise the human rights of Deaf individuals to a language that they can access with ease and also that deafhood is a cultural identity and not viewed as a medical deficit or even disability.
- Planners, Early Childhood Access Partners and LAC's need a high degree of not only Deaf awareness but comprehension of all the different types of interventions and supports that may benefit a Deaf person or child. This requires high degree of knowledge specialisation.
- There is a misconception that people who are deaf are highly proficient in English even where English is their second language. This is not always the case. For many deaf people, poor access to a strong foundational language and subsequent access education being limited results in missed opportunities to develop strong English skills. Presentation of information in English is often ineffectual. Current NDIA web-based information is largely inaccessible to the Deaf community. Although there are Auslan translations about the NDIA they are lengthy and do not provide the practical and specific examples that a Deaf person with Auslan as their first language requires.
- Information is best delivered by a native or proficient Auslan signer with comprehensive knowledge of the details of the NDIS as they relate to deaf people.
- Where a planner is not Auslan proficient, an interpreter will need to be present at any engagement with the NDIA, the planner or the Access Partner for parents who are Deaf. The issue is not only the language as some Deaf people have had poor access to information over a long period of time, there is often gaps in their knowledge.



### Auslan recognised as linguistic minority group

Although deafness is defined as a disability under several legislative frameworks including disability discrimination across all jurisdictions and the NDIS Act, Deaf Services Queensland continues to advocate for Auslan being represented as linguistic minority group that would fit within a CALD framework. The Deaf community see themselves as a linguistic minority group and not as a disabled group. As such, the basic services and needs for a deaf individual fall around the issue of communication access needs (interpreters etc) as opposed to individual support needs etc. (in home care). According to Dawkins (1991, p. 20)<sup>x</sup> Auslan has been recognised by the Australian Government as a community group stating:

*"It is now increasingly recognised that signing deaf people constitute a group like any other non-English speaking language group in Australia, with a distinct sub-culture recognised by shared history, social life and sense of identity, united and symbolised by fluency in Auslan, the principal means of communication within the Australian Deaf Community"*

Deaf people who use Auslan as their first language thereby consider English as their second language and as such formulation of world views and general knowledge is via their understanding of the world through visual means and interactions with other deaf individuals rather than mass media.

Furthermore, it is our experience that Deaf individuals do not receive an adequate explanation on their care needs unless an active deaf organisation has provided such information or the person they are communicating within the Agency is familiar with Auslan or speaks through the use of an Auslan interpreter. Also, Deaf individuals with an additional disability who need to gain not just communication access but also individual support services will not receive adequate care and will experience communication difficulties with their carers where they are not a deaf specific service or interpreting is provided.



## References

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- <sup>v</sup> 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/convention-on-the-rights-of-persons-with-disabilities-2.html>
- <sup>vi</sup> 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), 143-175.
- <sup>vii</sup> Queensland Forum for Young Children with Hearing Loss (2013), the Parent Professional Charter (<http://www.health.qld.gov.au/healthyhearing/docs/parentcharter.pdf>)
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