

**Submission to the Joint Standing Committee on the
National Disability Insurance Scheme**

**Inquiry into the provision of hearing services under the
National Disability Insurance Scheme**

From First Voice

Submitted by:

Michael Forwood
Chair, First Voice
C/- Cora Barclay Centre
185 Melbourne Street
NORTH ADELAIDE SA 5006
Tel: 08 8267 9200
Email: mforwood@corabarclay.com.au

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6 February 2017

Committee Secretariat
Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
CANBERRA ACT 2600

Inquiry into the provision of hearing services under the NDIS

Dear Chairman and Committee Members

First Voice welcomes this inquiry into the transition of hearing services to the NDIS.

It comes at a critical time as several thousand children and young adults who are deaf or hearing-impaired transition into the full roll out of the NDIS.

If NDIS operating policies and funding arrangements for hearing-impaired children are deficient, deaf children's outcomes will suffer.

It is now 3 ½ years since the commencement of the NDIS trials and there are many areas of deep concern. These include: restrictive eligibility criteria; referral delays; scope of funded services; duration of services; qualifications and experience of service providers; NDIA planner inconsistencies; the interface between disability and mainstream health and education services; and inadequate funding.

These matters need to be resolved urgently.

Over the past 70 years, Australia has progressively developed an approach to identifying, diagnosing and meeting the hearing technology and early intervention needs of children who are deaf or hearing-impaired that is among the best in the world.

Reported outcomes of children participating in listening and spoken language early intervention programs of Australia's leading service providers show that the majority of early intervention graduates achieve age-appropriate speech and language before starting school and that more than 90% attend mainstream classes in mainstream schools. Graduate survey results from an Australian and New Zealand report shows high rates of school completion (86%), acceptance into higher education (82%), attainment of university qualifications (62%) and employment (77%) and high levels of social participation (84%). Similar results have been reported from North American graduate studies.

A recent cost benefit analysis of First Voice members' early intervention programs by Deloitte Access Economics shows that these programs have a 2.2 to 1 benefit to cost ratio; meaning that for every \$1 invested there is a return of \$2.20.

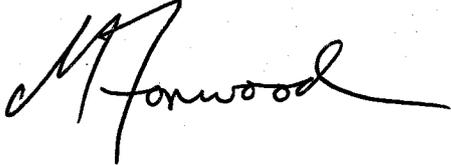
The mission of the NDIS is to optimise the social and economic independence of Australians with disabilities. Many hearing-impaired Australian children already achieve this, but there is more to be done if **all** Australian children who are deaf or hearing-impaired are to fulfil their potential. The NDIS offers a unique opportunity for further gains. However it also carries the risk of things becoming worse.

Children who are deaf or hearing-impaired are entitled to a clear and adequately funded pathway of services under the NDIS that will secure their future.

I would appreciate the opportunity to personally address the Joint Standing Committee at its next public hearing to elaborate further on the matters outlined within this submission. I look forward to receiving details from you once further hearings are scheduled.

Thank you for the opportunity to bring the matters outlined within our submission to the attention of the Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M Forwood'. The signature is fluid and cursive, with a long horizontal stroke at the end.

Mr Michael Forwood
Chair, First Voice
C/- Cora Barclay Centre
185 Melbourne Street,
NORTH ADELAIDE SA 5006
Tel: 08 8267 9200
Email: mforwood@corabarclay.com.au

About First Voice

We champion the right of children who are deaf and hearing-impaired to listen and speak

First Voice is a member based organisation that advocates for evidence-based early intervention services that give children who are deaf or hearing-impaired the listening and spoken language skills necessary to achieve fluent spoken communication, mainstream education, employment of choice and social integration within the hearing world. We champion the right of all children who are deaf or hearing-impaired to listen and speak.

Our members provide listening & spoken language early intervention services to more than 1,000 children across Australia and New Zealand

First Voice represents six member organisations in Australia and New Zealand, including some of the largest, oldest and most respected organisations specialising in early childhood hearing loss in the region. We have five Australian members:

- Cora Barclay Centre, South Australia
- Hear and Say, Queensland
- Taralye, Victoria
- Telethon Speech & Hearing, Western Australia
- The Shepherd Centre, New South Wales and Australian Capital Territory

First Voice member organisations provide listening and spoken language early intervention services to more than 1,000 children who are deaf or hearing-impaired. This is one of the largest cohorts of children receiving early intervention services for hearing loss in the world. Some members also provide services to clients into adulthood.

We advocate, conduct research & promote evidence-based practice

First Voice plays a leadership role within the early childhood hearing loss sector, influencing public policy and clinical practice related to services for children who are deaf and hearing-impaired. We are committed to providing evidence-based research to inform and influence public health policy in our region. First Voice and its members maintain an active research agenda and work with research institutions to conduct hearing research relevant to young people with hearing loss.

Our members deliver world-leading speech and language outcomes in children who are deaf and hearing-impaired

First Voice member centres achieve world-leading outcomes in the development of fluent speech and language in pre-school children with hearing loss. More than 70% of five-year-old graduates¹ from First Voice members' listening and spoken language early intervention programs achieve speech, language, comprehension and articulation scores equivalent to normally hearing children of the same age. These outcomes enable pre-school children who are deaf or hearing-impaired the opportunity to go onto mainstream schools, access mainstream (primary, secondary and tertiary) education, pursue their employment of choice and achieve social integration within the hearing world.

Two independent cost benefit analyses^{2 3} have demonstrated a positive cost-benefit of listening and spoken language early intervention services to the long-term wellbeing and productivity of young Australians with hearing loss.

¹ First Voice, 2014. Sound Outcomes: First Voice 2014 speech and language data.

² First Voice and Econtext, 2011. A social cost-benefit analysis of early intervention programs.

³ First Voice and Deloitte Access Economics, 2016. Cost-benefit analysis of First Voice's early intervention program.

1. Executive summary

Children who are deaf and hearing-impaired are currently at risk under the National Disability Insurance Scheme

While the National Disability Insurance Scheme (NDIS) offers significant advances to people with permanent lifelong disabilities, the scheme's services and funding framework is proving to be a "difficult fit" for childhood hearing services.

Evidence from the three year NDIS Children's Trial in South Australia shows the current NDIS service and funding framework is incompatible with Australia's best practice hearing service protocols, and the system is posing a real threat to children's outcomes, families and providers.

Issues of concern include restrictive eligibility criteria; referral delays; scope of funded services; duration of services; qualifications and experience of service providers; NDIA planner inconsistencies; the interface between disability and mainstream health and education services; and inadequate funding.

It is vital that infants and children diagnosed with permanent hearing loss receive timely referrals and appropriate funding within the NDIS to access the services they need. There are many instances where this is not occurring and it is critical that these problems are addressed.

Timing is critical in the management of childhood hearing loss. Failure to deliver an adequately funded and seamless process from screening to completion of early intervention will leave children with hearing loss at a substantial disadvantage. Research overwhelmingly shows that any delays in diagnosis, aiding/implanting of hearing devices and commencement of early intervention therapy are detrimental to communication, brain development and life outcomes.

Prescribed referral arrangements are needed under the NDIS to ensure:

1. informed choice by parents
2. streamlined, evidence-based identification, diagnosis, application of hearing devices/implants and other relevant technology (if chosen); and
3. commencement of appropriately funded early childhood intervention before 6 months of age if diagnosed at birth; otherwise commencement of intervention within 6 months of diagnosis.

While the NDIS holds great promise for many Australians with disabilities, it is evident from the three year trial period and now the full roll out of the scheme that the funding and service framework being applied to childhood hearing loss is placing children with hearing loss and their families at risk.

There is widespread concern from parents, professional groups, advocacy organisations and service providers that hearing-impaired children and their families may be worse off under the NDIS than under previous arrangements. A failure to resolve these issues has the potential to create life-long disadvantage to children with hearing loss, and set Australia's highly developed and internationally renowned hearing services sector back many years.

Despite the scheme now being in a stage of full rollout and there having been intensive and ongoing representations to the National Disability Insurance Agency (NDIA) over many months, many issues remain unresolved.

2. Background

2.1 Permanent hearing loss in young Australians

Hearing loss affects one in 300 children by the age of five years

Up to 1 in 500 children born will have some degree of permanent hearing loss. Further children will develop hearing loss in the first few years of life (due to progressive loss, disease, trauma etc) and by the time they are of school age approximately 1 in 300 children will have permanent hearing loss (approximately 4,000 children across Australia).

However despite these incidence figures, not all families access services. Some children with a diagnosed hearing loss “fall through the cracks” due to the absence of a guided referral pathway, while others go undiagnosed due to the absence of a national screening process after birth.

More than 90% of deaf children are born to hearing parents and most parents choose a listening and spoken language pathway for their child

More than 90% of infants born with deafness or permanent hearing loss are born to parents with typical hearing.⁴ More than 85% of these families choose spoken language as the primary mode of communication for their children with hearing loss.⁵ These parents typically select approaches that support listening and spoken language.

2.2 Australia’s management of permanent childhood hearing impairment

Australia has one of the best systems in the world for identifying and managing early childhood hearing loss. The system features a universal newborn hearing screening program, national arrangements for paediatric audiology and hearing aids (through Australian Hearing), access to cochlear and other implant technology and a range of highly skilled early intervention service providers.

The sector is supported by internationally regarded hearing research programs and institutions (eg National Acoustic Laboratories, HEARing CRC and Australian Hearing), and a high level of professional and clinical collaboration across the sector.

The COAG-endorsed National Framework for Neonatal Hearing Screening (2013) provides national guidelines for screening; diagnosis; early intervention, treatment and management; quality; professional education; and coordination, monitoring and evaluation.

The fundamental elements of Australia’s best practice early intervention arrangements for Australian infants and children who have a hearing loss and pursue a listening and spoken language pathway are outlined overleaf.

⁴ Mitchell & Karchmer, 2004

⁵ Alberb, Wilson & Roush, 2006; Dillon, Cowan & Ching, 2013

	Fundamental elements of best practice for early childhood hearing loss
1	Universal newborn hearing screening and very early confirmation of diagnosis.
2	The earliest possible fitting of hearing aids and/or implanting of cochlear and other assistive devices (if a listening and spoken language pathway is chosen) to provide the infant with as much hearing as possible as quickly as possible.
3	The earliest possible commencement of intensive early intervention to encourage and assist families.
4	Provision of intensive, evidence-based, family-centred, multi-disciplinary early intervention for as long as is necessary to meet speech/language/communication, comprehension and social development goals that are comparable with children of the same age with typical hearing.
5	Continuing support with hearing aids and assistive hearing devices (if chosen).
6	Ongoing monitoring and assessment throughout the school years with specialist intervention when additional support or remediation is required.

Table 1: Best practice arrangements in Australia for the majority of infants born or diagnosed with permanent hearing loss and whose parents pursue a listening and spoken language pathway

While there is room for improvement in certain areas (there are referral pathway deficiencies in some states and cochlear implant funding inconsistencies Australia-wide), these national clinical pathways provide the basis for the extraordinary outcomes that are achieved by children enrolled in multi/trans-disciplinary, family-centred listening and spoken language programs across Australia.

Australia's operating environment is the outcome of years of evidence-based research, advocacy and public policy development to develop an integrated national and state-based approach. It is critical that this operating environment is protected, maintained and built on in the years ahead.

2.3 International best practice guidelines

American Academy of Paediatrics, Joint Committee on Infant Hearing

> 2007 Position Statement

The American Academy of Paediatrics' Joint Committee on Infant Hearing published a position statement in 2007 that stipulates principles and guidelines for early hearing detection and intervention programs⁶.

The committee endorses early detection of and intervention for infants with hearing loss. The goal of early hearing detection and intervention is to maximise linguistic competence and literacy development for children who are deaf or hard of hearing. Without appropriate opportunities to learn language, these children will fall behind their hearing peers in communication, cognition, reading, and social-emotional development. Such delays may result in lower educational and employment levels in adulthood.

The position statement outlines the following principles:

1. To maximise the outcome for infants who are deaf or hard of hearing, the hearing of all infants should be screened at no later than 1 month of age. Those who do not pass screening should have a comprehensive audiological evaluation at no later than 3

⁶ American Academy of Pediatrics, Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics*. 2007;120(4):898–921.

months of age. Infants with confirmed hearing loss should receive appropriate intervention at no later than 6 months of age from health care and education professionals with expertise in hearing loss and deafness in infants and young children. Regardless of previous hearing-screening outcomes, all infants with or without risk factors should receive ongoing surveillance of communicative development beginning at 2 months of age during well-child visits in the medical home.

2. Early hearing and intervention systems should guarantee seamless transitions for infants and their families through this process.

> 2013 Supplement to Position Statement

A supplement to the Joint Committee on Infant Hearing Position Statement was published in 2013, entitled: *Principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing*⁷. This supplement outlines the following best practice goals for early intervention:

Goal 1: All children who are deaf or hard of hearing and their families have access to timely and coordinated entry into early intervention programs supported by a data management system capable of tracking families and children from confirmation of hearing loss to enrolment into early intervention services.

Goal 2: All children who are deaf or hard of hearing and their families experience timely access to service coordinators who have specialised knowledge and skills related to working with individuals who are deaf or hard of hearing.

Goal 3: All children who are deaf or hard of hearing from birth to 3 years of age and their families have early intervention providers who have the professional qualifications and core knowledge and skills to optimise the child's development and child/family wellbeing.

Goal 3a: Intervention services to teach sign language will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.

Goal 3b: Intervention services to develop listening and spoken language will be provided by professionals who have specialised skills and knowledge.

Goal 4: All children who are deaf or hard of hearing with additional disabilities and their families have access to specialists who have the professional qualifications and specialised knowledge and skills to support and promote optimal developmental outcomes.

Goal 5: All children who are deaf or hard of hearing and their families from culturally diverse backgrounds and/or from non-English-speaking homes have access to culturally competent services with provision of the same quality and quantity of information given to families from the majority culture.

Goal 6: All children who are deaf or hard of hearing should have their progress monitored every 6 months from birth to 36 months of age, through a protocol that includes the use of standardised, norm-referenced developmental evaluations, for language (spoken and/or signed), the modality of communication (auditory, visual, and/or augmentative), social-emotional, cognitive, and fine and gross motor skills.

Goal 7: All children who are identified with hearing loss of any degree, including those with unilateral or slight hearing loss, those with auditory neural hearing loss (auditory

⁷ Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing, *Pediatrics*, April 2013, VOLUME 131 / ISSUE 4, From the American Academy of Pediatrics, Statement of Endorsement

neuropathy), and those with progressive or fluctuating hearing loss, receive appropriate monitoring and immediate follow-up intervention services where appropriate.

Goal 8: Families will be active participants in the development and implementation of early hearing detection and intervention systems at the state/territory and local levels.

Goal 9: All families will have access to other families who have children who are deaf or hard of hearing and who are appropriately trained to provide culturally and linguistically sensitive support, mentorship, and guidance.

Goal 10: Individuals who are deaf or hard of hearing will be active participants in the development and implementation of early hearing detection and intervention systems at the national, state/territory, and local levels; their participation will be an expected and integral component of the early hearing detection and intervention systems.

Goal 11: All children who are deaf or hard of hearing and their families have access to support, mentorship, and guidance from individuals who are deaf or hard of hearing.

Goal 12: As best practices are increasingly identified and implemented, all children who are deaf or hard of hearing and their families will be ensured of fidelity in the implementation of the intervention they receive.

Expanded benchmarks and guidelines are also outlined within the 2013 supplement.

International best practice in family-centered early intervention for children who deaf or hard of hearing: An international consensus statement (Moeller principles)

A diverse panel of experts convened in Austria in June 2012 to develop consensus on the essential principles that guide family-centred early intervention for children who are deaf or hard of hearing⁸. The consensus panel included parents, deaf professionals, early intervention program leaders, early intervention specialists and researchers from 10 nations. All participants had expertise in working with families of children who are deaf or hard of hearing, and focus was placed on identifying family-centred practice principles that are specific to partnering with these families.

This international best practice consensus statement includes the following 10 principles:

1. Early, timely and equitable access to services
2. Family/provider partnerships
3. Informed choice and decision-making
4. Family social and emotional support
5. Family infant interaction
6. Use of assistive technologies and supporting means of communication
7. Qualified providers
8. Collaborative teamwork
9. Progress monitoring
10. Program monitoring

An expanded form of the consensus statement, which defines each key principle, is attached – see *Attachment 1*.

⁸ Mary Pat Moeller, Center for Childhood Deafness; Gwen Carr, U.K. Newborn Hearing Screening Programme; LeeAnne Seaver, 3Hands and Voices; Arlene Stredler-Brown, University of Colorado; Daniel Holzinger, Konventhospital Barmherzige Brueder Linz; Karl Franzens, Universitaet Graz

2.4 Early intervention communication choices and options

Families of children who are deaf or hearing-impaired have a range of choices in regard to the development of their child's communication.

Early intervention programs to develop communication and support cognitive development include listening and spoken language (ie auditory verbal and aural/oral therapy), total communication, cued speech, speech reading, lip reading and other visually assisted techniques, sign (Auslan), bilingualism and various combinations of mixed modalities.

As previously outlined, about 95% of infants born with deafness or permanent hearing loss are born to parents with normal hearing.⁹ More than 85% of these families choose spoken language as the primary mode of communication for their children with hearing loss.¹⁰

2.5 Listening and spoken language early intervention in Australia

Listening and spoken language therapy is multi-disciplinary, evidence-based and family focused

In Australia, listening and spoken language early intervention programs are typically provided through multi/trans-disciplinary teams comprising a range of specialist health and educational professionals including certified auditory-verbal therapists, teachers of the deaf, speech pathologists, paediatric audiologists, psychologists, child and family counsellors, social workers, occupational therapists, specialist kindergarten professionals, and youth workers.

A number of programs are also provided in conjunction with cochlear implant programs, in which case the team also includes cochlear implant surgeons, paediatricians and other medical and health personnel.

These programs are evidenced-based, family friendly and reflect early childhood early intervention best practice. First Voice member centres also track and report on consolidated speech and language outcomes annually.

Listening and spoken language programs have the singular purpose of assisting children with permanent hearing loss to learn to listen and speak. The approach is predominantly through parent education and training. It also assists a child achieve cognitive development, effective spoken communication, improved social participation, optimal schooling outcomes and post-schooling educational and employment options comparable to children with typical hearing.

Listening and spoken language programs differ in material respects from many early childhood early intervention programs that are designed to mitigate children's intellectual, behavioural, mental health or physical functional losses that are already manifest or imminent from the child's condition.

With early identification and the use of advanced hearing technology, the vast majority of children - even those with the most severe or profound hearing losses - can have access to all of the sounds of speech via audition and thus follow an intervention approach focused on achieving typical developmental milestones in listening, speech, language, cognition, and conversational competence.

One of the significant differences between listening and spoken language early intervention and early intervention programs for many other conditions and disabilities is the ability to predict high rates of successful habilitation outcomes based on normative assessments and published data. However, it is stressed that these

⁹ Mitchell & Karchmer, 2004

¹⁰ Alberb, Wilson & Roush, 2006; Dillon, Cowan & Ching, 2013

outcomes are predicated on the existence of optimal clinical protocols and pathways from newborn hearing screening to commencement of family-centred, multi-disciplinary listening and spoken language early childhood intervention.

2.6 Benefits of listening and spoken language early intervention

> Children with hearing loss develop speech and language on par with normally-hearing children

Children who are deaf or hearing-impaired that attend First Voice members' listening and spoken language early intervention programs develop speech and language outcomes by the age of five years that are on par with children with normal or typical hearing.

A 2015 report on speech and language outcomes of children enrolled in First Voice members' programs¹¹ found that listening and spoken language early intervention for childhood deafness resulted in [near normal speech and language skills by school commencement age](#).

The vast majority (74-87%) of children with permanent hearing loss scored within or above the normal range for typically hearing children in the same age. Measures included total language, auditory comprehension, expressive communication, vocabulary and speech performance. The findings were consistent with previous outcomes data on children enrolled in listening and spoken language programs of First Voice members.

> Children with hearing loss transition into mainstream schools

Almost all children with permanent hearing loss graduate from a listening and spoken language early intervention program at age five years and [transition into a local mainstream primary school](#).

> Graduates achieve strong education and employment outcomes

First Voice recently conducted a survey of young people who graduated from one of its members' early intervention programs between 1993 and 2002 to gather and evaluate data on long-term education, employment and social outcomes.

The survey found that these graduates – who were now aged between 18-28 years - were:

- [more likely to have completed year 12](#) (86%) than both the general population (78%) and those with a moderate or mild disability (73%)¹² and
- [more likely to be in regular paid employment](#) (77%) than the disabled or health-impaired population (53%)¹³.

It can be expected that outcomes will have further improved over the ensuing 10 to 15 years as a result of continuing improvements in assistive technology, early intervention therapy, and earlier identification and diagnosis since the introduction of universal newborn hearing screening in Australia between 2005 and 2007.

¹¹ Sound Outcomes: First Voice Speech and language data, 2015

¹² First Voice, 2017. Report on education, employment and social outcomes of First Voice member centre graduates, (First Voice, 2016c; ABS, 2016b)

¹³ Ibid

> It improves family wellbeing and identifies of other disabilities

A literature review has found that listening and spoken language early intervention also improves the wellbeing of families with children who are deaf¹⁴ and facilitates diagnosis of any additional disabilities.¹⁵

> Oral communication fosters independence and social participation

Early diagnosis, timely access to hearing technologies and participation in listening and spoken language early intervention therapy enables deaf children to develop oral communication, attend mainstream schools, secure and maintain employment and participate in and contribute fully to society. Spoken language provides the foundation for individuals to lead independent lives with optimal economic and social participation.

> It delivers a significant long-term cost-benefit

Deloitte Access Economics was commissioned by First Voice in 2016 to conduct a cost-benefit analysis of the listening and spoken language early intervention services provided by its six member centres.

The benefits attributed to this type of early intervention program included an increase in income due to improved employment and educational attainment of participants, improvements in participants' wellbeing and avoided special school costs.

Deloitte Access Economics found that investment in listening and spoken language early intervention provided value for money and demonstrated a long-term cost-benefit in terms of improving educational, employment and wellbeing outcomes for children with hearing loss.

The study found that the early intervention programs provided by First Voice member centres deliver a 2.2 to 1 benefit to cost ratio; meaning that for every \$1 invested there is a return of \$2.20¹⁶.

¹⁴ Liliegren et al, 2012

¹⁵ Wiley et al, 2011

¹⁶ The First Voice cost benefit analysis report by Deloitte Access Economics is currently being finalised and will be forwarded to the committee as an addendum document in coming weeks.

3. Responses to terms of reference

Term of reference 1:

The eligibility criteria for determining access to, and service needs of, deaf and hearing-impaired people under the NDIS.

All children with a diagnosed permanent hearing loss - including children with a mild loss or a unilateral hearing loss - are at risk of poor communication, education, social and employment outcomes.

Currently under the NDIS, not all children are being accepted where permanent hearing loss has the potential to result in a communication, educational or social impairment. Some children are being denied NDIS access solely due to an arbitrary audiological measure and an apparent NDIA perception that the hearing loss does not warrant inclusion – perhaps this is because it is a “hidden disability” and the possible consequences of exclusion from early intervention funding are not understood.

All children who are deaf or have a permanent hearing loss should be eligible for services within the scheme at the level required to achieve and maintain age-appropriate communication.

Children with a mild hearing loss, or a loss affecting only one ear, are at risk of developing communication, educational and social delays once they enter school. It would be a false economy to not provide early support to these children, only for them to fall behind and require more costly and longer term support in later school years and beyond.

The overall cost of effective early childhood intervention for children with mild bilateral hearing is less than that for children with moderate-profound bilateral hearing loss. Similarly, early intervention costs for children with unilateral hearing loss are markedly less than for children with bilateral loss.

It is critical that all children developing permanent hearing loss prior to age 6 (defined as a diagnosed permanent hearing loss of 21dB or greater, averaged over 3 or more frequencies, in one or both ears; including hearing loss due to Auditory Neuropathy Spectrum Disorder) are eligible for early intervention services under the NDIS. The scale of such supports would then be proportional to their current or expected reduction in functional capacity due to their hearing loss.

In addition to early intervention services, children with hearing loss also require hearing devices to improve their access to sound. As with the current practice of Australian Hearing under their Community Service Obligations, all children with diagnosed permanent hearing loss of 21dB or greater should be eligible for hearing devices.

Recommendation 1:

Accept all children with hearing loss into the NDIS who are at significant risk of poor communication, education, social and employment outcomes.

Recommendation 2:

Allow all children developing permanent hearing loss to be eligible for hearing devices under the NDIS.

Term of reference 2:

Delays in receiving services, with particular emphasis on early intervention services.

Hearing loss in a newborn is a neurological emergency

Hearing loss in newborn babies is a neurological emergency and any delay in access to evidence-based, multi/trans-disciplinary early intervention programs risks compromising the speech and language outcomes in these children.

Over 90% of families who have a child born with hearing loss have no previous experience with childhood deafness. As a result they are completely uninformed about choices, options and pathways at a time when they are also often in shock, grieving and pre-occupied with the needs of their newborn child.

The evidence clearly shows that optimal outcomes require urgent, informed decisions followed by immediate action. Without appropriate guidance, parents will not have the knowledge to make the informed choices that would make possible the outcomes they wish for their child. A guided referral pathway is required so that parents are provided with the information and options they need for their child to achieve the outcomes they want.

Infants and children diagnosed with hearing loss need immediate access to services

Specialised services must commence when a child is very young and cannot be delayed until funding is available. A baby's brain is able to detect sounds from half way through pregnancy. However, if the specialised brain area (the auditory cortex) is not stimulated by complex and interesting auditory signals then it will progressively deactivate (the concept of 'use it or lose it'). This commences during the first six months after birth and the negative effects progressively worsen the longer the baby is left without the ability to listen.

For children who are born with or acquire a permanent hearing loss in the first years of life, early diagnosis and intervention is critical to optimal development. Speech, language and cognitive development are substantially impaired without early auditory stimulus from the child's environment to the brain. Delays in access to services result in additional disability.

Unless remediated early, childhood hearing loss impacts directly on literacy, learning, social and emotional development, educational attainment and future employment. At both an individual and community level, the ongoing social and economic costs of childhood hearing loss can be profound.

International best practice and timings to remediate hearing loss in infants for optimal outcomes

In terms of the timing and sequence of these interventions, Australia has endorsed and adopted the Joint Committee on Infant Hearing's international best practice guidelines for children with hearing loss.¹⁷ Known as the *1-3-6 guidelines*, these guidelines recognise the critical window of opportunity in which to diagnose and remediate

¹⁷ Joint Committee on Infant Hearing, "Year 2007 Position Statement: Principles and Guidelines of Early Hearing Detection and Intervention Programs" *Paediatrics*. 120 (4): 898-921; and Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing, *Pediatrics*, April 2013, VOLUME 131 / ISSUE 4, From the American Academy of Pediatrics, Statement of Endorsement

hearing loss in infants for optimal outcomes. The timings of these interventions are outlined below.

By when	Action needed
1 month	All infants should have access to hearing screening using a physiologic measure at no later than 1 month of age.
3 months	All infants who do not pass the initial hearing screening and the subsequent re-screening should have appropriate audiological and medical evaluations to confirm the presence of hearing loss at no later than 3 months of age.
6 months	All infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but at no later than 6 months of age.

Table 2: Internationally accepted best practice guidelines for the timing and urgency of interventions for infants diagnosed with permanent childhood hearing loss

Any delay to the referral pathway impacts directly on life outcomes

A child with hearing loss is at significant risk of developing a permanent language, speech, social and/or academic impairment, often with a significant communication disability, if there are delays or disruptions along this pathway. *Each of these steps* must be rapidly completed, *without loss to follow up between them*, to ensure each child has a reasonable opportunity to achieve successful outcomes.

If this pathway is complete within six months (from the emergence of the hearing loss through to enrolment in a specialist early intervention service), that child has a good chance of developing age-appropriate language/communication and social skills, despite their hearing loss.

However any delay beyond six months negatively impacts on the child's development; and the latest evidence from the largest study performed on the language outcomes of children with hearing loss (the Longitudinal Outcomes of Children with Hearing Impairment study, conducted in Australia) indicates that the delay will cause a long-term reduction in language/communication ability.

Delays and administrative steps associated with the NDIS are affecting the rapid progression of an infant from diagnosis to therapy

Children with permanent hearing loss should be immediately accepted as being NDIS eligible on confirmation of a diagnosis and be able to access funding at the level required to achieve age-appropriate communication.

Delays and administrative processes associated with the NDIS are adding *new administrative steps* to the timeline between screening and early intervention. As these steps have not been required previously, this complex pathway *dramatically increases the time before specialised early intervention is provided and increases the risk of children not reaching early intervention*.

For children to achieve the best possible outcomes, they need fast and effective diagnosis of hearing loss, access to hearing technologies and commencement of early intervention.

Recommendation 3:

Accept all children on diagnosis; and simplify and fast-track the referral pathway.

Term of reference 3:

The adequacy of funding for hearing services under the NDIS.

Current NDIS funding arrangements are inadequate for infants and children receiving an intensive, multi/trans-disciplinary listening and spoken language early childhood intervention service

The early childhood intervention funding arrangements currently in place within the NDIS do not work for children enrolled in intensive multi/trans-disciplinary early intervention programs, leaving a significant gap between levels of funding provided to parents and actual costs of service delivery. This is placing the sustainability of these early intervention providers at risk.

More than 95% of infants who are deaf or hearing-impaired are born to parents with normal hearing¹⁸. About 85% these parents choose for their child to participate in an intensive listening and spoken language program, seek out programs such as auditory-verbal therapy, and aim for a mainstream classroom education.

These intensive early multi/trans-disciplinary services include complementary programs that promote social skills development; educate supporting childcare, kindergartens and school staff; ensure ongoing hearing technology upgrades and maintenance and provide parent support, education and training - all of which are tailored to ensure that children with hearing loss or who are deaf are able to achieve and maintain age-appropriate speech and language.

These intensive services cost in excess of the standard funding allocation for early childhood intervention services and it would be unsatisfactory if the exemplary outcomes currently being achieved for this cohort of children were diminished and the longer term associated costs increased as a result of a perceived short term savings of funds.

Funding and pricing arrangements must be consistent with children attaining their goals in regard to communication, education and life-long economic and social independence. If appropriate funding is provided, these children can achieve language and communication outcomes at the same level as children with typical hearing. This delivers a significant and life changing outcome for children and families, and a long-term economic benefit to the Australian government.

A scalable funding model is needed to accommodate children's different communication needs

The funding provided by the NDIS for a child should be sufficient to pay for the services that a child needs to achieve and maintain age-appropriate communication outcomes and social development. The cost of services varies according to the needs of the child and their families' chosen approach to developing communication, however in general:

- Children who are pre-lingual and those with communication skills below their peers require intensive services to enable them to develop and improve their communication up to their age-appropriate level. These services typically involve integrated assessments, audiological management, therapy services, social skills intervention and family support, which costs from \$18,000 to \$24,000 per annum depending on the specific needs and circumstances of the child.

¹⁸ Mitchell, R.E. & Karchmer, M.A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf or hard of hearing students in the United States. *Sign Language Studies*, 4, 2, 138-163

- Children with risk factors that mean that they are likely to have communication skills below their peers require intensive services to enable them to improve up to their age-appropriate level. These services involve integrated assessments, audiological management, therapy services, social skills intervention and family support which will cost from \$18,000 to \$24,000 per annum depending on the specific needs and circumstances of the child. Known risk factors include late diagnosis, delayed commencement of early intervention, children from culturally and linguistically diverse (CALD) families and children with additional disabilities.
- Children with communication developing along an age-appropriate trajectory but with risk factors that will put their ongoing development at risk require ongoing therapy and supports to ensure they maintain their rate of communication development in line with their peers. These services involve integrated assessments, audiological management, therapy services, social skills intervention and family support which will cost from \$12,000 to \$18,000 per annum depending on the specific needs and circumstances of the child. Most children with hearing loss will fit in this category.
- Children with communication developing along an age-appropriate trajectory and without risk factors that put their ongoing development at risk require sustaining therapy to ensure they maintain their rate of communication development in line with their peers. These services involve integrated assessments, audiological management, therapy services, social skills intervention and family support which will cost from \$6,000 to \$12,000 per annum depending on the specific needs and circumstances of the child.

Current NDIS planning and funding arrangements are manifestly inadequate and are resulting in a typical gap of \$6K-8K per child per year between the service delivery cost of listening and spoken language early intervention programs and the level of funding provided to NDIS participants with children who are deaf or hearing-impaired.

During the three years of NDIS trials, and since, service providers have continued to provide the full level of services necessary to achieve optimal outcomes for each child. This has been possible because, with the exception of South Australia, only a small proportion of each provider's caseload has been located in one of the NDIS trial sites. In the South Australian NDIS Children's Trial, the main provider of listening and spoken language early childhood intervention, the Cora Barclay Centre, has suffered a shortfall in NDIS revenue in the region of \$600-\$800,000, attributable directly to under-funding of participants and to funding delays. The Trial Site experience of the Cora Barclay Centre, which is a member of First Voice, is described in its own submission to this inquiry.

Current NDIS planning and funding arrangements cannot be allowed to continue under the full scheme. This would mean that a service provider with, say, 300 clients would be faced with an annual shortfall in funding of \$1.8M to \$2.4M. If NDIS funding to families of children who are deaf or hearing-impaired remains inadequate, early intervention services will have to be reduced and children's communication, education, social participation and whole of life outcomes will be compromised.

This would seem to be significantly at odds with NDIS principles, aims and objectives, including its underlying insurance principle and its commitments to early intervention, evidence-based practice and value for money.

Recommendation 4:

Fund scalable early childhood intervention programs at the level required for children to achieve and maintain age-appropriate communication.

Ongoing follow-up is needed for children during their school years

As with all other children with disabilities, children who are deaf or have a permanent hearing loss are at significant risk of poor social, emotional and psychological health and wellbeing, particularly during their school years.

There is increasing evidence that children learning to listen and speak are at risk of losing skills and falling behind their hearing peers as they age if they do not continue to receive appropriate levels of services and support. This can vary significantly from one child to the next.

For many children who are deaf or have a permanent hearing loss, it is necessary to continue to provide services and supports in order to sustain and build on early childhood gains in developing communication and to effectively address emerging risks to their social and psychological wellbeing. Such investment will maximise the number of children successfully completing their schooling and progressing to further education and employment.

Recommendation 5:

Provide funding beyond the age of six where needed to sustain early childhood gains and manage risks to communication and social and psychological wellbeing.

Term of reference 4:

The accessibility of hearing services, including in rural and remote areas.

Special arrangements are needed within the NDIS for children with hearing loss in rural and remote areas of Australia

As part of the provision of specialist hearing services to children with hearing loss within the NDIS, special arrangements are required in regional, rural and remote areas where it is difficult for families to access professional staff and services with the requisite knowledge, experience and expertise.

Such arrangements might include:

- video-conferencing
- funding for itinerant professional services
- funding for families and children to access services in metropolitan areas and
- development of professional linkages between generalist rural practitioners (eg speech pathologists) and more highly specialised colleagues in capital cities and regional cities for training, development and consultant support.

These arrangements will impact on the cost to deliver services to children in some regional, rural and remote areas of Australia, and these costs should be factored into NDIS funding arrangements.

Recommendation 6:

Provide special service and funding arrangements within the NDIS for children with hearing loss in rural and remote areas of Australia.

Term of reference 5: The principle of choice of hearing service provider.

NDIS planners need education and training to understand the range and complexity of services available

Choice in this sector means being able to select an expert service provider that can provide an interconnected range of services that are tailored to a child's long-term technology and therapy needs.

However choice and control are difficult to exercise soon after birth when many families are grappling with an unexpected diagnosis of deafness and are still grieving their experience of disability. This is the time when critical decisions are needed, and a family's need for support, information and education is greatest.

First Voice member centres are specialist multi/trans-disciplinary centres where professionals have specialist training in the delivery of listening and spoken language (especially auditory-verbal therapy), audiological, educational and family support services. They are also highly experienced in working with families and young children with hearing loss.

All First Voice member centres work closely with Australian Hearing to support children's hearing aid devices. They also all provide paediatric audiological services and operate integrated cochlear implant programs.

There is a vast difference – in terms of services, support and outcomes - between a large specialist multi/trans-disciplinary centre and a sole provider practice. However parents, particularly in the immediate period following diagnosis, have little/no understanding of the factors that help to shape/inform a choice of provider.

Expert opinion strongly supports the provision of early childhood intervention programs by comprehensive, integrated, multi/trans-disciplinary family centred providers. Such provision is supported by the literature and has been recommended to, and endorsed by, the NDIA. It is also reflected in Moeller's 10 principles set out in *Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement* (refer *Attachment 1*).

We therefore recommend a program of education, training and awareness of the programs available within the sector for NDIS staff and contractors involved in supporting families in their choice of service provider, who play a critical role during the period immediately following confirmation of diagnosis.

Recommendation 7:

Provide initial and ongoing training for NDIS staff and contractors involved in the advocacy and decision-making process that support client referral and program selection and funding. First Voice member centres would be willing to support and assist this process.

Enable parents to make an informed choice based on the publication of outcomes

Without expert oversight and the transparent reporting of client outcomes, the sector is at risk of attracting new entrants that are focused on high profit, low input models of service – centred on provider inputs rather than client outcomes. Children and families are the major losers in this new model of service.

Given the significant communication outcomes that are now possible for children with hearing loss, providers of children’s hearing services should be required to:

- routinely assess and publish communication outcomes of funded children using validated and standardised assessments; and
- over time, achieve agreed targets for age-appropriate communication unless the child has additional factors that the NDIA agrees impacts on their communication.

Language development – whether oral, visual, or both – in children who are deaf or have a hearing loss is critical to achieving lifelong social and economic independence. Therefore it is imperative, in the interests of the child, for families to have access to information to make informed choices based on published outcomes of different intervention approaches.

This framework needs to be developed in a way that does not disincentivise or penalise providers that work with children and families with more challenging needs or with factors known to impact on outcomes, such as maternal education, socio-economic needs or CALD backgrounds.

Recommendation 8:

Fund NDIS participants based on the costs, benefits and reported outcomes of their chosen communication intervention.

Special provision is needed to safeguard the needs of children with hearing loss as the Australian Government Hearing Services Program transitions to the NDIS

In addition to current issues as outlined within the NDIS, children who are deaf or have hearing loss and their families are among those most at risk from plans to transfer the responsibility for delivering their services from the Australian Government Hearing Services Program to the NDIS.

Under the NDIS there will be a choice of service provider for the first time. Personal choice is a concept broadly supported by First Voice, however it is concerning in this instance because the private market is untested in the delivery of audiology services to children with hearing loss.

The introduction of contestability introduces significant risks that must be understood and managed in terms of access, expertise, quality, standards and client outcomes. We recommend the establishment of an expert panel with strong professional and clinical representation to develop guidelines relating to the program transition and implementation.

Recommendation 9:

Establish an expert panel to review and provide recommendations on special provisions for children with hearing loss impacted by the transition of the Australian Government Hearing Services Program into the NDIS.

Term of reference 6:

The liaison with key stakeholders in the design of NDIS hearing services, particularly in the development of reference packages.

In early 2014 the NDIA established an Early Intervention (Hearing) Expert Reference Group (EIHERG) to provide advice on operating policy guidelines for children who are deaf or hearing-impaired.

The reference group has broad membership and First Voice member centres are well represented on it. However the group has only met three times in two years and opportunities to influence the design of NDIS hearing services or the development of reference packages have been limited. The result is that the myriad of policy and funding issues that have emerged since the commencement of the NDIS trials are still unresolved as the full scheme is being rolled out.

Given the intense pressure on the NDIA to meet its enrolment targets, and the pattern of delays in participant reviews, there is a real risk that children with hearing impairment will continue to be denied access to the scheme, suffer delays in funding and receive less funding than the cost of the communication program their families have chosen for them. Such a situation would jeopardise children's outcomes and threaten the financial sustainability of tried and proven service providers.

Over and beyond the expert reference group, First Voice and its member centres have made many representations (written, face-to-face, phone/email) to the NDIA with little effect. While access to regional and national NDIA senior management has been good, and a positive and collaborative working relationship has been established, we have nevertheless been unable to satisfactorily resolve the fundamental issues with the NDIS service and funding framework being applied to childhood hearing services.

Meetings of major service provider groups, peak bodies, parent representative bodies and others have subsequently been held within the sector to prioritise and achieve consensus on the major issues and concerns and to advocate collectively across the sector.

Recommendation 10:

Allow the NDIA's Early Intervention (Hearing) Expert Reference Group – which includes major service providers and consumer advocacy groups - to influence the design of NDIS hearing services, and the development of the scheme's reference packages.

Term of reference 7:

Investment in research and innovation in hearing services.

First Voice and its member centres maintain an active research and innovation agenda. We are committed to undertaking evidence-based research in consultation with our client families and leading research institutions for the continuous improvement of our services, programs and children's outcomes and to inform and influence public health policy in our region.

Our members conduct research independently and in conjunction with leading research institutions and invest in the development of individual and family-focused services and programs that meet the growing needs of young people with hearing loss.

Any funding arrangement under the NDIS that is less than that which meets the actual cost of services delivered threatens the ongoing viability of early intervention providers that are currently investing in research, development and innovation in the delivery of world-class hearing services.

First Voice member centres are not-for-profit organisations that derive their operating revenue largely from government funding and professional fundraising (eg trusts and foundations and donations). Revenue from fundraising is expected to contract – or at the very least become more difficult - due to a public perception that all disability services costs are now being met by the NDIS.

A strong and robust early intervention sector is critical to both the delivery of evidence-based programs and services to young people with hearing loss, and also to the

ongoing investment of centres in research and innovation. We must ensure that Australia retains its place as a world leader and innovator in the development and delivery of childhood hearing services.

Recommendation 11:

Fund early childhood intervention programs at a level that covers the cost of actual services delivered to enable providers to continue to invest in research and innovation.

**Term of reference 8:
Any other related matters.**

Develop a national approach to early childhood hearing screening

While there are good processes for identifying newborn hearing loss, there is currently no national approach for identifying, diagnosing and referring the majority of children that develop their hearing loss after birth but prior to school.

Two thirds of hearing loss identified prior to school commencement age occurs after birth. This may be due to a deteriorating loss, disease, trauma or a failure to detect in the birth screen. There is no consistent approach to identifying these children prior to school entry, leading to major issues during the first years at school.

There is a lack of structured programs to efficiently detect hearing loss in this group or ensure that children receive appropriate support. A Senate committee has recommended extending hearing screening to all children on commencement of their first year of compulsory schooling¹⁹, and this recommendation should be actioned.

Recommendation 12:

Develop a national approach to identify early childhood loss at school commencement age, such as a screening program and/or the establishment of an annual self-referral to an audiologist for a bulk-billed hearing check (equivalent to the vision check currently funded under Medicare).

Develop a program of quality assurance, which includes service provider accreditation and professional credentialing

Ensuring a child who is deaf has the best chance to realise their full potential in the hearing world requires an intensive, multi/trans-disciplinary, holistic, evidenced-based program.

Listening and spoken language specialists across the First Voice member network have a base degree/or training as a speech pathologist, teacher/early childhood educator, teacher of the deaf, audiologist or equivalent and many are either certified or working towards a three year international certification as part of the AG Bell Academy for listening and spoken language. This international peak body has established a certification process that sets professionals apart in their knowledge, experience and application of skills to change outcomes for children with hearing loss.

First Voice recommends that all sole practitioners and service delivery organisations provide regular evidence in support of their child/client outcomes and are also specifically accredited to deliver the specialised support required for children with hearing loss.

¹⁹ Commonwealth of Australia (2010) *Hear Us: Inquiry into Hearing Health in Australia*. Canberra

This preliminary list is by no means exhaustive however aims to provide some insights for the committee into the complexities associated with childhood deafness and paediatric hearing loss. International and Australian best practice protocols clearly state the importance of services being provided by expert and credentialed professionals with routine reporting of outcomes.

Traditionally, listening and spoken language programs for children with hearing loss have received proportionately less funding than other communication methods and it is encouraging to see that the NDIS may now provide funding reflecting the choices for the families who have chosen this future for their child.

Quality assurance mechanisms including service provider accreditation, professional credentialing and outcomes reporting are necessary in the new NDIS service provider environment. We welcome the work already underway within on this front, and support the further development of these standards in consultation with professional bodies.

Recommendation 13:

Develop a program of quality assurance, which includes service provider accreditation and professional credentialing with routine reporting of outcomes.

Strengthen the pathway to early intervention

The systems for ensuring that children with hearing loss access an appropriate therapy service are universally poor. While children enrolled in an integrated multi/trans-disciplinary early intervention service can achieve language outcomes on par with children with typical or normal hearing, only about 50% of children with hearing loss across Australia access an appropriate service.

There is currently no guided referral pathway to equip parents with the information and options they need to access these available services. There are known deficiencies in referral arrangements (from diagnosis to early childhood intervention) in NSW, ACT and SA.

The consequence of this situation is two-fold: (1) there is a delay to the start of early intervention that affects children's outcomes and (2) not all children who would benefit from early childhood intervention find a service at all.

Recommendation 14:

Develop a guided referral pathway to enable parents to easily find and access the early intervention services needed for their infant/child with hearing loss.

Develop consistent and equitable access to cochlear implants and other implantable devices

Decisions about which technology to adopt are based on a range of factors, including the nature and severity of hearing loss. While the provision of hearing aids is well managed by Australian Hearing, funding and access of implantable hearing devices are more ad hoc. Currently, state-based eligibility criteria and differential funding levels are creating inequality of access based on geography rather than need. The NDIS offers the possibility to address this issue of equity of access.

Recommendation 15:

Develop a more consistent and equitable approach to the funding of cochlear implants and other implantable devices for children with an established clinical need.

Provide special arrangements for children with complex needs

Children and families with complex needs (multi-disability, ethnicity, indigeneity etc) require even more specialised services.

The service and funding framework needs to be developed in a way so it does not disincentivise or penalise providers that work with children and families with more challenging needs or with factors known to impact on outcomes, such as maternal education, socio-economic needs or CALD backgrounds.

These arrangements will impact on the cost to deliver services to this sub-set of children, and these costs should be factored into NDIS funding arrangements.

Recommendation 16:

Provide special service and funding arrangements within the NDIS for children with complex needs.

4. Summary of recommendations

Recommendation 1: Accept all children with hearing loss into the NDIS who are at significant risk of poor communication, education, social and employment outcomes.

Recommendation 2: Allow all children developing permanent hearing loss to be eligible for hearing devices under the NDIS.

Recommendation 3: Accept all children on diagnosis; and simplify and fast-track the referral pathway.

Recommendation 4: Fund scalable early childhood intervention programs at the level required for children to achieve and maintain age-appropriate communication.

Recommendation 5: Provide funding beyond the age of six where needed to sustain early childhood gains and manage risks to communication and social and psychological wellbeing.

Recommendation 6: Provide special service and funding arrangements within the NDIS for children with hearing loss in rural and remote areas of Australia.

Recommendation 7: Provide initial and ongoing training for NDIS planners involved in the advocacy and decision-making process that support client referral and program selection and funding.

Recommendation 8: Fund NDIS participants based on the costs, benefits and reported outcomes of their chosen communication intervention.

Recommendation 9: Establish an expert panel to review and provide recommendations on special provisions for children with hearing loss impacted by the transition of the Australian Government Hearing Services Program into the NDIS.

Recommendation 10: Allow the NDIA's Early Intervention (Hearing) Expert Reference Group – which includes major service providers and consumer advocacy groups - to influence the design of NDIS hearing services, and the development of the scheme's reference packages.

Recommendation 11: Fund early childhood intervention programs at a level that covers the cost of actual services delivered to enable providers to continue to invest in research and innovation.

Recommendation 12: Develop a national approach to identify early childhood loss at school commencement age, such as a screening program and/or the establishment of an annual self-referral to an audiologist for a bulk-billed hearing check (equivalent to the vision check currently funded under Medicare).

Recommendation 13: Develop a program of quality assurance, which includes service provider accreditation and professional credentialing with routine reporting of outcomes.

Recommendation 14: Develop a guided referral pathway to enable parents to easily find and access the early intervention services needed for their infant/child with hearing loss.

Recommendation 15: Develop a more consistent and equitable approach to the funding and provision of cochlear implants and other implantable devices for children with an established clinical need.

Recommendation 16: Provide special service and funding arrangements within the NDIS for children with complex needs.

5. Supporting documentation

First Voice is currently finalising two research studies/reports that it wishes to provide to the committee in support of its submission:

1. First Voice and Deloitte Access Economics, 2017. Cost-benefit analysis of First Voice member's early intervention programs
2. First Voice, 2017. Report on education, employment and social outcomes of First Voice member centre graduates

Both reports are expected to be completed shortly and will be forwarded to the committee as an addendum to this submission.

6. Endorsement of First Voice member submissions

First Voice strongly supports and endorses all submissions and representations to the committee by its member centres across Australia. These include:

- The Shepherd Centre, New South Wales and Australian Capital Territory
- Cora Barclay Centre, South Australia
- Hear and Say, Queensland
- Taralye, Victoria
- Telethon Speech & Hearing, Western Australia

These representations outline some of the more detailed clinical and operational impacts on the front-line delivery of early intervention services to young Australians with hearing loss.

7. Conclusion

One of the core principles of the NDIS is to invest in early intervention with the aim of reducing future disability supports. Nowhere is this more relevant than for children with hearing loss who, if diagnosed, referred and supported early with effective strategies including amplification and education, can indeed achieve their full life potential.

Properly managed and resourced, children who are profoundly deaf or have a hearing loss have enormous potential to develop fluent oral communication, attend mainstream schools, participate in further education, achieve employment of their choice and thereby participate in and contribute fully to society.

First Voice is committed to ensuring that the desired outcome of social and economic participation for infants, children and young people with hearing loss is realised. Appropriate policy settings and investment in children who are deaf or have a hearing loss will yield substantial returns in terms of economic productivity and quality of life.

To that end, we must ensure that the key principles of Australia's world leading hearing services system for early childhood hearing loss – which includes early diagnosis, timely referral and amplification, and access to adequately funded service pathways – are fully supported and fully integrated into a “good fit” public policy operating framework within the NDIS, and not diluted or compromised in any way.

Failure to do so would create systemic and life-long disadvantage to generations of children with hearing loss and their families, and set Australia's highly developed and internationally renowned hearing services sector back many years.

Despite working collaboratively with the NDIA over the past three years to address the litany of issues outlined within this submission – the concerns of which are shared by peak bodies, parent advocacy organisations and major service provider groups – these issues remain unresolved.

Attachment 1

MOELLER'S 10 PRINCIPLES

Journal of Deaf Studies and Deaf Education

Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

Mary Pat Moeller*,¹, Gwen Carr², Leeanne Seaver³, Arlene Stredler-Brown⁴, Daniel Holzinger^{5,6}

1 Center for Childhood Deafness; 2 U.K. Newborn Hearing Screening Programme; 3 Hands and Voices; 4 University of Colorado; 5 Konventhospital Barmherzige Brueder Linz; 6 Karl Franzens Universitaet Graz

A diverse panel of experts convened in Austria in June 2012 for the purpose of coming to consensus on essential principles that guide family-centred early intervention with children who are deaf or hard of hearing. The consensus panel included parents, deaf professionals, early intervention program leaders, early intervention specialists, and researchers from 10 nations. All participants had expertise in working with families of children who are deaf or hard of hearing, and focus was placed on identifying family-centred practice principles that are specific to partnering with these families.

Principle 1: Early, Timely, & 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 characterised 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 the necessary knowledge, information, and experiences to make fully informed decisions. This includes educating families regarding special education laws and their rights as defined by these laws. Decision making or change decisions in response to the child's and families' changing abilities, needs, progress, and emotional well-being.

Principle 4: Family Social & 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 children.

Principle 5: Family Infant Interaction

Families and providers work together to create optimal environments for language learning.

Principle 6: Use of Assistive Technologies and Supporting Means of Communication

Providers must be skilled in the tools, assistive devices, and mechanisms necessary to optimally support the child's language and communication development.

Principle 7: Qualified Providers

Providers are 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 optimising the child's development and child–family well-being.

Principle 8: Collaborative Teamwork

An optimal family centred early intervention team focuses on the family and includes professionals with experience in promoting early development of children who are deaf or hard of hearing. Ongoing support is provided to families and children through trans-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 child and family outcomes.

Principle 10: Program Monitoring

Family centred early intervention programs evaluate provider adherence to best practices and include quality assurance monitors for all program elements.

Attachment 2

First Voice 2016 Annual Report – please refer separate PDF