

**Submission to the House of Representatives Standing
Committee on Health, Aged Care and Sport**

Inquiry into Hearing Health and Wellbeing in Australia

From First Voice

Submitted by:

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1. About First Voice

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 deaf children to listen and speak.

First Voice represents six member organisations in Australia and New Zealand that 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.

Our members include 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 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 members maintain an active research agenda and work with research institutions to conduct hearing research relevant to young people with hearing loss.

First Voice centres achieve world-leading outcomes in the development of fluent speech and language in pre-school-aged children with hearing loss and in their subsequent education, social participation and employment. Published early childhood intervention outcomes (0–5 years) show that over 70% achieve speech, language, comprehension and articulation equivalent to children of the same age with normal hearing.

With regard to the outcomes of First Voice centres' early intervention graduates, a recent survey of shows that:

- 95% attended a mainstream high school
- 86% completed Year 12
- 82% had been accepted into university or vocational/technical tertiary study
- 62% had a tertiary level qualification
- 77% had at some point been in regular paid employment for a period of 6 months or more and
- 84% had been involved in community activities or organisations.

These results demonstrate the effectiveness of First Voice centres' early intervention programs in optimising the wellbeing and productivity of hearing impaired children to the benefit of both the children and the Australian community.

First Voice centres have a positive benefit to cost ratio as demonstrated in cost benefit studies in 2011 and 2016.

2. Key message

The social and economic impact of hearing loss in Australia's adult population is significant and well documented^{1, 2}.

The cost of ameliorating many of these impacts - by ensuring that children with permanent hearing loss are diagnosed early, aided with technology and receive timely access to speech and language intervention - is modest and has a proven benefit to cost ratio.

The life outcomes of children with hearing loss who benefit from this process - and subsequently have access to mainstream education, employment of choice and social integration within the hearing world - are enormous (refer page 1 above).

However, Australia's world-leading practices and deaf children's outcomes are at risk.

Funding and policy for early childhood hearing services is currently in the process of being transitioned into the National Disability Insurance Scheme (NDIS). Evidence from the three year NDIS Children's Trial in South Australia shows that the current NDIS service and funding framework is incompatible with Australia's best practice hearing service protocols. Issues of concern include NDIS eligibility, referral delays, scope of funded services, duration of services, qualifications and experience of service providers, planner inconsistencies, the interface between disability and mainstream health and education services, and inadequate funding.

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.

First Voice and others in the children's hearing services sector are striving to work with the National Disability Insurance Agency to address these urgent issues - however this critical situation needs urgency, focus and immediate action to mitigate these significant risks.

¹ Access Economics, 2006. Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia

² Commonwealth of Australia, 2010. Hear Us: Inquiry into Hearing Health In Australia

3. Submission

Background

First Voice is a member-based organisation representing six early intervention organisations that provide listening and spoken language early intervention services to more than 1,000 children living with hearing loss in Australia and New Zealand.

Our region leads the world in its approach to early childhood hearing loss. 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.

Our members work with children and families whose lives have been transformed by access to sound and language. Spoken language provides the foundation for individuals to lead independent lives with optimal levels of economic and social participation.

Australia has one of the best and most highly developed service frameworks for children who are deaf or have a permanent hearing loss anywhere in the world. This is set out in the COAG-endorsed National Framework for Neonatal Hearing Screening (2013) which provides national guidelines for screening; diagnosis; early intervention, treatment and management; quality; professional education; and coordination, monitoring and evaluation.

While there is room for improvement in certain areas, for example early intervention referral arrangements in NSW/ACT, these national clinical pathways provide the basis for the extraordinary outcomes that are achieved by children enrolled in multi-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 maintained and built on in the years ahead.

The integration of early childhood hearing services into the NDIS is currently underway, and these best practices are proving to be a "difficult fit" within the NDIS.

There is widespread concern from parents, professional groups, advocacy bodies and service providers that hearing impaired children and their families may be worse off under the NDIS than before and that Australia's highly developed system and international reputation in childhood hearing loss may be set back many years.

Term of reference 1:

The current causes and costs of hearing loss, and ear or balance disorders to the Australian health care system should existing arrangements stay in place

Incidence and cause of permanent hearing loss

Hearing loss is identified in about one in 1,000 newborns³ and in most cases there are

³ Access Economics (2006) *The Economic Impact and Cost of Hearing Loss In Australia*. Melbourne

no known risk factors. By school entry (age 5 years) the rate of hearing loss increases to 3 to 3.2 per 1,000 children in a birth cohort, representing about one in 300 children. This increase can be attributed to a range of factors including:

- failure to detect at birth
- progressive hearing loss in either or both ears or
- trauma, infections and childhood diseases such as meningitis.

In Australia, there are about:

- 3,300 children aged 0 to 5 years fitted with a hearing aid or cochlear implant
- 18,400 children under the age of 21 years fitted with a hearing aid or cochlear implant; and
- a further 2,450 young adults aged from 21 to less than 26 years of age fitted with a hearing aid or cochlear implant⁴.

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 the necessary auditory stimulus from the child's environment to the brain.

The profound impact of early childhood hearing loss

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.

Communication impact

Speech and language outcomes for children born with permanent childhood hearing loss have historically been compromised⁵. While there have been recent improvements for children with early identified hearing loss, research continues to suggest that many children are at risk of not achieving speech and language outcomes commensurate with their typically hearing peers.⁶ Late diagnosis of hearing loss has been associated with significant delays in speech and language, which subsequently has been associated with delays in literacy development.⁷ In 2007, the *Journal of Deaf Studies and Deaf Education* reported that 30 per cent of school graduates with severe/profound hearing loss were functionally illiterate.⁸

Socio-economic impact

Compromised speech, language and literacy outcomes are known to contribute to long-term psychosocial problems, as well as reduced employment opportunities, particularly for those with congenital severe/profound hearing loss.⁹ Higher rates of self-reported depression are also evident for these children.¹⁰ Parents of children with hearing loss report high levels of stress¹¹ as well as increased marital breakdowns, particularly for those families where children have greater severities of hearing loss.¹² Significant delays in speech, language and literacy have been associated with consequent limits to educational, occupational and socio-economic options.¹³ The

⁴ Australian Hearing, Demographic details of young Australians aged less than 26 years with a hearing impairment, who have been fitted with a hearing aid or Cochlear implant at 31 December 2013)

⁵ Allen, 1986; Holt, 1994

⁶ Ongoing Australian study 'Longitudinal Outcomes of Children with Hearing Impairment', <http://outcomes.nal.gov.au>

⁷ Francis, Koch, Wyatt, & Niparko, 1999; Lin & Niparko, 2006

⁸ Marschark, Archbold, Grimes, & O'Donoghue, 2007

⁹ Kentish & Mance, 2009; Venail, Vieu, Artieres, Mondain, & Uziel, 2010

¹⁰ Theunissen et al., 2011

¹¹ Meadow-Orlans, 1995

¹² Henggeler, Watson, Whelan, & Malone, 1990

¹³ Francis et al., 1999; Lin & Niparko, 2006

diagnosis of severe/profound hearing loss has been associated with lifelong consequences for these children and their families.

Financial impact

Economic reports identify a significant financial burden associated with permanent childhood hearing loss. According to the Access Economics Report (2006), costs associated with hearing loss for the Australian economy were approximately \$11 billion per annum. These costs include the supply of personnel and equipment associated with diagnosis of hearing loss, ongoing supply and maintenance of paediatric audiological devices (hearing aids and/or cochlear implants) and the provision of services from specialised medical personnel, audiologists, and educational facilities/clinicians. Long term lost earnings for individuals with hearing loss was listed as incurring the greatest costs, accounting for more than half (56.7%) of all financial costs. Governments have therefore become progressively motivated to research and access solutions for congenital hearing loss, ideally in early childhood, before these expensive long-term consequences take effect.

Given the dramatic adverse life outcomes that can arise from permanent childhood hearing loss, it is critical that supports for children with hearing loss are provided in a timely, effective and accessible way.

Term of reference 7: Best practice and proposed innovative models of hearing healthcare to improve access, quality and affordability.

Australia is a world leader in managing permanent childhood hearing loss

Australia's highly developed industry and sector framework

Australia has one of the best systems in the world for identifying and managing 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 the Australian Hearing Hub) and a high level of collaboration within the sector.

Best practice early intervention for children with hearing loss

The fundamental elements of best practice early intervention for children who are deaf or have a hearing loss are outlined below:

	Fundamental elements of best practice
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.

1-3-6 Guidelines

In terms of timings of these interventions, Australia has endorsed and adopted international best practice guidelines for children with hearing loss.¹⁴ Known as the *1-3-6 guidelines*, they recognise the critical window of opportunity in which to diagnose and remediate hearing loss in infants for optimal outcomes.

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.

Threats and shortcomings of the current system

Any delay in the referral pathway impacts directly on communication and 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 6 months (from the emergence of the hearing loss through to enrolment in a specialist early intervention service), that child has a very good chance of developing age-appropriate language/communication and social skills, despite their hearing loss.

However any delay beyond 6 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.

The evidence shows that every day, week or month of delay in regard to any of the above-listed measures, jeopardises an individual's potential to achieve an optimal life outcome.

¹⁴ Joint Committee on Infant Hearing, "Year 2007 Position Statement: Principles and Guidelines of Early Hearing Detection and Intervention Programs" *Paediatrics*. 120 (4): 898-921

Pre-school children that develop hearing loss after birth are not diagnosed or referred to a specialist service

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.

The pathway to early intervention is poorly developed

The systems for ensuring that children with hearing loss access an appropriate therapy service are universally poor. While children enrolled in an integrated multidisciplinary early intervention service can achieve language outcomes on par with children without any hearing loss, only about 50% of children with hearing loss across Australia access an appropriate service. There is no guided referral pathway to equip parents with the information and options they need for their child to achieve the outcomes they want.

Listening and spoken language early intervention in Australia

Overview of listening and spoken language therapy and programs

In Australia, listening and spoken language early intervention programs are typically provided through multi-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.

In some cases programs are provided in conjunction with a cochlear implant program, in which case the team will also include 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.

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.

More than 95% of deaf children are born to hearing parents

About 95% of infants born with deafness or permanent hearing loss are born to parents with typical hearing.¹⁵ The vast majority of these parents choose spoken language as the primary mode of communication for their children with hearing loss. In fact, it is reported that this choice is occurring in more than 85% of cases.¹⁶ These parents are typically selecting approaches that support listening and spoken language, such as auditory-verbal therapy, without initiating visual communication systems.

¹⁵ Mitchell & Karchmer, 2004

¹⁶ Alberb, Wilson & Roush, 2006; Dillon, Cowan & Ching, 2013

Speech and language is available to the majority of deaf children

With early identification and the use of advanced hearing technology, the vast majority children - with even the most severe or profound hearing losses - can have access to all 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.

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.

Benefits of listening and spoken language early intervention

Speech and language skills in pre-school years are on par with hearing children

A 2015 report on speech and language outcomes of children enrolled in First Voice members' programs¹⁷ found that listening and spoken language early intervention for childhood deafness resulted in near normal speech and language skills by school commencement age. The report, known as Sound Outcomes, found the vast majority (74-87%) of hearing impaired children 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 in First Voice member centres.

Recipients achieve strong education and employment outcomes

A recent survey of graduates of First Voice listening and spoken language early intervention programs between 1993 and 2002 found that respondents (now aged 18-28 years) had achieved remarkable education and employment outcomes. It found:

- **Education:** First Voice graduates were more likely to have completed year 12 (86%) than both the general population (78%) and those with a moderate or mild disability (73%) (First Voice, 2016c; ABS, 2016b).
- **Employment:** First Voice graduates were more likely to be in regular paid employment (77%) than the disabled or health-impaired population (53%) (First Voice, 2016c; ABS, 2016c).

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.

Early intervention improves family wellbeing and the identification of other disabilities

A literature review has also found that listening and spoken language early intervention improves the wellbeing of families with children who are deaf¹⁸ and facilitates diagnosis of any additional disabilities.¹⁹

¹⁷ Sound Outcomes: First Voice Speech and language data, 2015

¹⁸ Lilliegren et al, 2012

¹⁹ Wiley et al, 2011

Investment in early intervention delivers a significant 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 First Voice members. The benefits attributed to the First Voice early intervention program include the increase in income due to improved employment and educational attainment of participants, improvements in participants' wellbeing and avoided special school costs.

Compared to the costs, the benefits of the First Voice early intervention programs are realised over a variety of timeframes. Some benefits are realised later in the child's life, such as the increased income due to improved employment and educational attainment, while other benefits are realised throughout the child's life such as the improvements in wellbeing.

Deloitte Access Economics found that an investment in listening and spoken language early intervention provides value for money in terms of improving educational outcomes, employment outcomes and wellbeing outcomes for children with hearing loss.

Term of reference 3:

Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology.

Children's outcomes are currently at risk under the NDIS

Funding for childhood hearing services delivered by early intervention providers is in the process of transitioning into the NDIS. While the scheme offers significant advances to people with permanent lifelong disabilities, the scheme's service and funding framework is proving to be a "difficult fit" for childhood hearing services.

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.

In particular, the NDIS Children's Trial in South Australia has shown that inadequate funding and a breakdown in established clinical pathways and quality assurance arrangements are posing a real threat to children's outcomes, families and providers.

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. It is critical that these problems are resolved before the full scheme is rolled out.

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.

With the full scheme now in operation across Australia, a number of key policy matters relating to childhood hearing loss remain unresolved. These relate to eligibility, scope of services, duration of services, funding, interface issues with health and education, referral arrangements, quality assurance, professional credentialing and more.

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 making things worse, rather than better, for children with hearing loss and their families.

Key issues and risks for childhood hearing loss under the NDIS

Despite the scheme now being in a full stage of roll-out and ongoing representations to the National Disability Insurance Authority (NDIA), the following issues and risks remain unaddressed:

(a) Key issues and risks

1. Funding arrangements are inadequate for infants and children receiving an intensive, multi-or 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 who are deaf or have a hearing loss enrolled in a listening and spoken language program, 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. Inadequate funding will result in poorer outcomes and increase longer-term costs. Funding and pricing arrangements must be consistent with children attaining their goals in regard to communication, education and life-long economic and social independence.

2. Funding is not tied to the delivery of outcomes (and long term cost benefit).

More than 95 per cent infants who are deaf or hearing impaired are born to parents with normal hearing²⁰. Therefore most parents choose for their child to participate in a listening and spoken language program, seek out programs such as auditory-verbal therapy, and aim for a mainstream classroom education. These intense, multi-or trans-disciplinary services cost in excess of the standard funding allocation for early childhood intervention services. However, if appropriate funding is provided, these children can achieve language and other 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 cost benefit to the Australian government. Scalable funding models based on managing costs to secure optimal outcomes are currently not accommodated within the scheme.

3. The introduction of additional administrative steps is affecting the rapid progression of an infant from diagnosis to specialised therapy.

A new pathway introduced in February 2016 for early childhood early intervention added *three new administrative steps* between screening and early intervention. As these steps had 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.*

²⁰ Mitchell, R.E. & Karchmer, M.A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4, 2, 138-163

4. Not all children are being accepted where permanent hearing loss has the potential to result in a communication impairment.

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 then having to subsequently receive much greater support to try and help them catch up.

(b) Other concerns

5. We need consistent and equitable access to cochlear implants and other implantable devices for children with an established clinical need.

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 through Australian Hearing has met demand, adequate funding to provide implantable hearing devices has been inconsistent and insufficient. 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.

6. Ongoing support is needed for children in mainstream schooling.

Clarity is also needed on the funding responsibility for services and supports for children who are deaf or have a hearing loss who have completed early intervention programs and entered mainstream schooling. The evidence shows that hearing impaired children aged between 6 and 18 years are at significant risk of:

- loss of communication and language gains made in early childhood intervention
- being unable to continue to develop communication, language and comprehension at the same rate as their normal hearing peers
- low self-esteem and associated social, psychological and emotional problems particularly during adolescence.

Fundamental requirements for children with hearing loss under the NDIS

In order to achieve best practice for children who are deaf or have a hearing loss, the following elements are required within the NDIS.

1. Fund early childhood intervention at the level required to achieve and maintain age-appropriate communication.

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. 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 children 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.

- 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 ongoing 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.

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

To provide value for money and achieve the high level of outcomes now possible for children who are deaf or have a 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 Agency 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 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.

3. Simplify and fast-track the referral pathway.

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

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

4. Accept all children at high risk of communication impairment.

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.

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.

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.

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

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 grow older 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.

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

The development of fluent language in a child who is deaf or has a hearing loss requires high levels of professional expertise across all of the relevant disciplines (eg paediatric audiology, listening and spoken language, deaf education and Auslan).

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 the relevant professional bodies.

In summary, mandated 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 early childhood intervention before 6 months of age if diagnosed at birth; otherwise commencement of intervention within 6 months of diagnosis.

Term of reference 4:

Current access, support and cost of hearing health care for vulnerable populations, including culturally and linguistically diverse people, the elderly, Aboriginal and Torres Strait Islanders and people living in rural and regional 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.

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

Term of reference 5:

Current demand and future need for hearing checks and screening, especially for children (12 years and younger) and older Australians at key life stages.

A national approach is needed to early childhood hearing screening

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.

International evidence shows that many hearing impaired children have poor educational outcomes and experience difficulties with social participation that may impact on the rest of their lives.

A Senate committee has recommended extending hearing screening to all children on commencement of their first year of compulsory schooling.²¹ There is a lack of structured programs to efficiently detect hearing loss in this group or ensure that children receive appropriate support.

²¹ Commonwealth of Australia (2010) *Hear Us: Inquiry into Hearing Health in Australia*. Canberra

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

Term of reference 9:

Whether hearing health and wellbeing should be considered as the next National Health Priority for Australia.

First Voice and its member centres fully support the proposal to make hearing health and wellbeing the next National Health Priority for Australia, and strongly support Deafness Forum of Australia's *Break the Sound Barrier* campaign.

As an advocacy organisation in the area of childhood deafness, we lend our strong support to this campaign and in particular those recommendations that impact directly on children and young people with hearing loss and their families, including:

Hearing checks for all Australian children at key stages of life

Australia has one of the world's best hearing screening programs for newborns, however more needs to be done to stop children falling through the gaps as they develop. Access to hearing checks should be provided at critical stages of a child's development, such as before starting primary school and before entering high school. Regular hearing screening for all school children is absolutely critical to making sure every Australian child has the best start in life, and a chance to realise their full potential. *[Please also refer Term of reference 5, above.]*

A national hearing awareness promotion campaign

One in six Australians – or nearly 4 million people – are affected by hearing loss or chronic ear disorders, with rates particularly high among Aboriginal and Torres Strait Islander people. By 2050 that number will grow to one in every four Australians. Hearing loss is also costing the nation \$11 billion a year in lost productivity, plus costs to our health system and the cost of informal carers. We support the call for a high profile national hearing awareness campaign to encourage people to take better care of their hearing, to promote early detection and early treatment, and to make Australia a more inclusive place for people who are deaf or have hearing loss.

Special provision for children with hearing loss as the Australian Government Hearing 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 we would all support, 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. The Government should ensure an expert panel has proper representation of the people who will be most affected by these changes to advise it on the risks and the ways to minimise them.

**Term of reference 10:
Any other relevant matter.**

First Voice wishes to reference the submission made to the Standing Committee on Health, Aged Care and Sport from one of its largest members, The Shepherd Centre.

First Voice and its member centres fully support the issues and recommendations as outlined within The Shepherd Centre's paper where they are supplementary to our own.

The executive summary of these concerns, and a list of recommendations as proposed by The Shepherd Centre, are included within this submission, please refer Appendix 1.

Conclusion

One of the core principles of the NDIS is to invest in early intervention with the aim of reducing future disability supports. This is never more relevant than for children with hearing loss who, if diagnosed, referred and supported early with effective strategies including amplification and education, can 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 two 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 – they still remain unresolved.

Appendix 1

Extract of submission presented to the Standing Committee on Health, Aged Care and Sport from First Voice member, The Shepherd Centre

Executive summary and recommendations

Early childhood hearing loss has profound impacts on children. The literature demonstrates that children with hearing loss have significantly lower outcomes than other children; in terms of speech, language, literacy and social inclusion. In Australia the current support for these children depends on whether they have their hearing loss evident at birth or whether they develop it between birth and school age (by school age 1 in 300 children have permanent hearing loss). There are good processes for identifying newborn hearing loss and ensuring these children reach Australian Hearing where they receive audiological support and hearing aids. The diagnosis and referral system for the majority of children, that develop their loss between birth and school, is poor. However those children that do present to Australian Hearing receive good audiological support and hearing aids. The systems for ensuring that children access an appropriate therapy service are universally poor. Children accessing services such as The Shepherd Centre (services providing a specialised, integrated multidisciplinary early intervention service) can achieve language outcomes on par with children without any hearing loss. However across Australia, of the 4,000 children with permanent hearing loss below school age, only about 50% currently access an appropriate service.

This situation should improve dramatically with the roll-out of the NDIS. Unfortunately the situation is actually set to worsen, with the lack of NDIS reference packages resulting in children not being funded for the services that have been demonstrated to achieve language outcomes; and the quality, independence, affordability and accessibility of future paediatric audiology services at risk under NDIS contestability.

In addition, there is a lack of a guided referral pathway to equip parents with the information and options they need for their child to achieve the outcomes they want; and there is no national approach for identifying the majority of children that develop their hearing loss after birth but prior to school.

As a result The Shepherd Centre makes the following recommendations:

1. Immediate adoption of the appended 'Protocol for NDIS EI support for children with permanent hearing loss' (or an equivalent) to ensure that children with hearing loss can continue to achieve spoken language at the same level as their peers without loss.
2. Development and implementation of a guided referral system following diagnosis to ensure that children rapidly receive appropriate support from a specialised, integrated multidisciplinary early intervention service.
3. Development and establishment of a national early-childhood hearing screen.
4. Amendment of Medicare schedules to enable annual self-referral of children aged up to 7 to a suitably qualified paediatric audiologist with bulk-billing to Medicare.
5. A national procurement process be established (along the lines of the existing Australian Hearing tender) to source paediatric assistive hearing devices at the lowest practical cost.

6. The NDIS payment process to include significant loadings to ensure appropriate provision of services to children located in difficult to access locations.
7. Audiologists working with children below 5 must have specialist skill and to work within an accredited paediatric facility (with the criteria to be established by the Audiology Australia; including for maintaining status).
8. Audiologists working with children must not receive any part of their remuneration based on the sales value of the assistive hearing devices they provide or prescribe, with this requirement forming part of their specialist accreditation.
9. The accreditation of a paediatric audiology facility to require the use of systems that collect and collate standard information, including audiologic assessment information (detection, discrimination & identification) on children before and after fitting of assistive hearing devices, with mandatory provision of this information to the national guided referral system.
10. Hearing Health and Wellbeing should be established as the next National Health Priority for Australia.