



The Shepherd Centre

Giving deaf children a voice



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Submission to the House Standing Committee on Health, Aged Care and Sport inquiry into the Hearing Health and Wellbeing of Australia

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December 2016

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About The Shepherd Centre – for deaf children

The Shepherd Centre is one of the world's leading services providing audiological, early intervention and family support for children with hearing loss. We are a specialist in working with these children, with a family- and person-centred approach, to enable them to achieve spoken language.

We assist over 450 children each year through both face-to-face and telepractice services. These children range from less than 1 month of age through to school-age and onwards; come from remote and metropolitan areas; all socioeconomic backgrounds; many cultural and linguistic backgrounds; and include many children with further needs and disabilities beyond hearing loss alone.

We focus on assisting these children to develop their listening, spoken language and social skills so that they can achieve their potential in life. **The outcomes achieved by the program are world leading, with the children typically developing spoken language at the same level as their peers without hearing loss.**

The children in our specialised early intervention service receive a multidisciplinary program incorporating specialist Listening and Spoken Language Specialists and therapists; Paediatric Audiologists; Child and Family Counsellors; and ENT Specialists (amongst other professionals). Our centres incorporate audiology booths designed for paediatric patients; individual therapy rooms; group clinical rooms; with videoconferencing facilities for remote service delivery. The program includes an integrated cochlear implant program for those children requiring this level of assistive hearing device. The early intervention children are aged up to 6 years; with hearing loss that may be bilateral or unilateral; and losses of all levels ranging from mild to profound.

Children 'graduate' from our early intervention program with the same profile of spoken language skill as other children of the same age. **More than 90% of all graduates go on to attend mainstream classes at a mainstream school.** The 'typical' (median) graduate has standardised language scores at the same level as the median child in the overall population. The statistics for the overall program – including the many children with additional needs, etc – are outstanding, with the overall median language well within the normal range.

We also provide support for children at school and ongoing support for those children who have received a cochlear implant with us.

Our whole-program early intervention outcomes are published each year. The research we conduct and the outcomes we achieve are presented at multiple national and international conferences. In addition, the Shepherd Centre is:

- a member of First Voice (a globally-leading organisation joining together six like-minded charities from across Australia & New Zealand);
- a founding institution within the Australian Hearing Hub; and
- a member of the Hearing CRC.

The vision of The Shepherd Centre is that:

Every child with hearing loss can achieve their full potential in the world through their listening, spoken language and social skills.

Executive summary

Early childhood hearing loss (also referred to as hearing impairment) 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 is 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 be personally incentivised to maximise 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.

Context

This submission is provided in the context of the significant changes being planned for the provision of services and support to children with permanent hearing loss (permanent hearing impairment) in Australia, namely:

- the funding of the provision of therapy services and support currently moving to the NDIS (with resulting changes to referral pathways, eligibility criteria and support levels); and
- the subsequent transfer of most of the Community Service Obligation placed on Australian Hearing to the NDIS (with the subsequent services being provided by a number of entities on a competitive basis).

These changes offer the potential for improved outcomes for children with permanent hearing loss, but they also put at risk many of the unique features that make the hearing services of Australia the gold standard on the world stage.

This submission focusses on key issues for children with permanent hearing loss and provides recommendations aimed at ensuring that these children are supported to achieve the outcomes necessary so that their hearing loss does not limit their social inclusion and their ability to be productive members of the society. These key issues fall across a number of the Terms of Reference for the inquiry and this has been made clear in the discussion of each issue.

The profound impact of early childhood hearing loss

Children with early hearing loss face numerous challenges on their road to achieving full social inclusion. This document focusses on children who have a permanent hearing loss (which may be due to sensorineural, conductive, or be mixed in nature; or due to Auditory Neuropathy Spectrum Disorder; and which may affect one or both ears) diagnosed in the first 5 years of life.

Children diagnosed with hearing loss in both ears (bilateral hearing loss) have been demonstrated to have the most profound deficits in speech, language, literacy and social inclusion. However children with loss in one ear only (unilateral hearing loss or single-sided deafness) also suffer significant impacts. As listening through one year alone is often sufficient when a child is in a quiet environment, these impacts often only become evident once a child is in a challenging auditory environment such as day care or school. However at that time the same impacts as with bilateral loss then often become evident – poor development of language, speech and/or literacy; and poor social inclusion.

As with children with bilateral loss, an early investment into children with unilateral loss also prevents a significantly larger future cost to the child, their family and to society.

Speech and Language

Speech and language outcomes for children born with permanent childhood hearing loss (PCHL) have historically been compromised (Allen, 1986; Holt, 1994). Late diagnosis of PCHL has been associated with significant delays in speech and language, which has subsequently been associated with delays in literacy development (Francis, Koch, Wyatt, & Niparko, 1999; Lin & Niparko, 2006). For instance, a review in 2008 reported that **67% of deaf children were taught outside of traditional mainstream classes**; and historically the **average oral and written language age of high school deaf graduates from the United States of America was at or below that of the average hearing seven to eight year old child** (Durieux-Smith, Fitzpatrick, & Whittingham, 2008).

In recent years, a positive shift in the speech and language outcomes for children with early identified PCHL has occurred. However, international research data (not that on children graduating from The Shepherd Centre) continues to suggest that the **majority of these children are unable to achieve speech and language outcomes commensurate with their typically hearing peers**. (e.g., Forli et al., 2011; Niparko et

al., 2010; Tait, De Raeve, & Nikolopoulos, 2007). Moreover, the limited research concerning speech development suggests that the acquisition of clear, intelligible speech for this population has been particularly challenging (e.g., Blamey, Barry, & Jacq, 2001).

Literacy

In 1979, Conrad stated that 92% of school leavers with severe-profound hearing loss were unable to achieve reading levels commensurate with their chronological age. For the children with profound PCHL, this figure increased to 99%. An editorial in the *Journal of Deaf Studies and Deaf Education* in 2007 suggested that **30% of school graduates with severe/profound SNHL were functionally illiterate** (Marschark, Archbold, Grimes, & O'Donoghue, 2007). Given the repeated reports of close links between long term literacy outcomes with early speech and language development success (e.g., Overby, Trainin, Smit, Bernthal, & Nelson, 2012; Pennington & Bishop, 2009), these poor literacy outcomes are of significant concern.

Socioeconomic Issues

Socioeconomic problems are well reported for children with severe-profound hearing loss, however the extensive issues documented for people with hearing loss in Australia (Hogan, 2012) indicate the likelihood of effects on children will all levels of loss.

A logical consequence of compromised speech, language and literacy outcomes has been the persistence of substantially unacceptable long term psychosocial problems as well as **reduced employment opportunities** particularly for those with congenital severe-profound PCHL (Kentish & Mance, 2009; Venail, Vieu, Artieres, Mondain, & Uziel, 2010).

Higher rates of self-reported depression are noted for these children (Theunissen et al., 2011). Parents of children with PCHL report high levels of stress (Meadow-Orlans, 1995) **as well as increased marital breakdowns**, particularly for those families where children have greater severities of PCHL (Henggeler, Watson, Whelan, & Malone, 1990). Significant delays in speech, language and literacy has been associated with consequent limits to educational, occupational and socio-economic options (Francis et al., 1999; Lin & Niparko, 2006).

Economic reports also identify significant financial burden. For example, 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); supply of 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 (57%) of all financial costs. An analysis of the cost-benefit of early intervention for children with hearing loss in Australia demonstrated significant benefits (First Voice, 2011). Governments have thus become progressively motivated to research and access solutions for congenital PCHL, ideally in early childhood, before these expensive long term consequences take effect.

More recently, the improvements to newborn hearing screening, diagnosis, therapy, and use of technologies such as cochlear implantation, has resulted in significant improvements in speech and language outcomes for children with all levels of hearing loss (Forli et al., 2011; Geers & Sedey, 2011; Siningr, Grimes, & Christensen, 2010).

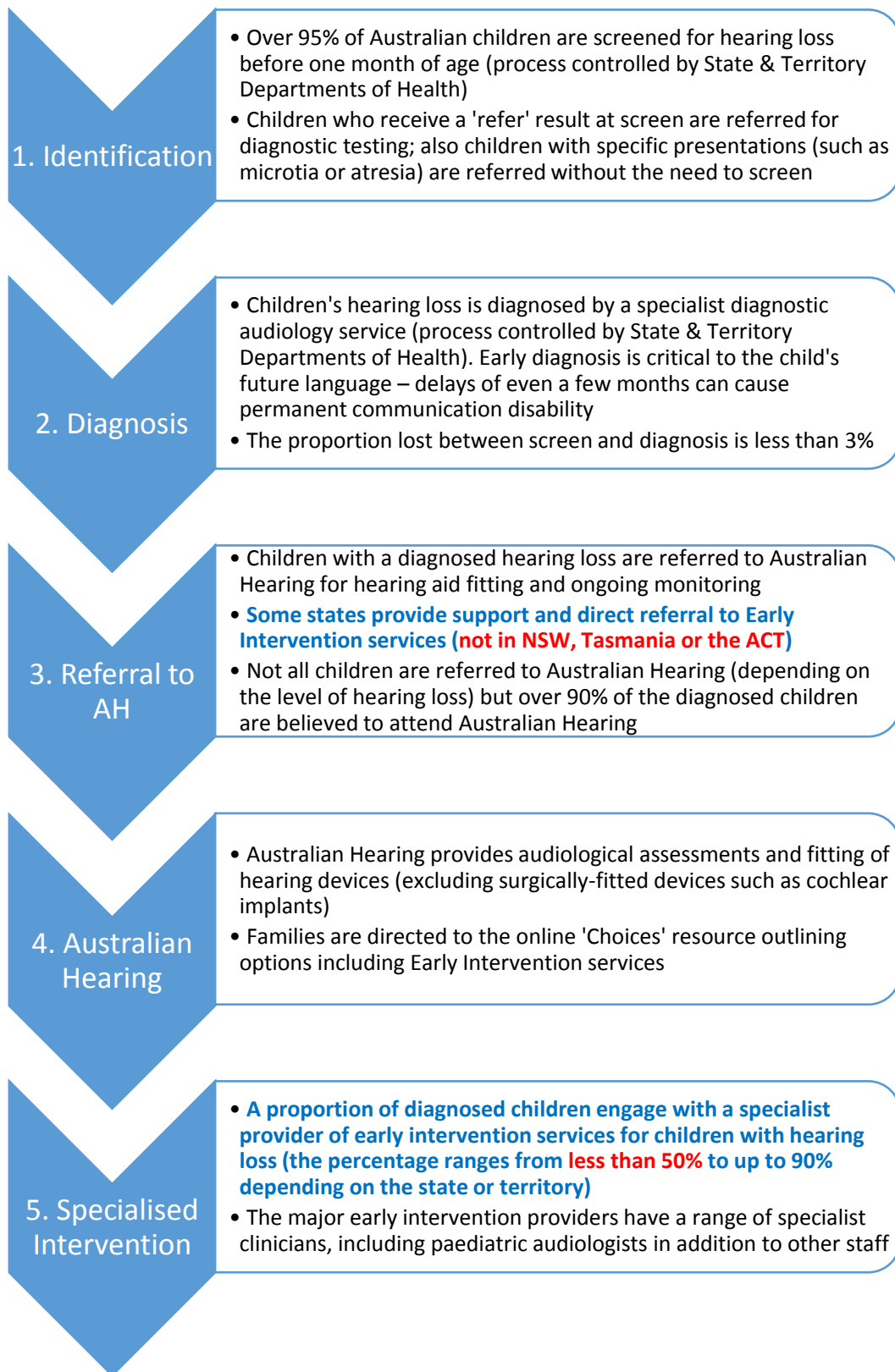
Given the dramatic adverse life outcomes that can arise from PCHL, it is absolutely critical that supports for children with hearing loss are provided in a timely, effective and accessible way.

Critical aspects of support for children with hearing loss

The current clinical pathway for children with PCHL consists of:

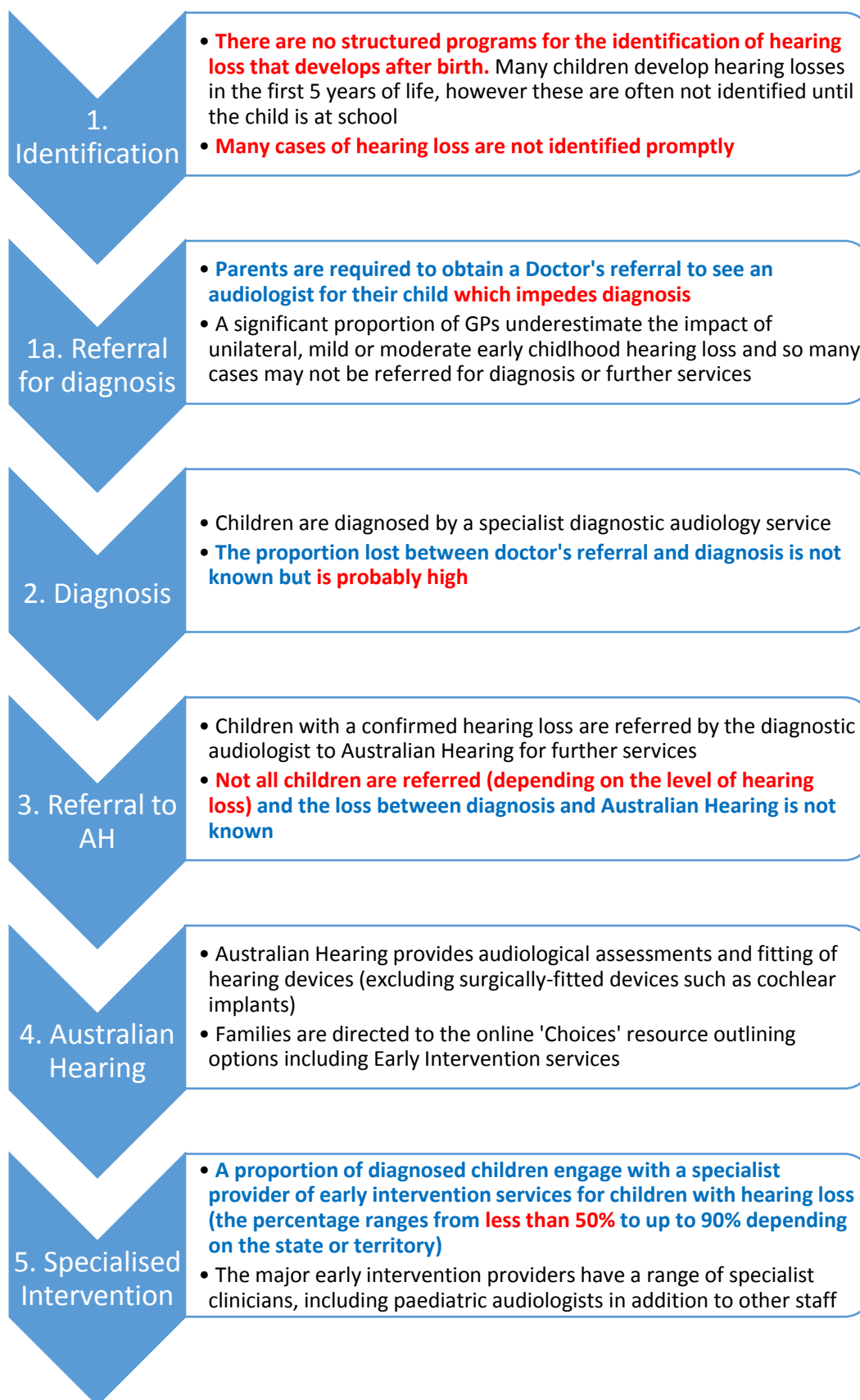
Current pathway for children diagnosed at [Newborn Hearing Screening](#)

Up to **1 in 500** children born will have some degree of permanent hearing loss.



Current pathway for children diagnosed between birth and school

Approximately **1 in 300** children will have some degree of permanent hearing loss by school.



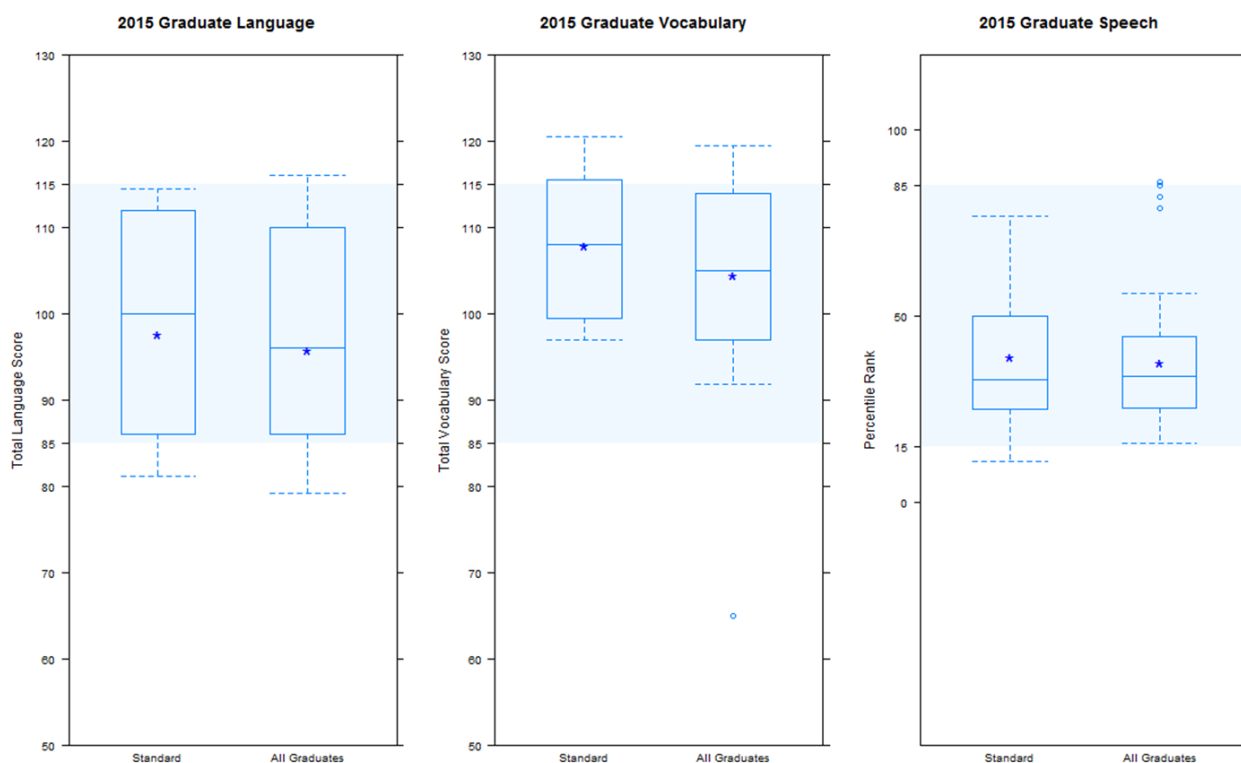
As can be seen from the preceding pathways, the current system for children diagnosed through newborn screening is most developed, with the vast majority of children being diagnosed and referred to Australian

Hearing. However still **only about 50% of these children reach a specialist provider of early intervention services.**

There is no structured system for children that develop their hearing loss after birth. We have little understanding of when their hearing loss develops (we only know that it becomes evident during their first years at school); we do not have a way for rapidly diagnosing hearing loss; and we do not have a pathway for ensuring diagnosed children reach Australian Hearing or reach a specialist provider of early intervention services. As a result **children who develop hearing loss after birth often do not receive the help they need to achieve their potential, and when help is accessed it is often late.**

Outstanding outcomes are possible

As demonstrated by the outcomes of The Shepherd Centre (where over 90% of children go on to a mainstream classes in mainstream school), if this pathway is complete within 6 months (from the emergence of the hearing loss through to enrolment in a specialised, integrated multidisciplinary EI service), that child has a very good chance of developing age-appropriate language and social skills, despite their hearing loss:



The blue shaded area is the range of 'normal' language. The results for the children graduating from The Shepherd Centre program are shown by the box & whiskers plots. There are two groups for each of language, vocabulary and speech clarity: 'standard' children on the left (without additional disabilities or other complicating factors), or all children on the right (all children graduating from the program including those with multiple disabilities). (The Shepherd Centre, 2016)

These outcomes are attributable to a specialised, integrated multidisciplinary service that provides:

- Rapid provision of services, within a few months of diagnosis;
- Optimising access to sound for the child through management of hearing devices, child education and carer education;
- Teaching the child's caregivers the specialised approaches needed for them to enable their child to develop spoken language in the child's natural environments; and
- Supporting the child and the caregivers through the multiple challenges and transitions that these children face due to their disability.

Some of these services are delivered through interaction with a single clinician. However, the poor outcomes from services that only have this component demonstrates it is not sufficient to deliver the required outcomes. Success is critically dependent on other elements including:

- Provision of caregiver training outside of face-to-face sessions (such as through offline materials or online eLearning);
- Tracking of assessments of individual children versus program norms and development of individualised intervention programs;
- Refinement and implementation of specific interventions for each child based on their individual progress and circumstances; and
- Provision of extensive caregiver support and discussion channels to enable them to be effective language therapists in the child's natural environment.

International experience also demonstrates that specialised, integrated multidisciplinary services are able to deliver outcomes that other services do not (Yoshinaga-Itano, 2015). The importance of early provision of services, as quickly as possible after the emergence of the hearing loss, is emphasised by the impact of any delay of cochlear implantation for children with congenital deafness. As demonstrated within the largest prospective study of children with hearing loss, any delay of implantation after six months of age results in progressively poorer language outcomes (Ching, 2015).

The outstanding outcomes achieved by children attending The Shepherd Centre, and the other similar centres across First Voice, should be possible for all children with hearing loss across Australia, not just to a few.

To make this possible a series of key issues need to be addressed, which are presented in the subsequent sections of this submission.

Key issues for children with permanent hearing loss

1. Lack of NDIS reference packages

With the introduction of the NDIS the services available to children with hearing loss, and the subsequent outcomes that they are able to achieve, is completely dependent on the nature and amount of funded service.

The NDIS has not established any protocols for the support of children with hearing loss and as a result children are not being funded for the services that have been demonstrated to achieve these outcomes.

Relevant Terms of Reference:

3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology
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
6. Access, availability and cost of required drugs, treatments and support for chronic ear and balance disorders sufferers
7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability

The NDIA established an Early Childhood Intervention (hearing loss) expert reference group in 2014 to develop the reference packages required to ensure that children with hearing loss receive plans that are appropriate to them. This group has only been called to meet twice over two years and no guidelines or reference packages have been produced. The next meeting of the group is scheduled for late January 2017.

As a result of the lack of reference packages, children across Australia who have been transferred to the NDIS have received widely varying and normally totally inadequate funding packages, covering down to only one-third of the cost of service. All varieties of services are being supported (including sole practitioners that are unable to provide the collaborative teamwork practice needed for good outcomes); significant delays to funding of service are common (averaging about 6 months); and eligibility assessment is inconsistent with some children with permanent hearing loss being denied any support.

These problems are extremely severe and acute. If allowed to continue, they will prevent children from being able to achieve the outcomes that their families and society can currently expect.

A proposal is appended to address these issues, that defines the level of service that would be funded for each child, based on diagnosis and need, with scaled maximum levels of funding.

Across Australia, there are approximately 4,000 children aged 0-6 with permanent childhood hearing loss (this is an estimate based on the fitting figures from Australian Hearing and is supported by the analysis of the NDIA). The Shepherd Centre estimates that of these children:

- 25% would probably not engage with a funded service;
- 30% would be eligible for a 'low' package;
- 25% would be eligible for a 'medium' package; and
- 20% would be eligible for a 'high' package

This would require a total annual funding of approximately \$47 million.

Recommendation 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. Lack of an appropriate guided referral pathway to specialised EI services

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 at a time when they are also often in shock, grieving and already coping with a newborn child.

Due to the need for urgent action to enable the development of a good language (either spoken or signed), appropriate options must be chosen very early for a child with hearing loss.

Without appropriate guidance, parents will not have the knowledge to make the informed choices for their child, that would make possible the outcomes they wish. 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.

Relevant Terms of Reference:

3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology
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
7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability

The national approach to newborn hearing screening means that children born with a hearing loss are typically identified, diagnosed and referred on to Australia Hearing for hearing aid fitting. However, development of appropriate language also requires rapid enrolment into a specialised, integrated multidisciplinary service. This is recognised by a number of Australian states and territories, with the establishment of a dedicated service that guides the referral of these diagnosed children into the specialised early intervention service of the family's choice.

However this service is absent in NSW, the ACT, Tasmania and the Northern Territory. With the introduction of the NDIS, the continuation of this service may be at risk in the other states.

The need for the guided referral pathway is demonstrated by the experience in NSW, where despite two large and very active specialist services (The Shepherd Centre and the Royal Institute for Deaf & Blind Children) less than 50% of the children being supported by Australian Hearing for their hearing loss are in a specialised, integrated multidisciplinary service.

Across Australia, the total number of children in a specialised, integrated multidisciplinary early intervention service, is not known, however it is not believed to be significantly above 2,000. As a result it is expected that the national enrolment is approximately 50% of children.

Based on the existing models of referral services, with the addition of a national coordination service, it is likely that a total of approximately 20 FTE would be required (including any State staff) to provide a national guided referral pathway, at an annual cost of approximately \$3 million.

Recommendation 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. Lack of early childhood hearing screening

Most of the children with hearing loss at school entry have developed that hearing loss after birth (such as due to a progressive deterioration in their hearing, disease or trauma). However these children are not being detected promptly.

For children to be able to develop their potential in language, hearing loss must be identified soon after its onset.

Relevant Terms of Reference:

3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology
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
7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability

Newborn hearing screening has been very well implemented in Australia. However of the 1 in 300 children with hearing loss by school age, only about one-third are born with that loss. The remaining two-thirds develop it between birth and school, due to a deteriorating loss, disease, trauma, etc.

There is no national approach to identifying these children prior to school entry, leading to major issues during the first years at school. Some jurisdictions (such as the ACT) have developed their own early childhood system, however this is not in a manner suitable for national implementation.

A national approach is required to identify early childhood loss, such as a screening program and establishment of an annual self-referral to an audiologist for a bulk-billed hearing check of children aged up to 7 (equivalent to the vision check currently funded under Medicare, however with age restrictions).

Given the national focus on the high uptake of early childhood education, a clear possibility for hearing screening would be at entry into this system. With a total of 300,000 children in Australia aged 4, the potential cost of a screening service could be up to \$8 million per year (assuming use of a screening app along the lines of Sound Scouts www.soundscouts.com.au with administration in a controlled way, with payment of \$20 to the early education provider per completed test, with an additional 25% on-cost allocation for screening program management and quality assurance).

Diagnosis following screening could be via self-referral to a suitably qualified paediatric audiologist with bulk-billing to Medicare. If the Medicare schedules were amended to allow bulk-billing by audiologists without a doctor's referral (with limits of one test per year), and if an additional 25,000 diagnostic assessments were made with a Medicare rebate of \$163, the annual cost would be approximately \$4 million.

Recommendation 3. Development and establishment of a national early-childhood hearing screen.

Recommendation 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.

4. Future contestability of paediatric audiology services

Currently the only service receiving funding for the provision of hearing aids and associated audiology services to children is Australian Hearing. Paediatric audiology is very different than service to adults or teenagers and requires different facilities and equipment as well as specialised skills (a baby can't press a red button depending on whether they hear a beep!). Families of children with hearing loss rely on the expertise and independence of their paediatric audiologist, however there is currently no way to certify the appropriateness of individuals or facilities to provide paediatric audiology. Despite this, the provision of these services is due to become contestable across Australia by July 2019. This offers new areas of choice and service innovation, however also offers substantial risks to current services.

The quality, independence, affordability and accessibility of paediatric audiology services must be maintained.

Relevant Terms of Reference:

3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology
7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability

Paediatric audiology is complex and calls on different techniques and different equipment than is used with adults or older children who are able to reliably take direction. Australian Hearing currently provides a free service to all Australians up to 26 years of age, free hearing aids and maintenance as well as audiology services.

The transition of this to become contestable will affect all of:

1. The referral pathway and the number of children lost to follow-up;
2. The cost of the hearing aids provided; and
3. The accessibility, professionalism and independence of the audiological services.

Referral pathway: as Australian Hearing is currently the sole provider, referrals and follow-up are simplified, enabling the current excellent proportion of children being fitted with aids following diagnosis of hearing loss at birth. This could be put at risk with a contestable service, however this could be addressed by a guided referral pathway, as proposed for ensuring take up of an appropriate early intervention service ([recommendation 2](#)).

Cost of aids: Australian Hearing currently sources the paediatric hearing aids it uses via tender with a sole primary manufacturer and is able to secure excellent prices this way, as this tender is one of the largest globally.

Under the NDIS it has been proposed to simply offer a set price for each level of aid, based on the current prices. However this is not feasible, as under the divided market of contestability no provider will have the purchasing power to acquire aids at the same price as achieved under a bulk tender. As a result this proposal would result in the cost of aids to government increasing significantly.

To maintain the current low price a national procurement service would be required (which could still be managed through the Office of Hearing Services), which would provide agreed devices that could be purchased by participating paediatric audiology services at a price acceptable to government.

Paediatric audiology accessibility, professionalism and independence: Because of Australian Hearing's central role and professional self-regulation, it is able to ensure that it is able to offer a consistent high-quality and independent services across Australia, along with collection of data on that service to enable national planning and evaluation.

There are a number of concerns with a potential contestable market:

1. The experience of the contestable adult market has shown that providers prefer to service locations where the consumers have the highest disposable income and where they will have lower operating and travel costs. Australian Hearing can cross-subsidise locations to ensure equity of access across Australia, however this would have to be explicitly built in to a contestable market.
2. In the adult market, providers have a strong financial incentive to induce people to pay more to obtain upgraded hearing devices, that may not clinically offer significant advantage. Audiologists receive substantial incentive payments to convince their clients to pay for these optional upgrades. If this financial incentive existed when supplying devices for children, where parents were unable to assess the clinical benefit and where they would always want the best for their child, there would be an unacceptable risk of exploitation.
3. Many audiologists may want to provide services to the paediatric market without having appropriate expertise or facilities. It is impossible for a parent to be able to assess the capabilities of an audiology practice, and by the time any issues were evident the child involved would have suffered irreversible effects.
4. The effectiveness of paediatric audiology can only be assessed in the long term, with the progressive development of language, and the need for this information will become more critical with the fragmentation of the market. These long term statistics are currently made possible through Australian Hearing however competitors will not be willing to provide this to them. An alternate centre for national data collection is required.

Based on the above the following recommendations are made:

Recommendation 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.

Recommendation 6. The NDIS payment process to include significant loadings to ensure appropriate provision of services to children located in difficult to access locations.

Recommendation 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).

Recommendation 8. Audiologists working with children must not be personally incentivised to maximise the sales value of the assistive hearing devices they provide or prescribe, with this requirement forming part of their specialist accreditation.

Recommendation 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.

5. Hearing health and wellbeing as the next National Health Priority for Australia

Hearing loss is a unique condition in that it causes tremendous economic and social losses; is easily diagnosed; and is relatively cheaply ameliorated with current established technology and therapies. Despite this, the burden of poor hearing health is unacceptably high.

The economic and social wellbeing of Australia would be improved if a nationally coordinated action plan was established to address hearing health and wellbeing.

Relevant Terms of Reference:

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

The rate of hearing loss in children is relatively constant, at about 1 in 300 by school age. However, as discussed previously, the provision of services to these children can be dramatically and profitably improved.

However, after childhood the incidence of hearing loss increases with exposure to noise and with age. With the combination of increased recreational exposure to noise and with increasing lifespan, the incidence of hearing loss among the total population is increasing rapidly.

This hearing loss causes both societal effects – increased use of social services, decreased employment and tax payments; and individual effects – including decreased mental and physical health. A particular area of concern is the significant linkage established between profound hearing loss and increased risk of early dementia, presumably due to social isolation and subsequent reduced mental activity (a recognised risk factor for dementia).

The overall cost to Australia is dramatic, as well reported.

Importantly, the system and approaches to both diagnose and manage the effects of hearing loss are well established, even though they are not uniformly made available.

A nationally coordinated action plan, as part of establishing hearing health and wellbeing as a national health priority, will enable the implementation of services and approaches to both minimise the development of hearing loss and ameliorate its effects. This would provide a significant net economic boost to Australia and to the individuals affected.

Recommendation 10. Hearing Health and Wellbeing should be established as the next National Health Priority for Australia.

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Protocol for NDIS EI support for children with permanent hearing loss

Specific access requirement

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 ANSD.

Assessment of level of core program support required

The key aim of the core program (collaborative teamwork practice or transdisciplinary early childhood intervention) is to support the development of age appropriate communication & social skills by the child. The level of support required (Nil, **Low**, **Med**, **High**) is determined by the individual needs of the child.

All children require an initial 6 months of **High** level core program support. After this first six months, the default level of support is determined according to: whether the hearing loss affects both ears or one; age of child; level of hearing loss; level of current communication skill; and any additional risk factors (including delayed entry to early intervention). The appropriate level is determined as per the following tables:

		0-36 months		37-72 months	
		Appropriate communication	Delayed communication	Appropriate communication	Delayed communication
Bilateral HL					
Hearing loss in <u>less-</u> affected ear	Mild 21-40dB	- risk: Low + risk: Med	- risk: High + risk: High	- risk: Low + risk: Med	- risk: High + risk: High
	Moderate 41-70dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High
	Severe* 71-90dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High
	Profound 91+dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High
Unilateral HL		Appropriate communication	Delayed communication	Appropriate communication	Delayed communication
Hearing loss in the affected ear	Mild 21-40dB	- risk: Low + risk: Low	- risk: High + risk: High	- risk: Nil** + risk: Nil**	- risk: High + risk: High
	Moderate 41-70dB	- risk: Med + risk: Med	- risk: High + risk: High	- risk: Low + risk: Low	- risk: High + risk: High
	Severe* 71-90dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: Med	- risk: High + risk: High
	Profound 91+dB	- risk: High + risk: High	- risk: High + risk: High	- risk: Med + risk: High	- risk: High + risk: High

* children with Severe or Profound hearing loss are to be evaluated for cochlear implantation candidacy.

** no further core program support after the initial 6 months.

In the above tables:

Bilateral hearing loss: both ears with permanent hearing loss of 21dB or more (averaged over 3 or more frequencies), as diagnosed by a qualified paediatric audiologist. The level of hearing loss for use in the table is determined by the ear that has the better hearing.

Unilateral hearing loss: one ear does not have a permanent hearing loss.

Delayed communication: the level of communication (spoken or signed) of the children must be assessed according to a validated and standardised assessment tool. Delayed children are those that fall 1 SD or more below the population norm.

+ Risk factors: the presence additional risk factors that significantly increase the support needs of the child. Relevant risk factors are listed below.

Provision of the core support program

The core support program for hearing loss is provided in addition to any therapy provided due to any other disabilities.

All core support programs must include the following:

1. Therapy to support age-appropriate communication development (either spoken or signed) from a provider with specialist skills in supporting children with hearing loss and their families;
2. Intervention to support the development of age-appropriate play and social skills;
3. Audiological management where necessary to ensure assistive devices are being appropriately and effectively utilised;
4. Support and education for the family and for inclusion of the child into the family's community;
5. Assessments (at least annually) of communication (using a standardised tool), of any delay to play or social skills, and of support for the family; administered by a qualified individual.

All services providing core support programs must document the effectiveness of their program; such as through tabulation of the communication assessments of the children in their program, demonstrating that fewer than 35% of the children (excepting those affected by additional disabilities that affect learning) have delayed communication. Services unable to document the effectiveness of their program are eligible to provide specialised individual therapy on a per-hour basis but are not eligible to provide a core support program.

Services are to determine an appropriate individual support plan for each child, based on their needs and the goals established for them by their family. The maximum that can be funded for the core support program is:

1. **Low** - \$12,000 per annum
2. **Med** - \$16,000 per annum
3. **High** - \$21,000 per annum

Provision of additional support beyond the core program

Further support in addition to the core program is required in specific situations:

1. Additional needs – if a child has further disabilities beyond hearing loss they will require additional therapy specific to that disability. The scope of that support is not part of this protocol.
2. If the child is learning sign language but the parents use spoken language – an additional \$6,000 per year for up to 3 years for sign language training of parents, caregivers and extended family.
3. If the child will be undergoing critical transitions between care environments (such as home to day care, or day care to school) – an additional \$6,000 for intensive support to the child, family and new care givers in preparation for and during each transition.
4. If the child is in the care of extended family members for 6 or more hours a week – an additional \$2,000 per year for up to 3 years for training of the extended family.

Risk factors

- Presence of additional needs
- Delayed fitting of devices
- Complex family needs
- Bilingual/multilingual environments
- Late diagnosis
- Delayed entry to Early Intervention
- Poor device compliance/reduced access to sound
- Recurrent middle ear pathology