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Submission to the Standing Committee on Health, Ageing and Community Services inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT

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About The Shepherd Centre

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 500 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.

Currently we support 45 children from the ACT, with approximately two-thirds of these children of early intervention age.

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.**

We have been supporting children in the ACT for many years and were historically part-funded out of the Education Directorate. We transitioned to the NDIS with the launch of the NDIS trial site in the ACT.

Summary

This submission focusses on the second term of reference for this inquiry, in particular the availability of early intervention services.

The Shepherd Centre strongly supports the supports the intent of the NDIS and we believe that the sector in which The Shepherd Centre operates, of early intervention for young children with permanent hearing loss, should be an outstanding example of how early intervention under the NDIS can transform the lives of children and provide a positive benefit to society.

However, the current approach of the NDIA to this area will lead to the cessation of effective early intervention for these children in the ACT. These children will then be permanently disadvantaged.

The key problems are:

- Poor pathway to eligibility and inappropriate NDIS plans – Australian Hearing should be funded to perform a guided referral and planning function out of existing NDIS money
- Uncertainty on the provision of audiology and hearing devices from 1 Jul 2019 – Australian Hearing should be retained as the exclusive provider of paediatric hearing services
- Inadequate and inconsistent funding of early intervention services – national reference packages should be established that: are funded from immediately after diagnosis; are appropriately reflective of the needs of each child; and are funded at a level that enables achievement of good spoken language (which is currently achieved but will not occur in future if the current NDIS plans are continued)

The Shepherd Centre would welcome the opportunity to appear before the Committee.

Submission

It has been well documented (see Appendix) that if children with childhood hearing loss are not provided with the appropriate early intervention, they will be held back significantly in their independence, social & economic participation. Conversely, if they are provided with the correct specialist early intervention support they will be able to achieve the same quality of language (either spoken or signed) as any other person (subject to any other disabilities they may have), enabling them to finish school, participate in tertiary education, and participate in the workforce at the same rate as the general population.

The provision of these specialist supports is more expensive than generalist services (such as speech pathology sessions, etc), however the economic value provided by these services is much more than their cost to government (with Deloitte calculating that there is approximately \$4 of return for each dollar invested by the government www.firstvoice.org.au/wp-content/uploads/2016/09/First-Voice-Deloitte-Access-Economics-Cost-Benefit-Analysis.pdf).

These benefits from these specialist services speak directly to the Objects of the NDIS:

- Allowing for independence, economic and social participation of these children through the development of language at the same level of the rest of society;
- These services being reasonable (they are cost effective given the benefit provided) and necessary (without these specialist services this level of language will not be achieved);
- Families exercise choice in the services and goals they select for their child (through the mode of communication and the service provider); and
- The quality and innovation of these services have been demonstrated to be world-leading in their ability to enable children with hearing loss to live an independent life with full inclusion in the community.

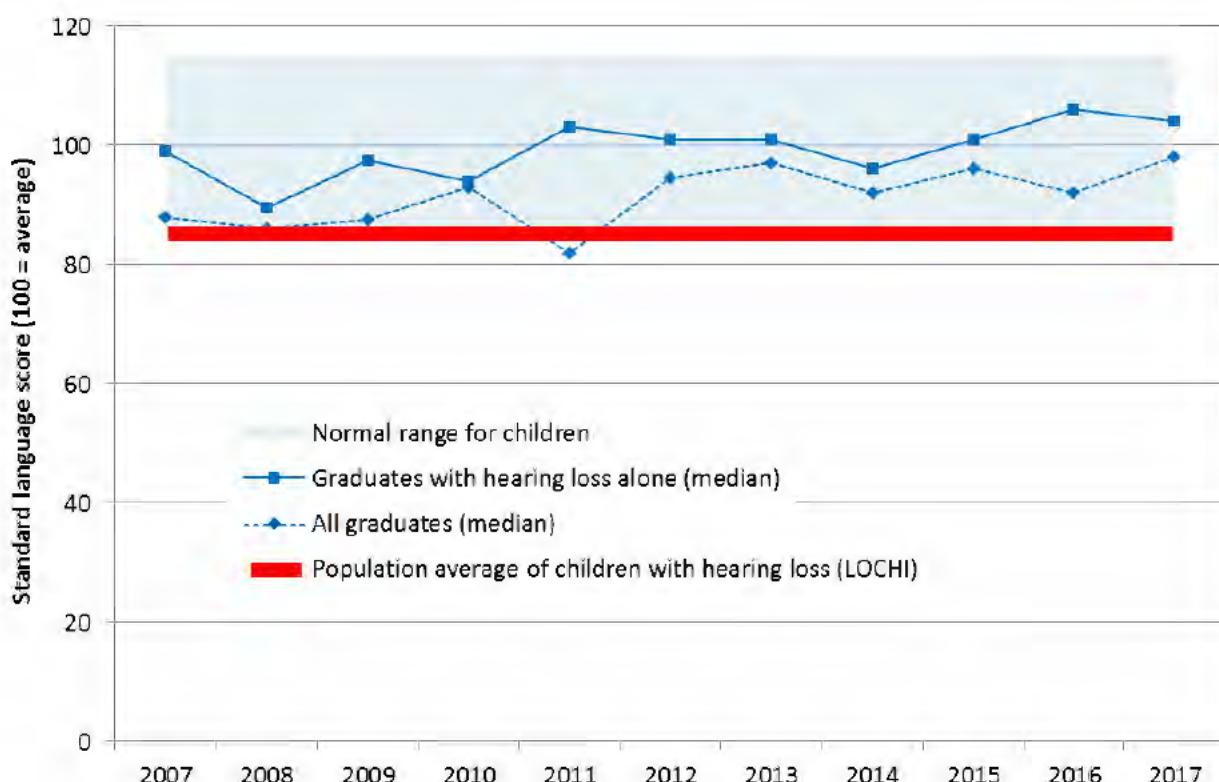
However the NDIA is treating childhood hearing loss as if it were a permanent disability (where it funds inputs in proportion to the need); rather than a disability that benefits from early intervention (where the funding should be in proportion to the improvement provided).

The approach that the NDIA has implemented results in:

- incentivising the provision of ineffective service (through paying the same amount for a cheap ineffective service as it does for an effective but more expensive service);
- no incentives for quality (as measured by achievement of goals; through not differentiating between providers who provide no positive outcomes to the children and providers who do enable children's outcomes);
- dis-incentivising the specialist team services required for outcomes (through their preferred 'per occasion of direct service' invoicing model);
- reduced innovation (though imposing an input-based pricing model rather than an outcomes-based one); and
- reduced opportunity for families to act as informed consumers (by not providing guidance and falsely implying that increasing hours of direct services equates to better quality service).

An appropriate early intervention investment into children with hearing loss enables them to achieve spoken language at the same level as any other child. For instance, the following graph depicts the language of children who have completed the EI program at The Shepherd Centre. Of our 'graduates' (children completing the EI program and going into school) typically achieve slightly better language than other children of their age (with a median language score of 104) if they have hearing loss alone (these children are about 1/3rd of the total). Even across all of our children (including those with additional disabilities, who mainly hear languages other than English, or who received delayed intervention), the median was 98, very close to the normal average of 100.

These are substantially better than the typical language for children with hearing loss in Australia, as assessed in the LOCHI study.



An appropriate investment into early intervention for children with hearing loss allows for the above outcomes to be achieved. The NDIA must move to an approach that incentivises services that achieve the goals that parents have for their children, in a way that is cost-effective for the government.

With regards to this, there are currently a number of key issues in the early intervention approach for children with hearing loss under the NDIS:

- 1. Poor pathway to confirming NDIS eligibility and subsequent development of an appropriate plan of supports**

This is a major problem. Families of children with hearing loss normally do not have any prior experience with deafness and as a result they rely on expert guidance in assisting them to navigate the market.

The NDIS does not provide that guidance – indeed many families have reported that their planners have simply encouraged them to go for the lowest-cost service provider, ignoring any indications of effectiveness.

A guided referral pathway, that enables families to make the decisions that will enable their children to achieve the goals they desire, is required. The sector has overwhelmingly supported that this function should be performed by Australian Hearing and Australian Hearing is open to that – it is in line with its current activities and the incremental cost of them fulfilling this role would fit within what the NDIS pays other organisations for this function.

However the NDIA has not accepted this. So far it is wanting to upskill its planners to perform this function; which is costly, ineffective and slow. Children must receive support immediately after their diagnosis otherwise they will have permanent delays to their language. Currently we are finding that it can take 12 months to get a NDIS plan approved, which is an unacceptable delay. Also, as the NDIS planners are not specialists, they are not setting appropriate plans – variability is massive and the value provided does not fund the specialist supports needed to achieve good language development.

Recommendation: Australian Hearing should be funded to perform a guided referral and planning function out of existing NDIS money.

- 2. Uncertainty around the future provision of audiology and hearing devices**

We don't know what will occur with this. Currently the provision of audiology and hearing devices for children is exclusively funded to be provided by Australian Hearing, who offer nationally consistent high quality services, with a low cost to government due to their economies of scale.

However this is due to become a contestable market as of 1 July 2019. **The sector has overwhelmingly supported that contestability should not occur and that this service should stay exclusively with Australian Hearing.** Choice under a contestable market is only of advantage if it is informed; but the vast majority of parents of children with hearing loss are not informed about hearing loss, hearing aids, or how to best achieve language for a child with a hearing loss. They have no personal experience of hearing loss or of aids and they cannot determine from their baby whether their child is gaining the benefit they hope for from the choices they make. **As a result parents are under huge pressure to do everything they can for their child, which could be exploited by unscrupulous providers.**

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.

The transition of the services from Australian Hearing to a contestable market could affect all of: the referral pathway and the number of children lost to follow-up; the cost of the hearing aids provided; and the accessibility, quality and independence of the audiological services.

Recommendation: Australian Hearing should be retained as the exclusive provider of paediatric hearing services.

3. Inadequate and inconsistent funding of early intervention services

This is a major problem. The NDIS has recently provided figures to the specialist providers that give the average committed value of supports for capacity building at approximately \$11,500; with families allocating an average of less than \$9,000 to their specialist provider.

This is approximately 50% of the average cost of the services the families are receiving.

As the specialist providers are all charities, they are attempting to fund the gap between their cost (for effective services) and their NDIS income through their financial reserves.

This gap is unsustainable. The NDIS is presumably hoping that service innovation will occur that enables effective services to be provided at 50% of the current cost. **There is no indication, anywhere in the world, that effective services can be provided at this price.**

As a result providers are ultimately faced with the choice of:

1. providing non-effective services within the NDIS funding; or
2. ceasing to operate as an independent organisation.

Already 2 of the specialist providers have decided to exit the market – Taralye (folded into RIDBC as of 1st February 2018) and Cora Barclay (expected soon). **There are no new effective entrants to the market and none are expected, as the price offered is 50% of the cost.**

In the absence of funding proportionate to the value provided, all of the current effective suppliers must exit the market as their financial reserves are exhausted. This will result in more and more children receiving ineffective services; poor language; and reduced social and economic participation.

Recommendation: national reference packages should be established that:

- **are funded from immediately after diagnosis;**
- **are appropriately reflective of the needs of each child; and**
- **are funded at a level that enables achievement of good spoken language (which is currently achieved but will not occur in future if the current NDIS plans are continued).**

Appendix: 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.

Up to 1 in 500 children born will have some degree of permanent hearing loss. Further children will develop hearing loss in the first few years of life (due to progressive loss, disease, trauma, etc) and by the time they are of school age approximately 1 in 300 children will have permanent hearing loss (approximately 4,000 children across Australia). **More than 90% of these children are born to parents who use a spoken language in the home and who would normally want their child to speak their home language.**

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, Berenthal, & 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.
