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Website: www.shepherdcentre.org.au

ABN: 61 000 699 927

# Submission to the Parliamentary Joint Committee on the National Disability Insurance Scheme, March 2016

Dr Jim Hungerford, CEO

## 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 online services. These children range from 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, with over 90% of all of our children going on to attend mainstream classes at a mainstream school. 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 (an 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.



#### Summary

To enable children with hearing loss to be able to develop language and social inclusion equivalent to their typically-hearing peers, the NDIS must:

- Ensure its processes enable children to reach specialist early intervention rapidly, without being delayed for review in non-specialist services;
- Allow all children with hearing loss to be assessed and, if necessary, provided with the required specialist supports; and
- Fund evidence-based therapy at the level required to enable the children to achieve outcomes at the same level as their typically-hearing peers.

## The profound impact of early childhood hearing loss

Children with hearing loss face numerous challenges on their road to achieving full social inclusion.

#### Speech and Language

Speech and language outcomes for children born with permanent childhood hearing loss have historically been compromised. For instance, the average oral and written language age of high school deaf graduates from the United States of America was <u>at or below that of the average hearing seven to eight year old child (Durieux-Smith, Fitzpatrick, & Whittingham, 2008).</u>

In recent years, the positive shift in the speech and language outcomes for children with early identified hearing loss has increased. However, research data (not that on children graduating from The Shepherd Centre) continues to suggest that the <u>majority of these children are unable to achieve speech and language outcomes commensurate with their typically hearing peers</u> (ongoing Australian study 'Longitudinal Outcomes of Children with Hearing Impairment' <a href="http://outcomes.nal.gov.au">http://outcomes.nal.gov.au</a>).

#### Literacy

In 2007 the Journal of Deaf Studies and Deaf Education suggested that 30% of school graduates with severe/profound sensorineural hearing loss were <u>functionally illiterate</u> (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, these poor literacy outcomes are not unexpected. This level of outcome and the consequent limitations to life choices are of major 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 <u>reduced employment</u> <u>opportunities</u>, particularly for those with congenital severe-profound hearing loss (Kentish & Mance, 2009).

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

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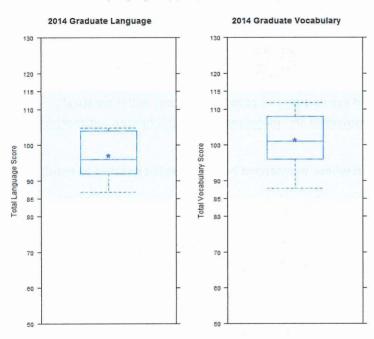
## Critical aspects of support for children with hearing loss

A child with hearing loss is at significant risk of developing a permanent language, speech, social and/or academic impairment, often with in a significant communication disability, as described previously. However this can be effectively minimised if the child is quickly:

- 1. accurately diagnosed;
- 2. effectively fitted with appropriate assistive hearing devices (hearing aids, cochlear implants, etc; depending if spoken language communication is selected by the parents); and
- 3. enrolled in a specialist early intervention service.

<u>Each</u> of these steps must be rapidly completed, <u>without loss to follow up</u> between them, to ensure each child has a reasonable opportunity to achieve successful outcomes.

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 specialist El service), that child has a very good chance of developing age-appropriate language and social skills, despite their hearing loss:



The blue shaded area (from 85 to 115) is the range of 'normal' language. The results for the children graduating from The Shepherd Centre program are shown by the whiskers of the box & whiskers plot. As the whiskers fall completely within the shaded area, the graduating children have achieved the same language as children without hearing loss.

(The Shepherd Centre, 2015) Children who have additional disabilities or other specific factors are not included in this plot.

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 ability.

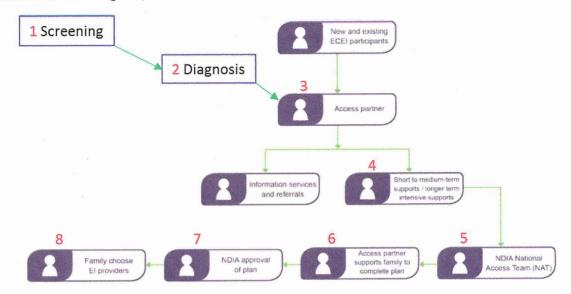
## The role and impact of the NDIS

The NDIS has already demonstrated its value in assisting children who require support due to their permanent hearing loss. For instance, the ACT roll-out has resulted in an almost doubling of the number of young children receiving specialised support – and as a result, gaining the opportunity to have improved language and improved life prospects. The children receiving NDIS-funded service (which averaged \$14,100; ranging from less than \$7,000 to \$22,000) from The Shepherd Centre in Canberra achieved spoken language outcomes (language, vocabulary, speech clarity; averaged across all children, including those with other disabilities), better than expected from typically-hearing children.

However a number of risks and challenges remain:

# 1. Introduction of additional administrative steps affecting rapid progression from diagnosis to specialised therapy

The new pathway proposed in February 2016 for early childhood early intervention, as applied to children with hearing loss, is:



As steps 3, 4 and 6 have not been required previously, this complex pathway will dramatically increase the time before specialised EI is provided and increases the risk of children not reaching EI.

# 2. Concerns about acceptance of all children where permanent hearing loss is expected to result in a communications impairment

Children with a mild hearing loss, or a loss affecting only one ear, are at high risk of developing communication, educational and social delays once they enter school. This area is still under consideration by the expert reference group convened by the NDIA, however it would be a false economy to not provide expert 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.

# 3. Risk to funding at the level required for the services that have been shown to provide outcomes equivalent to typically-hearing children

The expert, intense and transdisciplinary service that is required to enable these children to achieve age-appropriate language can cost up to \$25,000 per child per year (in excess of the 'standard' funding of up to \$16,000 per year). However, if this funding is provided, these children can achieve language and other outcomes at the same level as children with typical hearing. Funding below this level will result in poorer outcomes and increased longer-term cost.

#### Recommendations

The following recommendations are made to address the issues identified in this paper:

- 1. Simplify the referral pathway
- 2. Accept all children at high risk of communication impairment
- 3. Fund at the level required to achieve age-appropriate outcomes