



**Hear and Say**  
Opening worlds  
for deaf children

Hear and Say –  
centre for deaf children Ltd  
ABN 32 058 430 069  
Head Office and Brisbane Centre  
29 Nathan Ave, Ashgrove  
Qld 4060, Australia



P 07 3850 2111  
E [mail@hearandsay.com.au](mailto:mail@hearandsay.com.au)

[www.hearandsay.com.au](http://www.hearandsay.com.au)

## Submission to the Parliamentary Joint Committee on the National Disability Insurance Scheme – Townsville, 6<sup>th</sup> April 2016

### About Hear and Say

Established in 1992, Hear and Say has pioneered a highly effective parent-centred health care delivery model and currently services over 600 children throughout Queensland through centres in Brisbane, Gold Coast, Darling Downs, Sunshine Coast, Townsville, and Far North Queensland, and with a Tele-practice / e-health Program servicing rural and remote children and families unable to regularly attend centre-based programs.

Hear and Say is recognised as a global leader in paediatric Auditory-Verbal Therapy and implantable hearing technologies, such as the Australian invented cochlear implant. With around 70% of their clientele accessing services from regional and remote areas, this State wide not-for-profit organisation has established a reputation for delivering world-class early intervention programs teaching deaf children to hear, listen and speak. These time-critical, parent-centred programs help babies who are deaf establish required auditory brain neural pathways, learn how to listen using advanced hearing technologies and develop clear, natural language. As a result, by the time participants reach six years of age they are participating in mainstream education. This leads to improved educational and employment opportunities, increased social inclusion and strong extended family and community relationships.

Hear and Say is also a member of First Voice (a national organisation representing six charities from Australia and New Zealand that believe in listening and spoken language outcomes for children who are deaf), a member of the Hearing CRC, a member of the Hearing Expert Reference Group for the National Disability Insurance Agency (NDIA) and leads a number of hearing health and human bionics forums / networks in Queensland.

Additionally, in response to longstanding research that indicates that the incidence of hearing loss in children doubles by school age, Hear and Say launched a new program in late 2015 to conduct hearing screening tests on Prep-aged school children. With almost 3,000 children screened since, around 25% of these children were discovered as being unable to hear optimally in the classroom. A number of these children had previously undiagnosed hearing loss, perforated eardrums or foreign objects lodged in their ear canal with the vast majority suffering from potentially treatable hearing issues such as Otitis Media or middle ear infection.

### Social and Financial Impact of Hearing Loss

Hearing loss currently affects one in six Australians, over 3.8 million people annually and this is set to rise to 1 in 4 by 2050. It is the second most prevalent disability in Australia, and the most common disability affecting newborn infants globally. The impact of hearing loss is widespread – it reduces an individual's ability to fully participate in spoken communication, mainstream education, gain meaningful employment and develop fulfilling social roles.

**Brisbane**  
PO Box 930  
Toowong  
Qld 4066

**Gold Coast**  
PO Box 276  
Varsity Lakes  
Qld 4227

**Sunshine Coast**  
PO Box 5343  
SC Mail Centre  
Qld 4560

**Darling Downs**  
PO Box 1237  
Toowoomba  
Qld 4357

**North Qld Townsville**  
PO Box 930  
Toowong  
Qld 4066

**Far North Qld Cairns**  
PO Box 1132  
North Cairns  
Qld 4870

**Telepractice Rural & Remote Program**  
PO Box 930  
Toowong Qld 4066

The social and financial cost of hearing loss is significant. Financially, productivity loss and the costs for parents and carers contribute to a direct annual cost of \$11.75 billion to the Australian economy in 2005. There is no doubt those costs have increased substantially since this 2005 research.

### **National Disability Insurance Scheme – Queensland Launch**

The Queensland launch of the National Disability Insurance Scheme (NDIS) in Townsville heralds a new age for children and families affected by hearing loss in the region. Hear and Say is keen to continue supporting existing families and, even more importantly, ensuring that the same level of care is provided to new families yet to be given the news that their newborn or young child has a diagnosed hearing loss in order to help these children realise their full potential in the hearing world. It is the view of Hear and Say that while there is still much to be decided and resolved about the rollout of NDIS there are a number of issues that are worthy of being brought to the attention of the Parliamentary Joint Committee. Some preliminary issues that warrant further investigation, discussion or monitoring include but are not limited to:

- Referral pathways

The current Queensland Health (QH) diagnosis and referral protocols ensure that babies identified with hearing loss through the Universal Newborn Hearing Screening are connected with a QH Family Support Facilitator for support in finding a service provider to meet the needs of the child with hearing loss and the family.

It is important that the strengths of this existing process are acknowledged and the introduction of NDIA staff to the referral pathway does not add any time to that taken for children with hearing loss to access appropriate hearing technology and evidence-based Early Intervention programs.

- Initial NDIS Queensland launch clients

It is currently our understanding that of the initial 600 clients to be supported by the NDIS in Townsville region will consist of 300 existing Department of Communities, Child Safety and Disability Services (Disability Services), clients and 300 new NDIS clients. Hear and Say children and families traditionally have not aligned themselves with Disability Services (Hear and Say receives less than \$50,000 per annum from Disability Services) and accordingly it is worth reconsidering this distribution to ensure that eligible clients are not excluded from accessing the NDIS due to inequitable criteria.

- Education / training / awareness opportunities for NDIS Planners

The scope of disability to be covered by NDIS staff (including planners and Local Area Coordinators) may mean that deserving clients may be excluded as a result of a lack of awareness of the latest research and clinical findings in a specific field. Currently Hear and Say has a Research and Innovation team and a Training and Development team that consistently present at national and international conferences and is regularly published in peer reviewed journals and ensures that the latest research is shared across our trans-disciplinary team and incorporated into everyday clinical practices. Hear and Say would propose that those NDIS personnel influencing the decision regarding scheme eligibility are given annual presentations or the opportunity to participate in ongoing disability specific training with providers like Hear and Say. A hearing loss specific example of the importance of this type of training would be the changing research, candidacy criteria and the communication impairment risk for all children with unilateral or those affected by mild to moderate hearing loss.



- Funding available to service providers

Hear and Say already provides an intensive early intervention, trans-disciplinary service with complementary programs that promote social skills development; educate supporting childcare, kindergartens and school staff; ensure ongoing hearing technology upgrades and maintenance, and provide parent support, education and training; all of which are tailored to ensure that children with hearing loss or who are deaf are able to achieve and maintain age appropriate speech and language. These intensive preliminary services can cost around \$25,000 per child per year and it would be unsatisfactory if the exemplary outcomes currently being achieved for this cohort of children were diminished and the longer term associated costs increased as result of a perceived short term saving of funds. Findings at the South Australian trial site and the NDIS experience in other parts of the country reinforce the importance of providing funds adequate to support the realistic achievement of speech and language outcomes for these children at the same level as their naturally hearing peers.

- Workforce accreditation

Ensuring a child who is deaf has the best chance to realise their full potential in the hearing world requires an intensive, trans-disciplinary, holistic, evidenced based program. Listening and Spoken Language Specialists at Hear and Say who are part of the Early Intervention program all have a base degree / training as a Speech Pathologist, Teacher / Early Childhood Educator, Teacher of the Deaf, Audiologist or equivalent and are all either certified or working towards a three year international certification as part of the AG Bell Academy for Listening and Spoken Language. This international peak body has established a certification process that sets professionals apart in their knowledge, experience and application of skills to change outcomes for children with hearing loss. Hear and Say would recommend that all sole practitioners and service delivery organisations provide regular evidence in support of their child / client outcomes and are also specifically accredited to deliver the specialised support required for children with hearing loss.

This preliminary list is by no means exhaustive however aims to provide some insights for the Committee into the complexities associated with childhood deafness and paediatric hearing loss. Traditionally in Queensland, listening and spoken language programs for children with hearing loss have received proportionately less funding than other communication methods and it is encouraging to see that NDIS may now provide funding representative of the choices for the families who have chosen this future for their child.

### Summary Recommendations

An overview of the key recommendations to address the issues identified in this submission include:

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

The proposed NDIS registration process for the initial Queensland launch may exclude some eligible clients not accessing services from Disability Services.

Initial and ongoing training is suggested for NDIA staff involved in the advocacy and decision making process supporting client referral and program selection and funding. Hear and Say would be willing to provide such training and research support.

Appropriate funding is required to achieve and maintain age appropriate listening and spoken language outcomes for children and babies who are deaf or are affected with hearing loss.

Professional accreditation and the 'publication' of program outcomes will help ensure optimal outcomes for children and babies who are deaf or affected by hearing loss.

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Qld 4066

**Gold Coast**  
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