



Dear Committee

### **The provision of hearing services under the National Disability Insurance Scheme (NDIS)**

Canberra Deaf Children's Association (CDCA) is a non-profit community association that aims to provide support, information and social opportunities for families with deaf or hearing impaired children in the ACT and surrounding areas. This includes any type of hearing loss such as sensorineural, conductive and unilateral. CDCA is run by a volunteer committee of parents of deaf or hearing impaired children.

CDCA aims to:

- Help families in a positive way to meet the additional challenges of parenting deaf or hearing impaired children
- Share information to ensure families are aware of choices available and have correct and current information to make informed choices on behalf of their child or children
- Act as a lobby group to relevant government departments and other organisations on behalf of deaf and hearing impaired children, their parents and families.

This submission has been prepared in consultation with CDCA members. As our primary focus is children and young people with hearing loss, our comments below are written with paediatric clients (those aged from birth to 26 years) in mind.

#### Eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS

We believe the only eligibility criteria for deaf and hearing impaired people should be a permanent hearing loss (temporary hearing losses are usually medical in nature).

Excluding people (particularly children and young people) with a mild or unilateral loss will significantly disadvantage them. Many studies have shown the negative effects of such hearing loss, particularly mild losses (to experience a mild loss, we recommend the Committee spend some time conversing at a normal level while wearing foam ear plugs. You will find that listening takes more work and you will miss parts of words, particularly with unfamiliar subject matter, as is common in a classroom).



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CDCA member, 'P', is 5 years old and has a mild loss. Her parents say:

"P finds it extremely challenging to hear and engage when significant background noise is encountered, for example classrooms, public outings and any social or sporting activities.

"Through the NDIS, we have been able to access a high standard of early intervention services and technology which has ensured that our daughter is at the same level of development and education as her peers. This funding has been critical to developing her confidence, her social interaction skills and learning in general.

"(P's) schoolwork and attention span is greatly influenced by her ability to hear and engage with those around her. Our daughter wears hearing aids during her waking hours and even though her loss is mild, the effect on her day-to-day life is not. At the end of the day, having struggled to engage, she is often more tired and irritable than many children with full hearing. Without access to the NDIS we can only imagine the struggle she would experience on a day to day basis."

The Government has said that no child receiving government-funded hearing services will be worse off with the transition of hearing services to the NDIS. This will not be the case if people are excluded from the NDIS due to the severity or type of their hearing loss. A voucher system, like that currently used by pensioner clients of Australian Hearing, is wholly unsuitable for children and paediatric clients who are excluded from the NDIS.

**Recommendation: That the Government acknowledge that any level or type of permanent hearing loss can be disabling and not introduce new eligibility criteria (above the Australian Hearing baseline) to the NDIS.**

#### The principle of choice of hearing service provider

We support the principle of choice, but advise there is risk involved for some paediatric clients and their families. Under the current system, all babies, children and young adults are first seen by specialist paediatric audiologists at Australian Hearing. These audiologists have the skill and equipment necessary to appropriately, effectively and ethically diagnose, monitor and aid hearing loss. Training and support for Paediatric Audiologists is extremely rare outside Australian Hearing. Families are not over-prescribed hearing devices to boost profits. On this last point, families of young children must rely much more heavily



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on their audiologist's expertise (compared to adults) as children are unable to communicate whether their hearing devices are appropriate.

Families, most of whom have no prior experience of hearing loss, do not have to research the 'best' audiologist for their child. They are automatically referred to an audiologist with paediatric training, skills and equipment.

The current system, where newly-diagnosed babies and children are referred to Australian Hearing, works extremely well. The Australian system for new born screening and other diagnosis of hearing loss, with follow up through Australian Hearing has the highest percentage of children supported in the world. (See below).

Hearing loss in children is more consequential than it is in adults in terms of:

- Communication (speech and language): children need to learn to communicate with hearing loss; adults with later-onset loss typically already have well-developed speech, language and listening skills.
- Education: adults with later-onset loss have typically completed their education, while children with hearing loss have additional obstacles to overcome while acquiring their education.
- Social inclusion: children with hearing loss need to learn to develop social skills in spite of the challenges their hearing loss presents. Adults need to continue their social interactions with hearing loss.

These differences must not be ignored. Children, particularly those who are newly-diagnosed and/or babies, need specialised paediatric audiologists. This is particularly important as our members report their NDIS planners typically have no experience in hearing loss and were unable to provide guidance around what services or providers were available. In some cases the NDIS did not know and could not advise what support the child required, beyond hearing aids.

This leaves vulnerable families at the mercy of for-profit NDIS providers. In the hearing space these providers are effectively unregulated, there is no requirement for paediatric training or expertise, nor any quality framework around it. While it is unlikely to reach VET-FEE HELP proportions, there are nevertheless significant risks with this scenario.

We support choice, but it must be a choice between providers who have proven paediatric expertise, backed by some type of regulatory/quality framework.



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With regard to early intervention for speech and language, the introduction of the NDIS to the ACT has limited choice to families of deaf and hearing-impaired children. When the NDIS was rolled out, the ACT Government withdrew its successful Hearing Support Program (staffed with teachers of the deaf) and provided bulk funding for three alternate organisations to replace the hearing support program.

Despite these organisations ‘ticking the box’ to say they provided support for hearing impairment, all three (Noah’s Ark, Northcott and SDN) had extremely limited, and in some cases, no knowledge of the needs of children with hearing loss.

CDCA member, Baby O’s parents say:

“After initial diagnosis and specialist referral services provided by Australian Hearing, we chose the early intervention service we felt met our child’s needs. As we were part of the Canberra NDIS trial, we took a quote from the provider to our first NDIS meeting. At this point we were told by our planner - someone with no specialised training in hearing loss - that the quote was far too high and that we should look at other providers in Canberra.”

Baby O’s family made a choice for their son – they chose an early intervention provider with proven expertise in hearing loss. They were advised against this provider by the NDIS, despite most of the other providers in Canberra not having the expertise Baby O’s family needed.

Again, families must have choice between providers who have specialised paediatric experience and specialised hearing loss expertise. Families must be empowered to make the best choice for their child.

**Recommendation: Maintain the current pathway (to Australian Hearing) for newly diagnosed babies and children.**

**Recommendation: Introduce and maintain a standard for provision of hearing services to paediatric clients, including required training.**

Delays in receiving services, with particular emphasis on early intervention services



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Universal Newborn Hearing Screening programs mean that most children with congenital hearing loss have their diagnosis confirmed by three months and are fitted with hearing aids and in an early intervention program by six months of age.<sup>123</sup>

Early diagnosis and subsequent early intervention are critical to ensure children have the best chance of normal development of speech, language and learning.

The vast majority of our members are already participants in the NDIS and many have reported delays in:

- Having their initial or subsequent planning meetings
- Getting access to equipment approved in their plans (due to confusion about how to access funding etc)
- Getting timely responses from their planners or LACs\*.

\*One of our members reported they had a specific early-intervention program recommended to them by their early intervention provider part-way through their first plan. It took three months for their planner to respond to an email and several more follow-ups to get the program approved. By this stage, the program had already concluded. In this case, the provider felt the program would be so beneficial for the child that they agreed to fund it themselves. However, had this not been the case (and it's unlikely to be, in most cases) the child would have missed out of a program they needed to help their speech and language.

Another of our member's (Baby O – bilateral cochlear implants) parents reported that they had to have numerous reviews of their existing plan due to complications with an inexpensive specialist piece of equipment. During one of the reviews their funding was reduced by half. When this decision was questioned by the parents they were told that because Baby O was progressing well, the level of intervention was therefore no longer required and was reduced. The reason that Baby O was doing well on his hearing and language comprehension scores was because of the early intervention he had been receiving (through his NDIS funding). The reviewer had no comprehension of the benefits the early intervention was providing and without it, the family will probably need increased funding next year.

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<sup>1</sup>Neonatal Hearing Screening Working Group. National framework for neonatal hearing screening. Canberra: Department of Health, 2013. 7. Ching TY, Oong R, Van Wanrooy E.

<sup>2</sup>The ages of intervention in regions with and without universal newborn hearing screening and prevalence of childhood hearing impairment in Australia. Australian and New Zealand Journal of Audiology 2006;28(2):137-50.

<sup>3</sup>Outcomes for children who are deaf or hard of hearing. Renee Punch PhD. Victorian Deaf Education Institute.

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Baby O's family have still not received the piece of equipment 9 months after it was approved and have just started an internal review to try and get back to the previous year's level of funding.

A delay of a few months can have lifelong consequences for children with hearing loss, as there is only a limited window for speech and language acquisition.

**Recommendation: That the NDIA acknowledge the importance of early intervention (including fitting of hearing devices) for babies, children and young people with hearing loss and put safeguards in place to ensure there are no delays in people with hearing loss accessing early intervention or assistive technology.**

**Recommendation: That the NDIA review and improve the administration of the NDIS, as poor administration has direct, negative implications for families, despite the NDIS being a good scheme.**

Coupled with this is the risk of delay due to not having a clear pathway for newly diagnosed babies and children. Around 90% of babies with hearing loss are born to hearing parents (who do not have any experience with hearing loss). These parents are currently supported by the existing pathway, discussed above, and without it may not understand or value the importance of early intervention. For this reason, we re-state our above recommendation.

**Recommendation: Maintain the current pathway (to Australian Hearing) for newly diagnosed babies and children.**

#### Adequacy of funding for hearing services under the NDIS

Currently, children and young adults are routinely provided with high quality hearing aids –5mi or greater – by Australian Hearing and outside the NDIS. These hearing aids have greater functionality than the base model (3mi) and are necessary due to:

- The limited window for acquiring speech and language (which requires good access to speech and sound).
- Challenging listening environments in classrooms and lecture theatres - good access to sound is critical for learning.
- Challenging listening environments on sporting fields etc – children and young adults need to be able to hear properly when engaged in extra-curricular activities. This is important for social inclusion.



These levels of technology are needed to ensure that these children are given the opportunity to develop to their full capacity. If children and young adults do not have access to the current level of hearing technology they are currently provided with, it is extremely likely they will have much poorer outcomes in terms of speech and language acquisition, education and social inclusion. These poorer outcomes would have lifelong impacts for these children.

This is concerning, as the NDIA Operational Guidelines for Assistive Technology state, under section 24:

It is expected that the NDIS will generally only fund the minimum necessary or standard level of assistive technology. It is expected that the NDIS will generally be extremely unlikely to fund features above the minimum or standard level and that participants may choose to fund additional features themselves.

**Recommendation: Funding is adequate to ensure hearing aids provided to paediatric clients under the NDIS be, at a minimum, 5mi or equivalent, as this early investment is necessary to ensure whole of life outcomes can be achieved.**

Currently, paediatric clients are provided with batteries, repairs and replacements in addition to their hearing devices. When hearing services are transitioned to the NDIS, funding must be adequate to continue funding these necessities.

Hearing aid and cochlear device repairs can take around two weeks and currently children receive a spare or 'loaner' aid or pair of aids while theirs are being repaired. This is essential as two weeks represents 5% of a child's annual schooling – being without hearing aids or cochlear speech processors for this amount of time affects a child's education and social inclusion.

**Recommendation: Funding is adequate to ensure paediatric clients continue to have unhindered access to batteries, repairs and replacements as needed.**

#### Investment in research and innovation in hearing services

The National Acoustic Laboratories (NAL), Australian Hearing's research division, is a world leader in research relating to hearing loss and treatment.



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NAL's research and technology has directly benefitted many thousands of people, including our members. For example, the NAL-developed HearLab test alerted our member, Baby A's, audiologist that she was not accessing sound effectively, many months before she was able to participate in a hearing test. This meant the audiologist could adjust her hearing aids and give Baby A several more months of access to speech than she would otherwise have had.

Other members felt confident implanting their babies before they were 12 months of age due to the findings of NAL's LOCHI study.

These are just two examples from our members. People across the globe have benefitted from NAL's research.

With hearing services transferring to the NDIS, we fear that the funding NAL currently receives will be diminished. NAL's research and development should be a national priority, particularly considering 1 in 6 Australians now (and more in the future) have a hearing loss and NAL's research into hearing loss prevention.

**Recommendation: We strongly recommend the Government maintains (or increases) its funding to NAL when hearing services transitions to the NDIS.**



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