

T: 08 8298 0900
TTY: 08 8298 0960
F: 08 8377 1933

Townsend House 28 King George Avenue Hove SA 5048
PO Box 43 Brighton SA 5048
info@candogroup.com.au www.candogroup.com.au

Townsend House Inc. ABN 29 378 746 905

Can:Do
Group



25 January 2017

The Provision of Hearing Services under the National Disability Insurance Agency (NDIS)

Dear Committee Chairperson

We offer the following submission on the provision of hearing services under the NDIS and call for equity for every Australian who lives with hearing loss or impairment, a chronic ear disorder or tinnitus; are Deaf or deafblind; and their families.

Yours sincerely

Heidi Limareff
General Manager, Group Operations and Client Services

Introduction

The Can:Do Group consists of South Australia's two oldest charitable service providers, Townsend House, Can:Do 4Kids, and The Royal South Australian Deaf Society, Deaf Can:Do. The Can:Do Group also runs Can:Do Hearing, a not-for-profit multi-site audiology practice for adults and children. At Can:Do our mission is to alleviate the impact of sensory disability for individuals, families and communities.

With a combined 270 + years of experience, we are the leading experts in specialist services for people with hearing and vision impairments in South Australia and each year we touch the lives of over 20,000 people. Can:Do 4Kids has participated in the NDIS trial since 2013 and have earned a local and national reputation for successful management and transition into this new world for ourselves and for our clients. We currently provide therapy and additional services to over 200 children with NDIS plans in South Australia. Approximately one third of these children identify as Deaf or Hard of Hearing (DHoH). Deaf Can:Do, including Can:Do Hearing, commenced NDIS services in July 2016 and we have serviced approximately 20 NDIS participants, primarily through Auslan education and interpreting, to date.

We would like to offer comments and recommendations to the Joint Standing Committee on the NDIS – Hearing Services Terms of reference.

The first point we would like to make to the committee concerns the use of the term "hearing impaired". We believe that the community prefers the term Hard of Hearing (HoH) as many deaf people do not acknowledge that there is any impairment of hearing, but perhaps only in communication with hearing people. Hard of Hearing is the acceptable term around the world.

A. The eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS;

In regard to the eligibility criteria, we have concerns regarding a hearing average being used to determine eligibility for NDIS instead of functional outcomes or need as is the case with other disabilities. For some clients a mild hearing loss is devastating to their lifestyle, while for others a severe hearing loss is manageable without devices. It is critical that people themselves are able to determine what needs they have due to being deaf or HoH and that there is no predetermined 3 frequency average hearing loss (3FAHL) for eligibility, other than it must fall under the definition of hearing loss (currently set at 23 dB 3FAHL per ear under OHS). There is clear evidence that children with mild hearing loss fall behind their normal hearing peers at school, we cannot allow the NDIS to assume that a description of mild means support services and intervention are not necessary.

As a current NDIS service provider we have also been dismayed by the varying degrees of funding allocation and general acceptance into the NDIS scheme for children based on a unilateral vs bilateral loss and/or degrees of loss.

We have supported some families who have not been deemed eligible for NDIS supports due to having a unilateral loss. We have also supported three families that went through an appeal process with the NDIA which they found incredibly stressful. Two of the three of them ultimately received an NDS package for their child with a unilateral loss. It is important to

acknowledge that although this may require less intensive intervention or less funding, early intervention (EI) support and funding allocated for families to access support is important to minimise the need for further intervention and supports later on. Similar to mild hearing loss, there is evidence available to demonstrate that children with unilateral hearing loss do not keep up with their normal hearing peers in the classroom.

Whilst nearly 50% of children with a unilateral hearing loss may reject a hearing device this does not preclude the child from needing additional supports. Of course this leaves 50% that do benefit from both a device and therapeutic supports. Also of note is that children with unilateral hearing loss are currently supported under government funding through the CSO program in Australian Hearing. Given the fact that hearing aids cost a significant amount of money we would hope that the NDIA is not expecting those children who demonstrate benefit from the use of one hearing aid to have to pay out of pocket for their device while other children receive the devices at no cost to the family. What appears fair is that decision is based on functional need and demonstrated beneficial outcomes.

Can:Do 4Kids currently support several children with a unilateral hearing loss and note that the need for EI services including maternal bonding assistance, language building supports and input towards development of social skills have been required. In addition these families continue to have medical appointments and often hearing aid trials which require ongoing support from a therapy service. Lastly we would like to highlight the mounting evidence regarding success with fitting a bone anchored hearing aid (BAHA) to children with one deaf ear (profound hearing loss) which means they will require EI and additional services and support.

As well as unilateral hearing loss, it is important to also acknowledge and address the impact of a temporary loss on speech and language development due to a transient hearing loss. We note that the eligibility criteria for NDIS are around permanent loss. Whilst for some children this may be covered under early intervention, for others who can wait up to 18 months for intervention on the public health system in Adelaide, short term NDIS assistance for intervention is critical. This will assist to reduce ongoing need later for issues such as auditory processing disorder, which is found more often in children with repeated cases of conductive hearing loss. One possible solution for this issue is that the new ECIC framework covers children with ongoing transient hearing loss, given that this is about timely relevant specialised services.

There is a need for recognition of the benefits of support related to grief and loss, i.e. family support, family counselling. While this is not direct intervention for the child, it is important to see the connection between family capacity and reduced need for formalised or paid supports. Similarly, there is importance of funding family learning and training around understanding the hearing loss, use of aids/implants and Auslan development, if relevant. While this is something which currently is supported by EI, often the funding allocated is specific to a child centred goal and not related to the family or carer support. As well, notable is the need for social skill development and supports for children with hearing loss. Funding this type of support will significantly reduce long terms costs of the social impact of hearing loss.

Additional service needs include funding to support access to interpreters, both ESL and Auslan to ensure that families have adequate access to the information and details required to advocate for the required supports. Also in consideration for a 'peer' mentor or communication support for children to access community activities, local events, mainstream supports.

We believe that we have recently seen an increase in the support/ funding provided to carers or families and an acknowledgment of the importance of families to be supported and educated in order to in turn support the development and intervention with their children. This in turn has led to earlier reaching of goals and less use of the NDIS system. We commend NDIS for their response to this learning.

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

With the introduction of the Universal newborn hearing screening (UNHS) program in SA access to early hearing assessment for all families was a reality. This access has seen a significant increase in early identification (from an average of 24 months to 3 months in age) of the hearing loss and the potential treatment/support required- early intervention has been crucial. Evidence strongly suggests that there is a need for intervention with hearing impaired children between the ages of 3-6 months for optimum language outcomes.

The recent LOCHI study conducted by the National Acoustic Laboratories (NAL) provided evidence that early identification, when it is followed with early amplification and/or cochlear implantation leads to better outcomes than those for later-identified children. Many other variables also influence outcome, particularly access to early intervention. The current set-up of services to deaf and HoH children and their families means that all children receive their hearing aids/devices from Australian Hearing and all additional services from a provider of their choice. With a monopoly in the devices aspect of intervention, the referral to Australian Hearing is often quick and a certain amount of pressure is put on the families to commence device intervention.

Whilst we strongly agree that the UNHS process has some real advantages in terms of early diagnosis, we have concerns with families who have just given birth to their precious baby being told that there is a "problem" immediately. The issue that we have observed is the disruption in the mother-child attachment/bond. These families sometimes go on to question, doubt and experience associated grief and loss that without the right support and true EI support continues well into that child's life- effecting development and relationships. Too many families report feeling "medicalised". We believe opening up device provision to organisations beyond Australian Hearing will allow organisations that work within the current EI space with children who are Deaf or HoH to manage the whole child and family whilst also understanding the need for fast device intervention.

Due to the current model having a discrepancy between time delays in getting devices and obtaining additional, important support, we would advocate for a central point of contact who understands both the principals of early intervention and the impact of hearing loss on a baby and family. This acknowledges the difference between understanding that something is not quite right with a baby vs having a diagnosed lifelong condition. The role should be a psychologist, social worker or someone trained in both audiology and counselling. This will

assist in ensuring families are not overwhelmed with information or told that they need to head off and sort it all out on their own. An extremely successful program Can:Do 4Kids currently runs in Adelaide is called "From Diagnosis to....." which is aimed at the new families and run by a Can:Do 4Kids social worker. These families report feeling better prepared to manage their child's condition and also clearly understand the importance of the fundamentals of EI particularly around family wellbeing.

We would advocate that the committee considers recommending referral response times to the NDIA in order to ensure timeliness of response and the processing of each stage of NDIS participation. Using the information above the key takeaway message is that support needs to be immediate and specialised, and unfortunately to date, the NDIS has not consistently been either of these things in response to newly identified babies.

C. The accessibility of hearing services, including in rural and remote areas

As noted above given Can:Do 4Kids 140+ years' experience in working with deaf and HoH children we know that it is important for families of babies with a hearing related diagnosis to have access to specialist services. During our 3+ years of NDIS funding we have found that the NDIA encourages families to seek local assistance as a priority over specialised knowledge. We would purport that local service providers provide is often not able to identify what is needed for a family with a child with a hearing loss in the same way as a specialist service.

Our evidence of this is twofold. Firstly we have received an unprecedented number of contacts from regional (and metropolitan) SA over the last 3-4 asking us for advice and assistance with children with sensory loss. Some of this we have provided via Skype with great success, others we send information and support on the phone with limited success. Second, we have noted several deaf/HoH clients leaving our speech therapy services once they received an NDIS plan to go to a local speech therapist. Nearly all returned to us, stating that they would rather spend the travel funds to see someone who understand their specific therapy and family needs. In regards to Deaf culture the importance of this knowledge can absolutely not be undermined by sending participants to local providers.

We advocate for significant funds to be provided to rural and remote participants to allow them to access the required specialist services either in person or via the internet. For those that choose to travel to a metropolitan site for specialist services this should be embraced, encouraged and supported with funding appropriately.

D. Principle of choice in providers

We strongly believe that all participants regardless of age should have the ability to choose their hearing services provider for all aspects of support including device provision, EI and therapy. The current system directing all children to Australian Hearing has left some families feeling powerless in their ability to advocate on behalf of their child particularly when there is a clash between them and the clinician or when they require more appointments or services than allotted by AH. As an EI and therapy support organisation for deaf and HoH children we have

been repeatedly asked why children cannot have their hearing aid provision and therapy at the same location, given that we run several audiology clinics, including paediatric services.

In regards to concerns about children seeing anyone for their hearing problems it is important to note that there has never been regulation in Australia regarding the qualifications of service providers for children with hearing loss and we have some of the best outcomes for children around the world. A large and important part of this work is done outside of Australian Hearing with speech pathologists, audiologists, musical therapists, teachers of the deaf and psychologists/social workers.

We understand that there is concern about intervention occurring outside of Australian Hearing but we would like to acknowledge several points:

- All Australian accredited audiologists undertake a master's degree that includes paediatric training
- Audiologists work to a Code of Ethics, that includes working within their scope of practice
- Countries such as the US do not have a paediatric audiology degree and the market regulates itself with impressive outcomes
- There are a large number of ex Australian Hearing audiologists working for other organisations with paediatric experience and training, keen to utilise their education, experience and skills
- Australian Hearing does use general audiologists to see children due to need – we have audiologists within Can:Do that treated children whilst working at AH without specialist training.
- The principle of choice and control under NDIS appears to acknowledge the participant as the expert in their needs, why should this be different for deaf/HoH clients wanting to choose a provider?
- We are unaware of the coverage of paediatrics under audiometrist's training and are therefore unable to comment on the appropriateness of them treating paediatric clients

Beyond device provision, it is important that families are able to spend their NDIS packages across providers in order to gain an understanding of all approaches to services for deaf/HoH children. We often find families coming to us when their child enters school or is slightly older looking for assistance with language acquisition because they have never been exposed to sign language or any alternatives to spoken language and audition skills as they were required to engage with one service provider only and that provider's philosophy ultimately did not meet their child's needs.

We believe that all families with children who are deaf/HoH should be able to talk to experts on both oral and signed languages to gain insight into the world that their child was born. We do not think a family should be pushed into making this decision immediately but should instead focus on attachment, bonding and the early stages of (any) language development – such as turn taking and responding.

E. The liaison with key stakeholders in the design of NDIS hearing services, particularly in the development of reference packages

We believe that it is important to speak with stakeholders in regards to the design of NDIS hearing services and reference packages. Of utmost importance is speaking with a broad range of stakeholders, particularly deaf/Deaf/HoH clients and their families.

Within the deaf/HoH therapy and intervention space there are a lot of diverging opinions on the "right approach". There is evidence available to support most approaches, usually citing the

outcome important to that particular approach. Unfortunately we rarely find evidence that demonstrates success in every aspect of therapy for these children. By this we mean if the evidence is that XYZ therapy provides the best speech/spoken language outcomes the research rarely mentions the social emotional outcomes for those children. One also has to be mindful that speech and language are different and we should not diminish the use of signed languages or a combination of spoken and signed language to ensure a child is best able to communicate.

We advocate that the right approach for a child is what the family deems to be the right approach for that child and the family unit. This can only be determined over time and with a coherent understanding of all of the issues faced by children with a hearing loss (not to mention that often hearing loss coexists with other conditions). Therefore we believe that a reference package should not be based on the chosen therapy model but instead on the intervention needs of babies and children with hearing loss. This includes devices (which may change even within the first year of life), early intervention, family support, and therapy.

In regards to adults there is also a range of outcomes and we believe that the NDIS needs to be able to provide a range of hearing devices dependant on the client's functional needs. In addition the use of hearing aids and implants additional devices such as an FM, alarms, and batteries should be considered. Furthermore for adults the consideration of therapy and or language services may be warranted, particularly if the hearing loss is progressive in nature. In the case of adults reference packages should be based on lived experiences of OHS and private clients, with particular attention on outcomes with "top-up" hearing aids.

F. Investment in research and innovation in hearing services

The Can:Do Group strongly supports the ongoing funding of the National Acoustic Laboratories and the Hearing CRC. The advances made by NAL over the last 60 years have provided excellent outcomes to individuals, groups and organisations working within the deaf/HoH space. In addition the worldwide reputation of NAL means Australia is always on the map as a key expert in hearing services. Given the immeasurable amount of advances in medicine and technology there continues to be room for further innovation and growth which needs to be supported by the Australian government.