

Submission to the Standing Committee on Health, Aged Care & Sport inquiry into the 2017-18 Annual Reports of the Department of Health and Australian Hearing

26th February 2019; Dr Jim Hungerford, Deputy Chair

This submission is in response to the request from the Committee for our views on what we are hoping to see for children with hearing loss after the completion of the transition to the NDIS (ie, from 1st July 2020).

Key elements for the support of people with hearing loss under the NDIS, from 1st July 2020

The key issues from the perspective of First Voice are:

1. Retention of Australian Hearing as the exclusively funded provider under the NDIS for the provision of paediatric audiology services
2. The 4-tiers for the default plan for children with hearing loss are determined by a combination of level of hearing loss plus the presence of any specified additional factors
3. Children who have additional disabilities in addition to hearing loss have plans that separately specify the funding for hearing loss services and those for the additional disabilities
4. Families in complex circumstances are supported by their Early Childhood Partner to rapidly receive an appropriate plan and to engage with an appropriate specialist service provider
5. Paediatric audiologists are able to bill Medicare for hearing tests without requiring a medical referral

These are expanded on in the sections below.

1. Retention of Australian Hearing as the exclusively funded provider under the NDIS for the provision of paediatric audiology services

The new rapid referral pathway for children aged 0-6 years first diagnosed was introduced in August 2018 and it has been working well in most instances. The new pathway involves Australian Hearing initiating the enrolment process at their first meeting with a newly diagnosed child; with a highly structured system then resulting in a first plan for the child normally within the next 3 weeks or up to 6 weeks.

The outline of the new system is:

1. Subsequent to diagnosis a child engages with Australian Hearing as per the existing pathways.
2. Australian Hearing then initiates the process for an access decision and the decision will normally be made by the NDIS within 2 days (*a new process & timeframe*).
3. An experienced planner trained in hearing loss and deafness then works with the family to have a plan approved, usually within 2 weeks (*a new process & timeframe*). This plan will cover standard funding arrangements for Early Childhood Intervention providers.
4. The family are linked to an Early Childhood Partner to support implementing the plan and linking to Early Childhood Intervention providers if required.

The success of this pathway requires Australian Hearing to remain the exclusive provider of paediatric audiology services. Currently this exclusive role ends on 30 June 2020 and there has been no indication from the Government about what will happen then. If the exclusive role is lost the new pathway will cease to function. **First Voice recommends that Australian Hearing remains the exclusive provider of paediatric audiology services.**

2. The 4-tiers for the default plan for children with hearing loss are determined by a combination of level of hearing loss plus the presence of any specified additional factors

A major issue over the first few years of the NDIS has been challenges in setting appropriate plan funding levels. As part of the excellent work by the teams at the NDIA an interim approach of 2 standard tiers, based on audiological diagnosis, was introduced for children's first plans. The use of the audiological diagnosis allowed the plan to be established within the very short time frame required (as per Point 1, above). The interim 2 tiers are now being replaced by a 4-tiered system which is much more closely aligned to the service costs incurred, for children requiring low, medium, high or intense support.

The new 4 tiers for the initial plans are expected to be implemented on 1st March 2019.

However a critical remaining issue is that audiological diagnosis (degree of hearing loss) is the only factor considered for determining the appropriate tier for the initial plan.

The area of major focus during the initial management of children with hearing loss is on parental education and support. Success in this phase enables the family to make appropriate and informed decisions around communication approach, hearing technology, audiological management and language development. These must be made in the first few months after diagnosis, so that the short window of high neuroplasticity in a baby's early life is not lost. The cost of providing the activities is not proportional to the degree of hearing loss.

In addition, a significant proportion of children have additional factors outside of the audiological diagnosis that significantly increase the service they require, such as:

1. already having a diagnosed communication delay (from a formal assessment of their speech, language, etc);
2. where they have insufficient access to sound to provide for appropriate language development (such as the inability of the family to keep hearing aids on, preventing the child from hearing sufficient speech to develop language; or where the parents require increased support to ensure consistent integration of hearing technology and specialised therapy into their child's day-to-day life); or
3. where there is a complex family context that is preventing the family from appropriately implementing the therapy (such as the parents not speaking English and an interpreter being required; lower family literacy or learning levels that impact on ability to access program content; limited or no acceptance, understanding and commitment to the intervention program. All increasing the level of support required).

The impact of the early intense educational phase and of the additional factors means that the plan tier needs to take these into account in addition to the audiological diagnosis.

The preferred approach of the NDIA to address these factors is for the NDIA Hearing Stream Lead Coordinator to be responsible for alerting the Early Childhood Partners when the participant is identified as having additional disabilities or other areas of need (which may be flagged by Australian Hearing at initial contact stage). The Early Childhood partner would be requested to prioritise and see the participant as soon as possible.

First Voice believes that the reliance of the Early Childhood Partner will not be successful, especially where the additional factors are of a specialist nature (such as assessing parent understanding of early intervention requirements; communication in babies; access to sound; etc). Early Childhood Partners are under significant workload pressures and experience has demonstrated that they do not appreciate the impact of issues such as these.

Inclusion of these factors needs to be implemented into the first plan to ensure that appropriate funding is provided during the most critical year of a child's therapy. **First Voice believes the plans for children with hearing loss should recognise these factors in determining the level of funding required.**

3. Children who have additional disabilities in addition to hearing loss have plans that separately specify the funding for hearing loss services and those for the additional disabilities

Approximately one-third of children with hearing loss have an additional diagnosis, such as Down Syndrome, Cerebral Palsy or Autism Spectrum Disorder.

A significant issue has been that the value of an approved plan for a child with multiple disabilities is often much less than the total cost of the required services. In these instances the family is in the very difficult position of trying to judge the relative clinical need for the different services. First Voice has requested that the funding allocated according to the above 4 tiers be restricted for the intended purpose of specialist services for hearing loss.

The NDIA has determined that it is unable to do this; however we believe that the families require some guide as to how their funding was allocated so they can include that in their decision. **First Voice believes the NDIS should provide information to the families to assist in their choice, along the lines of 'The total plan value has been determined from \$x for specialised therapy for hearing loss and \$x for other supports'.**

4. Families in complex circumstances are supported by their Early Childhood Partner to rapidly receive an appropriate plan and to engage with an appropriate specialist service provider

The rapid referral pathway outlined in point 1 relies on phone calls from the specialist planner to the families to finalise the plan, which is generally productive. However for families in complex circumstances, or those struggling with the emotional turmoil of a new diagnosis, there can be challenges in engagement that can delay the first plan for several additional months.

Due to the challenges in engaging with these families First Voice agrees with the NDIS that the relevant Early Childhood Partner should be responsible for engagement with families that are struggling or are in complex circumstances, however we believe specific targets need to be established to ensure that these families are not allowed to drift (they are often the families most in need of support). **First Voice believes that the NDIS should establish performance benchmarks for Early Childhood Partners to ensure these families receive their initial plan within 2 months of their eligibility being established.**

5. Paediatric audiologists are able to bill Medicare for hearing tests without requiring a medical referral

Approximately 1 in 1,000 children are born with a significant level of hearing loss. We know that this incidence increases to approximately 1 in 300 by school age. As a result, for every child born with hearing loss there are a further 2 who acquire hearing loss sometime after birth but prior to school. We do not know when this occurs.

A major impediment to the early identification of this acquired hearing loss is that for hearing tests to be able to be charged to Medicare they must be conducted under a medical referral. This need restricts testing for families who have concerns about their child; both because of the extra visit required and because many doctors are unaware of the profound impact of early childhood hearing loss, or how children can mask their loss through visual and tactile attentiveness. If families could attend a paediatric audiologist for a bulk-billed hearing test many more children with acquired hearing loss would be identified and assisted. **First Voice believes that the Medicare Benefits Schedule should include items that allow for the appropriate hearing tests for children without the need for a medical referral.**