Situation following the recommendations of the Joint Standing Committee on the NDIS

27th February 2019

Dr Jim Hungerford, Deputy Chair; Ms Stefania Ruidiaz El-Khoury, RIDBC

As requested during the Committee hearing on the 26th of February, this document provides the comments of First Voice on the situation following the recommendations of two of the inquiries of the Committee (Provision of hearing services under the National Disability Insurance Scheme; and Provision of services under the NDIS Early Childhood Early Intervention Approach), as they apply to children with hearing loss.

Recommendations under the "Provision of hearing services under the National Disability Insurance Scheme" (September 2017)

Recommendation 2

2.58 The committee recommends the NDIA reviews immediately the cases of people with hearing impairment who were previously found ineligible and tests their eligibility against the revised guidelines.

Children who were previously found to be ineligible have been reassessed using the updated EI criteria and their status appropriately determined. There have been very few problems subsequent the new rapid referral pathway for newly diagnosed children, utilising Australian Hearing for eligibility assessment.

Recommendation 4

3.83 The committee recommends Australian Hearing be formally appointed as the independent referral pathway for access to early intervention services under the NDIS and funded appropriately to take on this new role.

Under the new rapid referral pathway for children aged 0-6 years first diagnosed with hearing loss, Australian Hearing initiates the process for eligibility assessment and then default plan determination. This process is generally working well, however with regards to Australian Hearing's role there are 3 specific issues:

1. This process only works if Australian Hearing is 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. Australian Hearing is not being funded for this role; it is undertaking the work by diverting some resources from its CSO funding. Whilst the quantum of funding is not large, this potentially puts this critical role at risk. **First Voice recommends that the NDIS funds Australian Hearing for these activities**.
3. The process only applies to new children (not to existing children still without a plan) aged 0-6 (not for children aged 7 or more). Whilst the urgency of immediate intervention doesn't apply to these children, they still require an appropriate referral pathway. **First Voice recommends that the NDIS should commission Australian Hearing to check, and if required, initiate the NDIS process at the next appointment Australian Hearing has with each child; and to apply the same process for children aged 7 or higher.**

Recommendation 5

3.87 The committee recommends NDIA ensures that the early intervention packages take a holistic approach to the needs of participants and include:

- *scaled funding, depending on need;*
- *funding provision for additional services beyond core supports, depending on need; and*
- *retrospective payment of the costs borne by approved service providers for the provision of necessary and reasonable supports between time of diagnosis and plan enactment.*

The introduction of the rapid referral pathway has substantially reduced the amount of time that services need to provide assistance to families *pro bono* and as a result retrospective funding is no longer required.

The agency is also introducing a new 4-tier scaled funding model which is appropriately scaled for low, moderate, high or intense service; however the tier is solely determined by audiological diagnosis and does not recognise the other factors that determine the 'need' of the child; in particular those children:

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 reliance on audiological diagnosis alone results in underfunding for these children.

An example of this is a particular case of a child aged 4 years 8 months who was granted a funding package through the rapid referral pathway. The child has moderate sensorineural hearing loss but this was only diagnosed at 3 ½ years of age which resulted in a severe language delay. The initial $16,000 package is not sufficient for the intense specialised intervention for hearing required in preparation for commencing school in 2020. Additional concerns were also raised by the child's keyworker and preschool teacher around the child's development of age appropriate fine and gross motor skills as well as his cognitive development. But when referred to the Early Childhood partner for a review of the funding, the family was advised to use the funding already granted and wait for the scheduled plan review (12 months later). This is clearly not appropriate.

First Voice recommends that the NDIS include additional factors impacting need (in addition to hearing loss) in determining the plan tier level for a child.

The agency is also designing a pilot of an Outcomes-based Funding Model. This model should address the concerns of the Committee regarding the additional services required by children.

Recommendation 6

3.90 The committee recommends the NDIA urgently finalise, publish and introduce the early intervention reference packages.

The levels for the new 4-tier first plan approach should be available in March 2019.

Recommendations under the "Provision of services under the NDIS Early Childhood Early Intervention Approach" (December 2017)

Recommendation 8

3.40 The committee recommends that the NDIA provide ongoing and targeted training to Planners creating ECEI Plans for children to ensure they are equipped with the most up to date knowledge, expertise and resources in their decision making.

The NDIS has established an internal specialised team of planners for children with hearing loss which has provided significant improvements. However the Early Childhood partners have not received this training and this particularly affects children who were diagnosed prior to the rapid referral pathway being implemented, or where there are other issues in addition to hearing loss. In these cases there are substantial delays in funding packages. These delays can be in securing an initial planning meeting with an Early Childhood partner which have been as long as 18 - 24 months in some cases. Even after a planning meeting is completed it has taken up to 6 months for a plan to be approved.

Furthermore, Early Childhood partners appear misinformed about the plans for children with hearing loss, particularly in how initial support packages for hearing are to be utilised. On a number of occasions Early Childhood partners have declined to review initial support plans where families have been instructed by providers to request a review for additional concerns.

The case of the child referred to under Recommendation 5, who had a severe language delay following late diagnosis, is also an example of where Early Childhood partners need additional education. The initial $16,000 package was not sufficient for the intensive specialised intervention required and additional concerns were also raised by the child's keyworker and preschool teacher around the child's development of age appropriate fine and gross motor skills as well as his cognitive development. When referred to the Early Childhood partner for a review of the funding, the family was advised to use the funding already granted and wait for the scheduled plan review (12 months later). Given the complexities of this child's case, the Early Childhood partner should have scheduled a follow up meeting with the family to discuss these additional concerns and review the funding provided.

First Voice believes that the NDIS should provide education to Early Childhood Partners and establish performance benchmarks to ensure families with additional concerns receive a review of their initial plan within 2 months of the concerns being raised.

Recommendation 14

4.76 The committee recommends funding be made available in Plans for interpreters, including funding an interpreter to communicate with the Participant's parents or carers.

This remains an issue, with inconsistent provision of interpreters. For example, families are being asked to pay themselves for support by Auslan interpreting agencies if this is not funded in their NDIS plans. In many circumstances, families are being incorrectly advised that Auslan interpreting for Deaf parents with no spoken language is not reasonable and necessary. Similar issues arise for families who only speak a language other than English and interpreting has not been included in the plan. The NDIA have communicated that TIS has been contracted to provide interpreting services to families of CALD backgrounds who do not have English language skills necessary to communicate with providers. This support is referred to as an "in-kind" arrangement and has been communicated widely with providers and participants. However, we have faced difficulties in engaging this support for families at time of service, as TIS have on several occasions advised no interpreters available at the requested time; in the requested language; or to conduct face to face interpreting (which is often imperative in the delivery of early intervention supports). Though the TIS arrangement may be suitable for interpreting during negotiations of service agreements or when explaining the administrative side of NDIS/service provision, it is not working well for use during intervention sessions. This has led to a lot of distress for some of these families and on

many occasions the therapy provider has had to pay these interpreting costs themselves due to this gap in funding.

First Voice requests that the Committee emphasises the need for action on the Recommendation and that a report on the provision of interpreters is provided to it.

Recommendation 18

5.38 The committee recommends that the NDIA allocate specific funding for information and support for vulnerable families to connect with ECEI Partners through the ILC.

This remains an issue, with isolated, vulnerable and disengaged families still having problems with establishment of a plan and connection with a service.

In particular we have noted that some participants from CALD backgrounds are progressing through to plan approval slower than other participants. In areas of particularly high cultural diversity, such as Western Sydney, many children (including some of those who were supported under state funding) have not been able to progress their NDIS journey due to the complex cultural and socioeconomic factors that kept parents and carers from engaging with planners and Early Childhood partners. **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**.