15 January 2017

Joint Standing Committee on the
National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

Submission to the Inquiry into the provision of hearing services under the National Disability Insurance Scheme (NDIS)

I am writing to the Inquiry to tell our experience of the NDIS with our daughter, . She has been a participant in the NDIS since November 2014.

is 5 years old and will start school in two weeks. She has a moderate hearing loss, wears hearing aids and uses a transmitting/receiving microphone (an 'FM') to enable her to hear in difficult environments (preschool class room, soccer field, dance class and anywhere with background noise).

is our third child and was diagnosed with a mild hearing loss at birth – it has been at the moderate level since she was 6 months old and we don't know whether it deteriorated or the initial diagnosis was incorrect. We had no experience with hearing loss before was born, and it was a very scary, overwhelming and confusing time.

We were fortunate that the system worked well for our family – was picked up during her newborn screen, diagnosed at five weeks, referred to Australian Hearing at 8 weeks of age and was fitted with hearing aids while still a young baby. She has been in early intervention since she was 9 weeks of age. She was given the best possible chance of developing normal speech and language before we'd really even figured out what hearing loss meant for her future. We will be forever grateful for that.

When was three years old, she was accepted as a participant to the NDIS. Our first planning meeting was not what we expected; our planner had no knowledge of paediatric hearing loss and was unable to provide any recommendations or guidance. Luckily, we had three years' experience under our belts, so were able to advocate well for our daughter. I don't know what we would have done had she been newly-diagnosed.

received funding for continued early intervention plus some assistive technology in her first plan. The equipment she received was – and continues to be –

an integral part of her day-to-day living and has meant she has wonderful access to sound and therefore has wonderful speech and language.

In this regard, and many others, the NDIS has been a very positive experience for our family.

However, there have been some negatives, too.

When was four years of age, she started to struggle with some aspects of her speech. It became apparently that she couldn't discriminate between some sounds (she could hear the sounds, but could not tell the difference between them). This affected deeply. She became angry and frustrated. She stopped participating in her early intervention sessions as she was so frustrated.

In response to this, audiologist at Australian Hearing recommended a higher model (but not the highest) of hearing aid. She wrote a letter of support and recommendation for us to take to our NDIS planner.

The request was refused, with our planner likening the recommended hearing aids to 'mag wheels on a wheelchair'. He said the NDIS won't fund anything other than the base model (under the NDIA Operational Guidelines for Assistive Technology) and it was on this basis that our request was refused.

So, we did what many other parents would – made many financial sacrifices (no holiday for our family that year) and self-funded the hearing aids. It was the right choice; within a month of being fitted was able to discriminate between the sounds, her speech improved and so did her self-esteem.

Another negative experience with the NDIS has been delays. Delays in our planner responding to emails (up to three months, at one point), delays in funding becoming available and delays in plan review meetings.

The thing with hearing loss is that a delay – even one of 'just a few months' can last a lifetime. There's a limited window for speech development and having to wait months for funding or action can mean your child 'misses the boat' so to speak. I challenge you to spend a week without hearing and see how far behind you fall at work. Now imagine that happening at school, and imagine the frustration of missing out while your peers and teacher move on.

Finally, prior to the introduction of the NDIS, had access to the ACT Government's hearing support program. This meant she got one hour of one-on-one therapy per week plus a wonderful playgroup with her deaf peers and teachers of the deaf. This service was closed to allow more competition under the NDIS. It was devastating to lose that support.

The agencies that were chosen for bulk funding to replace the hearing support program were staffed with lovely, well-meaning people. However, it became clear from conversations with the new providers who ticked the box to say they provided support for hearing impairment (Noah's Ark, Northcott and SDN) had limited and in some cases, almost no knowledge of the needs of hearing impaired children.

It was horrifying to see the ACT Government support providers who were unable to adequately support deaf kids. People with disability must come first, not the providers.

I have read your terms of reference and considered them with regard to our experiences mentioned above and those of our peers in the local paediatric deaf community. I ask you to consider my input with regard to the following terms:

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

   Please do not introduce eligibility criteria based on level of hearing loss. Babies and children with mild loss do not have a ‘mild’ effect on their lives – they too need assistive technology and early intervention to succeed. was initially diagnosed with a mild loss but it had a huge impact on her life.

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

   Please acknowledge that delays can be catastrophic for kids with hearing loss, it can affect their speech, language and education. Please consider putting precautions in place to acknowledge and address this risk.

3. **The adequacy of funding for hearing services under the NDIS**

   and her peers currently get access to mid-range hearing aids (5mi or similar) from Australian Hearing. I am deeply concerned that under the NDIS, only the base model would be available, as per the NDIS Operational Guidelines for Assistive Technology. This level of equipment is not good enough for paediatric clients, who are *learning to communicate with hearing loss* (as opposed to adults who develop hearing loss and are *continuing to communicate with hearing loss*).

4. **The principle of choice of hearing service provider.**

   As a consumer, I support and champion choice. However, I think there’s a lot of risk involved with newly-diagnosed babies and children.

   As you have read above, we have seen first-hand that organisations with no experience in hearing loss will step forward to receive funding to support deaf kids. Please, don’t let this happen again. and her peers need choice between providers who have paediatric expertise, experience and equipment. Anything less is a huge risk.

Yours faithfully