



6th March 2017

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

Thank you for the opportunity to provide the views of parents at the Hearing of the Joint Committee on the National Disability Insurance Scheme in Melbourne. We were disappointed that our experiences and feedback from families was not more extensively canvassed. The needs of families often diverge from those of service providers and we did not have the opportunity to discuss these with the Committee.

The following points are outlined for consideration by the Committee:

- We would like to reiterate the views of many at the Public Hearing. We have a robust system of providing timely and equitable hearing services and early intervention to children with hearing loss and their families. Any changes made under the NDIS must be an improvement on the current system and must not dismantle a system that is serving children and their families well. Since appearing at the Hearing, the National Deaf Children's Society (NDCS) in the UK has released a report highlighting the risks posed by altering our current paediatric hearing services. The Listen Up! Report found one third of audiology services were failing to meet basic standards in audiology. Four years after a quality accreditation program was introduced, only 15% of audiology services are accredited. Contestability of adult audiology services was found to impact on children's services as staff are moved from children to adult services to ensure the more lucrative adult market is not compromised. In addition, difficulties recruiting experienced staff was a concern for over 20 percent of respondents. The report is a sobering indication of the potential risks to paediatric hearing services posed by changes to our current approach. http://www.ndcs.org.uk/help_us/campaigns/our_current_campaigns/en gland/listen up.html#contentblock4
- All children continue to receive services through Australian Hearing so the sector
 is unable to give examples of where the new system for Hearing Services for
 CSO clients is failing. The transition of Hearing Services to the NDIS has not
 commenced. Our submission highlighted the need to test the risks that any
 changes our world-renowned system imposes, and we urge the Committee to
 make a recommendation that the risks to child and family outcomes be fully
 evaluated before any change is implemented. Refer Appendix 1 of our

submission.

- Parents need information and support from an independent source in order to make an informed decision. This must be someone who is knowledgeable about the needs of children with hearing loss and their families but unaligned with any service provider. The deafness sector is replete with strong methodological ideologies and opinions of service providers that do not serve parents well when they need to make informed decisions about their child. We are aware of numerous instances where the strong methodological views of service providers have nudged parents in a direction they are not comfortable pursuing. Current hearing disability groups such as Aussie Deaf Kids (ADK) and Parents of Deaf Children (PODC) are struggling for funds and limited in our capacity to deliver support as a result. Our future is uncertain under the NDIS. It is uncertain if we will be successful in gaining ILC funding to continue our work and deliver unbiased information and parent support.
- The Government has consistently reassured us that no child currently on the CSO program will be worse off after the transition of Hearing Services to the NDIS. We are very concerned that babies and children who are born after the transition period and who are ineligible for the NDIS will not receive the same level of services as their current counterparts. We want an equitable system for all children diagnosed with a permanent hearing loss into the future.
- Devices need to meet the clinical needs of the child so he/she can learn to listen
 and learn. The current CSO program allows for repair of failed or broken devices
 and replacement of lost devices. This issue has not been addressed in any
 quarter with the transition. Parents are increasingly nervous about any changes
 to assistive technology provision following the release of the ACCC report "Issues
 around the sale of hearing aids." https://www.accc.gov.au/media-release/hearingaid-sector-put-on-notice
- While most hearing parents want their child with hearing loss to talk, many also want to provide them with the opportunity to learn Auslan. This can enhance their ability to communicate and develop age-appropriate language. For a small number of children, spoken language is not an option for them. Most bilingual (English and Auslan) early intervention programs are provided by State Governments. We have seen the ACT Government move out of the early intervention space with the roll out of the NDIS in the ACT and are seeing similar changes in Queensland. We urge the Committee to investigate the future of bilingual early intervention programs currently provided by States and Territories and ensure that these services are not eroded. The Royal Institute for Deaf and Blind Children is the only NDIS provider currently able to provide families with the option for bilingual early intervention. The other early intervention providers discourage parents from signing with their children who are deaf or hear of hearing.

Early intervention providers for children who are deaf or hard of hearing have
expressed concern that funding levels for providers do not meet the true cost of
delivering a quality service. Inevitably, this will lead to a reduction in services, and
thus poorer outcomes for children. Adequate funding for service providers is
needed to ensure services can focus on quality service delivery and positive
outcomes for children who are deaf or hard of hearing and their families.

QUESTION ON NOTICE

Senator SIEWERT: I would like to go back to the review issue of plans and the comments you made about needs as a child develops. Have any of your members or have you come across the issue of a plan being suspended while it is being reviewed?

RESPONSE: Aussie Deaf Kids and Parents of Deaf Children have sought information from our parent members. No parent reported that their plan was suspended while being reviewed or during an appeal process. They were able to continue with services and utilise their allocated funding during both processes.

Your faithfully,

Ann Porter AM Aussie Deaf Kids Mark Wyburn
Parents of Deaf Children