Attachment A

Analysis of reference packages for children with a hearing impairment aged 0-6 years

This paper provides a summary of the work to date by the National Disability Insurance Agency's Office of the Scheme Actuary, to assist in the development of reference packages for children aged 0-6 years with hearing impairment who are participants of the NDIS. This work has included:

- A review of selected literature and evidence relating to interventions for children with a hearing impairment.
- Analysis of scheme data on participants with hearing impairment aged 0-6 years.
- Analysis of data collected on hearing impairment groups (including known risks to outcomes – KROs) for participants with hearing impairment aged 0-6 years.

Literature review

A literature review was undertaken which sought to identify the common features of good practice interventions for children aged 0-6 years with hearing impairment and provide information on models considered to be best practice, both within and outside the NDIA's remit. For example, a prominent feature within the literature is early screening, which is a responsibility of the health system.

The review noted that there is limited information available about best practice intervention models, with the majority of the literature being observational studies of children who are deaf or hard of hearing and/or their families. The lack of high quality research reflects in part the widespread recognition of the diverse needs of deaf or hard of hearing children and their families.

Out of the observational studies considered, the findings around best practice early intervention can be divided into four categories:

- Early screening and timely access to intervention
- The use of assistive technologies
- Family involvement and boosting the capability of the family
- Collaboration between qualified professionals.

However, no specific references were found in the literature regarding the *quantum* of support required.

Analysis of scheme data

Service providers supporting children with a hearing impairment in the NDIS (namely, the Shepherd Centre, Cora Barclay and the Royal Institute for Deaf and Blind Children-RIDBC) provided negative feedback on the adequacy of package amounts in current plans. Detailed analysis of participants in the NDIS aged 0 to 6 years with a hearing impairment was undertaken to investigate their feedback. This included understanding the numbers of participants, the types and amount of committed supports currently in plans, and the utilisation of these supports.

Key findings from this analysis included:

- Participants with a hearing impairment represent a small proportion of all participants aged 0 to 6 years in the scheme (3.5% at 30 September 2017) and generally have lower average committed supports than other disability groups ($13,200 compared with $16,100 for all 0–6 year olds in the scheme). This is not surprising giving the very high needs of some other children in the scheme (including intellectual, physical and neurological disabilities).
- The majority of committed supports in plans is for capacity building (87%).
- Overall, utilisation of committed support appears to be low, with 62% of participants having utilisation below what is expected based on how long plans have been in place.
- Participants receiving supports from Cora Barclay and Shepherd Centre have over 70% of their supports allocated to these providers. Participants receiving supports from RIDBC have a smaller portion (55%) allocated to RIDBC. For the remainder of funds that are not committed to these providers, most are unallocated to a particular provider (roughly 15-30% of total funds). It is also worth noting that service providers only see the proportion of the plan allocated to them. Hence, plan budgets may seem lower to service providers than they actually are, as participants have chosen not to allocate all the funds to the provider.
- The utilisation of plans and service bookings appears to be low across all three providers. For Cora Barclay, 92% of participants have utilisation lower than what is expected based on plan duration. This compares with 71% and 68% for RIDBC and the Shepherd Centre respectively.

Analysis of data collected on HIP-Q

Work was undertaken on a proposed Hearing Impairment Planning Questionnaire (HIP-Q) to assist with the development of reference packages. The HIP-Q allocates participants to a hearing impairment group (based on an audiology assessment) and then captures known risks to outcomes. The tool had not been externally validated or tested, and hence required additional analysis to confirm its reliability and validity as an objective measurement of function. The first step in this validation was the back-capture of data on current participants to test the overall impact on scheme sustainability. The questionnaire was collected on a representative sample of around 220 participants to effectively estimate the distribution of groups within the Scheme for comparison to expected, and testing of sustainability.

The back-capture of data was completed in December 2017. In particular, data was collected on participants supported by the three providers mentioned above, as well as a sample of other providers.

The sample data was completed by an audiologist based on a review of the participant's record and attached documentation. The quality of the sample data is heavily reliant on the quantity and quality of evidence provided in the participant's record and may be incomplete. In addition, the identification of additional supports for known risks to outcomes requires interpretation and some KROs were difficult or unable to be costed.

The HIP-Q has five proposed levels, ranging from HIP-A (severe or profound hearing impairment) to HIP-E (hearing impairment which does not require an individualised budget). Overall, 35% of participants were in HIG-A, 27% in HIG-B, 18% in HIG-C, and 20% in HIG-D. This distribution will continue to be monitored as more data is collected. Further analysis indicated that the most useful component of the HIP-Q in assisting with determining reference packages was the audiology assessment. Using this audiology assessment, along with the PEDI-CAT and guided planning questions, will result in a more consistent and appropriate distribution of packages across children then is currently resulting from the existing planning process. It is recognised that some negative feedback has been received about the PEDI-CAT in assisting with determining the plan budget, and it is important to acknowledge that the PEDI-CAT was never intended to be used in isolation of the guided planning (other assessment tools) in assisting with determining the plan budget. Further, using the PEDI-CAT and guided planning questions ensures consistency across children aged 0-6 years in the scheme. Lastly, Australian Hearing will still play an important role in assisting with determining access to the Scheme through audiology assessments.

The proposed reference packages vary by hearing impairment group and include supports for assistive technology, therapy and capacity building supports for the development of language and social skills, capacity building for parents/carers, and additional support for school transition. Planning guidance will be drafted in early 2018 based on the four groups, and the Agency's ECEI partners will assist in delivering this new approach.

Most importantly, the development of reference packages is a process of continuous improvement. The proposed packages for hearing impairment represent a starting point and these will be updated over time as more data and evidence on outcomes for children and costs of packages becomes available.