



Hear and Say
Opening worlds

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10th August 2017

Joint Standing Committee on
the National Disability Insurance Scheme

PO Box 6100
Parliament House
Canberra ACT 2600

PROVISION OF SERVICES UNDER THE NATIONAL DISABILITY INSURANCE SCHEME EARLY CHILDHOOD EARLY INTERVENTION APPROACH

To whom it may concern,

Thank you for inviting comment into the Inquiry into provision of services under the National Disability Insurance Scheme (NDIS) Early Childhood Early Intervention (ECEI) Approach. Hear and Say would also appreciate the opportunity to personally address the Joint Standing Committee at a public hearing to present further on the matters outlined within this submission.

In 2017, Hear and Say celebrates 25 years of providing hearing, speech and language support to children with hearing loss and their families. We are a not-for-profit organisation located in Queensland and a member of First Voice, the national voice for member organisations whose primary focus is the provision of listening and spoken language therapy services for children with hearing loss in Australia and New Zealand. Hear and Say has been a contributor to, and is supportive of, the separate First Voice submission which has been also been presented for this Inquiry.

The Hear and Say experienced transdisciplinary team comprises audiologists, speech and language pathologists, teachers of the deaf, occupational therapists, clinical social workers and physiotherapists who work with families to not only provide an end-to-end service package that meets families' health, education and disability needs; it also achieves a set of outcomes for these children/adults which allows them to interact in the community effectively like children/adults with natural hearing.

Our specialist transdisciplinary team assists each individual child and family using a coordinated approach, with a dedicated case manager or key worker who involves the family in all decisions related to their child's care.

With centres across Queensland, the evidence based programs at Hear and Say interface state-of-the-art hearing technology (digital hearing aids and implantable technology such as cochlear implants) with the Auditory-Verbal Therapy approach. Hear and Say has one of the largest paediatric hearing implant and listening and spoken language programs in Australia.

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In response to the invitation to comment, Hear and Say identifies three (3) key areas of opportunity as follows:

- Establishing Australian Hearing as the ECEI referral pathway for all children with a hearing loss.
- Implementing an accreditation model for Early Intervention Specialists.
- Introducing a tiered package approach for children with hearing loss - low, medium and high - to give families access to the full program of services based on the clinical needs of the child to ensure the best speech, language and communication outcomes.

Further comment on the Joint Committee Inquiry Terms of Reference are attached for your information and consideration. Please do not hesitate to contact Hear and Say if we may provide any further information or if there is an opportunity for Hear and Say to present to the Joint Committee.

Yours sincerely

Chris McCarthy
Chief Executive Officer



Submission to the Joint Standing Committee on the National Disability Insurance Scheme

Provision of services under the NDIS Early Childhood Early Intervention Approach

About Hear and Say

For the past 25 years, Hear and Say has been leading the way in pediatric early intervention services for children with a hearing loss. Our evidence based family centric approach utilising a trans-disciplinary approach with audiology, auditory-verbal therapy, occupational therapy, parent education/training and social skills development has enabled our children to live a life unlimited by their hearing loss. However this is only achieved through the family's ability to access the full spectrum of our specialist pediatric services which are tailored to the individual and changing needs of our children and their family's commitment and involvement in our ongoing program.

First Voice: The Future is Hear

Hear and Say is a member of the First Voice Alliance along with five other Australian and New Zealand Early Intervention Specialists for children with hearing loss. Hear and Say fully endorses the recent submission by First Voice: *'Sector Model: An Evidence-Based Approach to Early Intervention for Children who are Deaf or Hard of Hearing'* and its 9 key initiatives to ensure children with hearing loss can continue thrive in Australia.

Furthermore Hear and Say supports the national 'Breaking the Sound Barrier' campaign promoting that people with hearing health issues are heard by all levels of government. Hear and Say fully endorses its 6 key initiatives to ensure that 4,500 Australian children affected by hearing loss are identified and can access services.

Hear and Say welcomes the opportunity to present our experiences and recommendations at a public or private hearing.

The underlying NDIS issue we face – inconsistency of delivery

Throughout Hear and Say's experience with the NDIS, the common issue we have faced is the inconsistency in the interpretation of a child's Early Intervention needs by non-expert/generalist NDIA/ECEI staff. Every interaction with an ECEI service and/or NDIA planner is different based on their interpretation of the implementation of the NDIS and the funding available for children with hearing loss, turnaround time for plans, review of plans, allocation of funds and the way the plans are written. This makes it extremely difficult for us to:

- a) counsel our families through what is already a complex process and
- b) develop and implement internal processes and systems to support our families and to minimise the administrative burden we face in processing funding and invoicing arrangements.

The following outlines our experience in relation to the specific terms of reference.

Terms of Reference	Our experience	Actions
<p>The eligibility criteria for determining access to the ECEI pathway</p>	<p>Originally the NDIS did not cover all children affected by a hearing loss. This was evident in the case of "Owen" who after applying for NDIS funding was rejected on the basis that his disability 'was not significant enough'.</p> <p>Similarly with "Rachael" who had Microtia and Atresia resulting in a unilateral hearing loss who didn't receive any funding.</p> <p>We whole heartedly agree with recent changes to the eligibility criteria, allowing all children with a hearing loss to access services under the NDIS.</p> <p>This review has allowed "Owen" and "Rachael" to access services.</p> <p>However, the variability in the type and amount of funding/services approved in NDIS plans for children with similar needs by non-expert/generalist staff in ECEI remains a significant concern. This appears to occur as the NDIA planners are focussed on counting transactions with services rather than a "package" amount where services can be tailored to meet changing individual developmental needs by the experts who understand how to achieve communication outcomes for children with hearing loss.</p>	<p>Continue with new eligibility criteria to ensure all children with hearing loss can access support services.</p> <p>Ensure new criteria is effectively communicated to all planners involved in ECEI.</p> <p>Appoint expert referral managers to guide the referral pathway for families of children with hearing loss and work towards standardising a package of funding for children with hearing loss (such as Australian Hearing).</p> <p>Consideration be given to allocating "comprehensive package funding" to children with hearing loss to receive services from organisations "accredited" to provide multi-disciplinary programs with proven outcomes. This could be funded on a comprehensive package basis permitting pro rata monthly invoicing.</p> <p>Provider accreditation criteria to be developed in consultation with relevant parties.</p>
<p>The service needs of NDIS participants receiving support under the ECEI pathway</p>	<p>Our children and families are currently accessing audiology, auditory-verbal therapy, occupational therapy, social skills and parent education/training in our early intervention services. Through the combination of these services our children are able attend mainstream school. Our research demonstrates that the unique combination of the multi-disciplinary approach provides the best language and communication outcomes for children with hearing loss.</p> <p>Prior to the NDIS, families engaged with Hear and Say received a program of services tailored to their individual and changing needs. Under NDIS, this has changed, with funding allocated in a way that allows families and/or NDIS planners to cherry pick the services they</p>	<p>Services provided in the early intervention setting should be considered as a 'program' rather than individual transactions.</p> <p>While some families are able to clearly articulate the needs of their child and the services that their child needs, there are many families that struggle to adequately communicate their needs and risk not receiving the funding that is required to support their child. We have found this has led to the inconsistencies in the funding allocated by NDIS/ECEI.</p>

Terms of Reference	Our experience	Actions
	<p>want thereby impacting on the long term outcomes for the child. Hear and Say has more than 25 years' experience in ensuring language outcomes for deaf children and this is being compromised by the transactional nature of the NDIS.</p> <p>Hear and Say supports the concept of 'Choice and Control' for our families. However if families are not able to access the full program of services, we cannot guarantee the language outcomes for a child. If this level of service variability continues we believe we will start to see reduced outcomes for children with hearing loss in Australia.</p>	<p>Introduce a tiered package approach – low, medium and high – to give families access to the full program of services based on the clinical needs of the child to ensure the best language and communication outcomes.</p>
<p>The timeframe in receiving services under the ECEI pathway</p>	<p>The NDIS commenced rolling out in Toowoomba in January 2017, however Hear and Say still has a number of families waiting to receive their NDIS plans.</p> <p>Further to this, we understand the planning process takes a number of weeks. Hear and Say does not wait for plans to be confirmed as we do not want children to fall behind. However, this places an enormous financial burden on Hear and Say that we are not compensated for and cannot sustain indefinitely.</p> <p>A specific example of the lengthy process is "Elise", who we identified as having a delay through one of our prep readiness programs. It took 9 months for "Elise" to be able to access services. Without support for 9 months, "Elise" would have fallen further behind her classmates and would not have been ready to enter Prep.</p>	<p>Hear and Say provides diagnostic services but the challenge is that families and/or Hear and Say needs to fund the timely diagnoses and initial supports prior to the approval and implementation of an NDIS plan. This cannot be sustained and consideration should be given to provide better pathways for families to access experts (not just non-expert/generalist ECEI/DIA staff), particularly in the early diagnosis period.</p> <p>Introduce immediate funding packages to assist families to seek reimbursement for providers and families to recoup funds expended for timely diagnoses and prompt access to services.</p>
<p>The adequacy of funding for services under the ECEI pathway</p>	<p>The rate of \$175.75 covers normal face-to-face clinical sessions, however this rate is not adequate for diagnostic assessment sessions, which take longer and require non face to face time for report writing. Assessments and reports are essential for communication with families and other medical professions in a multi/trans-disciplinary approach.</p> <p>Current NDIS plans cover the cost of an annual assessment. However, best practice in early intervention for children with hearing loss is to undertake biannual assessments to allow clinicians</p>	<p>Create a new rate specifically for assessments. Create a new rate specifically for report writing.</p> <p>Update assessment protocol to allow plans to include funded biannual assessments for children with hearing loss.</p>

Terms of Reference	Our experience	Actions
	<p>to review a child's progress and adjust services as appropriate in order for a child to achieve optimal results.</p> <p>The cost of paediatric services needs to take into consideration 'do not attend' or appointment no shows. If a family does not attend an appointment it comes at the cost to Hear and Say as well as a missed opportunity for another child to receive services.</p>	<p>Fund a claimable amount for families who don't show for appointment.</p> <p>To overcome this issue, allow organisations to invoice for a "program" of services rather than per appointment or transaction.</p>
<p>The costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants</p>	<p>On average Hear and Say will spend up to 7 hours with a family to confirm a diagnosis of a child's hearing loss. This process includes audiology assessments, counselling and trial listening and spoken language lessons. Currently we are unfunded for this time and it is not sustainable for Hear and Say to continue this important work with families.</p>	<p>Similar to previous comment, introduce the capacity for Early Intervention providers to back claim for services rendered to confirm a diagnosis.</p> <p>Introduce immediate funding packages to assist families to seek reimbursement for providers and families to recoup funds expended for timely diagnoses and prompt access to services.</p>
<p>The evidence of the effectiveness of the ECEI Approach</p> <p>And</p> <p>The principle of choice of ECEI providers</p>	<p>Hear and Say's 25 years of Early Intervention experience seeks to identify children at risk and intervene prior to the onset of a delay to ensure children to reach their developmental milestones.</p> <p>However, Hear and Say believes there is a conflict of interest with ECEI partners in both managing plans and providing services. This is important, given the values of 'choice and control' of the NDIS. Families are overwhelmed and aren't always sure what they need to look for. We believe the role of the ECEI is to be an impartial information source for families and refer families to local providers. It should not be the role of the ECEI to also clinically diagnose and provide clinical services.</p> <p>Hear and Say advocates that no child should have to wait for services. They also deserve to receive services from experts in the field. Hear and Say does not believe that ECEI's as generalists should deliver any services to children, rather, they should be familiar with the services already established in the local area and refer children on to the experts.</p>	<p>Establish referral pathways for children who do not require NDIS plans to receive services from paediatric experts.</p> <p>Establish Australian Hearing as the ECEI referral pathway for all children with a hearing loss</p>

Terms of Reference	Our experience	Actions
	<p>Furthermore Hear and Say understood that ECEI were going to be selected based on their knowledge of the region in order to provide the best services to families. However where ECEI providers have been appointed, many are from outside the region and it is evident that they have little local knowledge and limited paediatric service expertise.</p>	
<p>The robustness of the data required to identify and deliver services to participants under the ECEI</p>	<p>Hear and Say has traditionally used a positive or 'ability' based model in reporting service encounters to families. This positive approach has the added benefit of helping families work through the grief of the diagnosis for their child.</p> <p>The NDIS reporting model uses a deficit or 'disability' model. Hear and Say has found that this deficit approach impacts a family emotionally as they need to reframe their perception of their child's ability. Hear and Say families experience significant grief upon diagnosis, however our work allows them to see the wonderful outcomes their children can achieve. Upon going through the 'deficit' model for NDIS reporting, some of our families have had to re-live the grief of the initial diagnosis.</p> <p>To help families on their journey to communication outcomes for their deaf child, Hear and Say continues to provide families with an "ability" based report for their information. But this impacts Hear and Say from an administrative perspective as it creates a need for the organisation to produce two reports. One for the family and one for NDIS, thereby doubling the administrative workload. The cost of this is not sustainable for Hear and Say.</p>	<p>Give consideration to the reporting requirements under NDIS to focus on the abilities of children rather than deficits.</p>
<p>The adequacy of the information for potential ECEI participants and other stakeholders</p>	<p>Information about ECEI's are not easy to find or understand.</p> <p>With more players in the sector looking to benefit from the NDIS, families are becoming overwhelmed with information. The process is very complex and exhausting for families. Some families are disappointed upon receiving their plan, but due to their experience, do not enter the review process as they do not want to go through it again.</p>	<p>Establish a simple referral system for all children with a Hearing loss through one provider – Australian Hearing.</p> <p>Provide "packages" for children with hearing loss based on high, medium and low intensity.</p>

Terms of Reference	Our experience	Actions
The accessibility of the ECEI Approach, including in rural and remote areas	<p>There is a lack of specialist services in rural and remote communities. In order for Hear and Say to adequately support families, both the providers and the families need to travel. However the travel allowances, which may be adequate for other parts of Australia, are not satisfactory for Queensland due to the size and nature of the State.</p> <p>We have also noted that families were previously able to use BetterStart funding to purchase equipment and resources, such as computers to support telepractice. This is not possible through NDIS and hinders families when they require the technology to access telepractice services.</p>	<p>Increase funding for clinicians to travel to see families.</p> <p>Increase funding for families to travel to attend clinical services.</p> <p>Improve funding for technology to assist with access to Telepractice services (such as laptops).</p>
The application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services	No comment	
Any other related matters		
Financial impact of funding	<p>The payment processes for each of the funding mechanisms (self-funded, intermediary organisation or NDIA) are different, which affects Hear and Say's financial management. For example the payment process on the NDIA portal is approximately 48 hours, where our experience with intermediary bodies can be up to 45 days with Hear and Say using additional resources to chase payments. Self-managed families pay for their services directly to Hear and Say. It is preferable for payment to occur at the time of service, however some families require invoices. Often Hear and Say has to chase families for invoice payment. This process is again complex and lengthy and is a significant administrative burden to our organisation.</p>	<p>Establish a package payment process to reduce administrative burden of ongoing payments.</p>

Terms of Reference	Our experience	Actions
Time and cost associated with setting children up with services is now higher	Our experience is that it is now taking Hear and Say significantly longer for families to access funding. This process is adding stress to our families. Furthermore it is adding more pressure on resources within Hear and Say with increased administration per family. This puts Hear and Say in the position to either make families wait while the process is being undertaken and potentially risk a further delay for the child, or implement services to benefit the child and family and carry the loss. The latter is not sustainable.	
Sharing plans	We have experienced instances where parents do not wish to share their plans. We completely understand it is their 'choice', however if we are not aware of the plan's details including the goals, we will not know what services have been approved or how to best cater to the needs of the child.	Encourage all families to share their plans with all service providers.

Hear and Say's Key Recommendations:

1. Establish Australian Hearing as the ECEI referral pathway for all children with a hearing loss.
2. Implement an accreditation model for Early Intervention Specialists.
3. Introduce a tiered package approach for children with hearing loss – low, medium and high – to give families access to the full program of services based on the clinical needs of the child to ensure the best language and communication outcomes.