

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

**Inquiry into the provision of hearing services under the
National Disability Insurance Scheme**

From First Voice

Submitted by:

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1. Introduction

This is a supplementary submission from First Voice following the public hearing of the Joint Standing Committee on the NDIS inquiry into the provision of hearing services under the NDIS held in Melbourne on 20 February 2017.

Its purpose is:

1. to reinforce the urgency of finding solutions to key policy and funding issues affecting hearing-impaired children under the NDIS; and
2. to promote further consideration of an alternative services and funding model that is specifically designed to support evidenced-based, outcomes-focused early intervention into the future.

2. Current situation

Current outcomes and return on investment

Australia currently enjoys world-class arrangements for identification and early intervention for children who are deaf or hearing impaired. These have been developed over many years and result in extraordinary outcomes for deaf children with:

- 95% of early intervention graduates from best-practice programs attending mainstream schools
- 86% completing year 12
- 82% progressing to higher education and
- 77% achieving regular paid employment¹

These results are being achieved through multi-disciplinary early intervention programs with an overall 2.2 to 1 benefit to cost ratio, representing a return of \$2.20 for every \$1 invested – and a return of \$4 to \$1 in relation to government investment.²

Unresolved NDIS policy and funding issues

However, these value-for-money outcomes are at risk under the NDIS. Since the new scheme started in 2013 a wide range of serious policy and funding issues have emerged following the transition of children's hearing services to the NDIS. These issues relate to eligibility; scope of services; duration of services; referral arrangements; inconsistencies in funded plans; unresolved interface issues with health and education and a substantial shortfall in participant funding compared with service costs.

Individually and collectively these pose a real threat to whole-of-life outcomes of future generations of deaf children in Australia. Notwithstanding concerted efforts over a long period, none of these issues has been resolved. This suggests that there may be a fundamental underlying incompatibility between NDIS policy and funding arrangements and requirements for successful early intervention for hearing-impaired children.

Urgency and impact

As at March 2017 only 235 hearing-impaired children have joined the NDIS of whom 150 are on service with the Cora Barclay Centre in the NDIS Children's Trial Site in SA. On current estimates a further 4,000 children are due to join the scheme in the next 12 to 24 months. Urgency is needed to fix these problems or a generation of hearing-impaired children will have worse outcomes than prior to the NDIS.

¹ First Voice, Report on education, employment & social outcomes of First Voice member centre graduates (18-

² Deloitte Access Economics, Cost-benefit analysis of First Voice's early intervention program – A sound investment, January 2017, <http://www.firstvoice.org.au/wp-content/uploads/2016/09/First-Voice-Deloitte-Access-Economics-Cost-Benefit-Analysis.png>

3. Specific solutions to immediate and urgent issues

In terms of daily operations and child/family outcomes, the following solutions are needed:

1. Mandate evidence-based clinical protocols including a guided pathway

It is essential that a national guided referral pathway to expert providers with proven outcomes be introduced as a matter of urgency.

This matter has frequently been raised with the NDIA during the NDIS Children's Trial in SA, and subsequently, but to no avail.

The extraordinary short and long term outcomes achieved by hearing-impaired children in Australia are predicated on the continuation and strengthening of current best practice clinical guidelines as detailed in a number of submissions to the Committee, including First Voice's original submission.

Based on service providers' knowledge and experience of the different referral arrangements across Australia, it should not be difficult to design a national guided referral pathway that is neutral, family friendly, transparent and accountable.

First Voice would be happy to work with the Royal Institute of Deaf and Blind Children (RIDBC) and other interested parties in drafting a protocol for consideration by the Committee and to submit it in time for the Committee's consideration.

2. Address NDIS funding shortfalls and payment arrangements

An urgent review of funding arrangements is urgently needed. This could be done either by adjusting existing arrangements or by introducing an alternative funding mechanism specifically for early intervention programs of the kind provided for hearing-impaired children.

Current NDIS funding arrangements result in a gap of \$6-8K per child per year between participant funding and the costs of early intervention program delivery. For a service provider with 250 children this represents an annual revenue shortfall in direct service delivery costs of \$1.5-2M. This is clearly not sustainable. However this issue has persisted for 18 months (since September 2015) and remains unresolved.

Two possible solutions have been flagged:

1. a proposal discussed by the Expert Reference Group to revise NDIS items of service relevant to complex, multi-disciplinary early intervention programs to include an hour of "integrated support" for every hour of direct face-to-face therapy; and
2. the initial South Australian solution in which the NDIA simply agreed to provide families with sufficient funding to cover the costs of their chosen early intervention communication program subject to certain conditions including transparency of costs; scaling of services in line with the child's measured progress in speech, language and social development; immediate passing back to the NDIS of savings from scaling down; annual reporting on program outcomes; and openness to audit at the discretion of the NDIA.

While it is for the NDIA to determine how best to proceed, First Voice sees advantages in the latter approach which would essentially be an outcomes-based funding approach similar to that which operated successfully with the Cora Barclay Centre during the first two years of the NDIS Children's Trial.

To date service providers have “carried” these revenue losses without refusing or reducing services to hearing-impaired children because of their commitment to children’s outcomes. They have also been absorbing the cost of providing unfunded services to children during the period between the child’s commencement of service and NDIA provision of funding to the child’s family. With some providers these unfunded service costs run into hundreds of thousands of dollars.

Under the NDIS Act the NDIA is prohibited from making retrospective payments to families or providers for services delivered prior to a child receiving a funded plan. This prohibition is inappropriate where immediate commencement of early intervention is necessary for the achievement of optimal outcomes for the child – as is the case with hearing-impaired children.

The NDIS Act, rules and terms of business need to be amended to address the problem related to retrospective payments where immediate commencement of early intervention is necessary – in the case of hearing impaired infants and children.

3. Include children with unilateral hearing loss

Under early intervention principles all children with diagnosed hearing loss should be automatically eligible for early intervention funding.

It is self-evident that the situation of children with unilateral or mild bilateral hearing loss (probably less than 500 new cases per year) is fundamentally different from that of the very large number adults with similar hearing loss acquired in later life after they have learnt to speak, been to school, become employed and so on.

As per previous submissions to the Committee:

- There is strong evidence that people with unilateral hearing loss and mild bilateral loss are at significant risk of diminished communication capability, poor educational outcomes and social emotional and psychological problems. It is estimated that about 30% of these children will suffer significant impairment. Current research in this field suggests that this statistic will rise.
- The purpose of early intervention is to maximise people’s well-being and to reduce service requirements and costs in later life. Thus it makes social and economic sense to provide children with unilateral hearing loss with the necessary services to achieve these goals.
- The cost of early intervention for children with unilateral hearing loss – which is predominantly short-term parent education and training followed by ongoing monitoring and assessment where appropriate – is low, often as little as of \$4-6K in the first instance.

Early intervention for children with unilateral hearing loss is inexpensive and an effective approach to minimising adverse impacts a significant number of children. It makes good sense in terms of improved life outcomes, avoided costs, and overall cost benefit.

The root problem (and potential structural solutions)

Key issues to date

Over the past two months industry and NDIA attention has focused on:

1. **eligibility:** specifically, the need for children with unilateral hearing loss and mild bilateral loss to be automatically eligible for funding for early intervention
2. **evidence-based clinical protocols:** specifically, a neutral, national guided pathway for newly diagnosed children to expert service providers with proven outcomes and
3. **funding:** specifically, closing the gap (estimated at \$6-8K per child per year) between participant funding for expert, multi-disciplinary early intervention and the actual cost of services.

However Committee questioning in Melbourne has directed attention to identifying the root problem behind all of these issues and addressing what might need to be done to achieve a broader and more long-term sustainable solution.

The root problem

Reflecting on the Committee's questions, First Voice believes that the root problem is that NDIS policies and funding arrangements are fundamentally at odds with what is required for evidenced-based early intervention programs to achieve and sustain high-level client outcomes.

The NDIS policy and funding arrangements for the full scheme have been developed primarily for people with disabilities requiring lifelong personal services and supports. These arrangements are inconsistent with basic requirements for effective multi-disciplinary listening and spoken language early intervention. It is therefore not surprising that these arrangements have given rise to the operating policy and funding issues that have defied resolution over an extended period of time.

The five main areas of disconnection between NDIS generic policy and funding arrangements and early intervention requirements are:

1. The main scheme principle of **participant choice and control** **conflicts with** the requirement for evidence-based early intervention to adhere to clinical best practice protocols to achieve optimal client outcomes.
2. The need for the main scheme to **limit Tier 3 funding** to people with significant, lifelong needs for personal care and support **conflicts with** the fundamental objective of early intervention to anticipate and identify health and disability needs at all levels and to prevent or reduce the need for lifelong supports to the greatest possible extent in the interests of the well-being of individuals and the national economic interest (the insurance principle).
3. **Planning and funding decisions** in the main scheme lie with NDIA planners (essentially an administrative function) and this **conflicts with** the fundamental need in early intervention for decisions about client service plans to be made by the clinical team in the light of all available evidence and in conjunction with the child's family.
4. **Funding allocations** in the main scheme are comparative and based on assessed functional impairments and this **conflicts with** the basic early intervention requirement for funding to be sufficient to meet the cost of a participant's chosen intervention for as long as is prudent and necessary to minimise functional impairment and maximise lifelong social and economic independence.
5. **Main scheme funding and payment arrangements** are based on inputs, are transactional, administratively burdensome for families and their providers and **undermine** the close relationship between families and providers that is necessary in intensive, inter-connected, family-centred early intervention. Wherever possible early intervention programs should be funded on outcomes, not inputs.

Potential organisational and public policy options/solutions

The NDIA's approach to date has been to attempt to minimise the impact of various issues by "massaging" solutions into the policy and funding settings within the main scheme. This hasn't worked. So if an "issue by issue" approach within existing NDIS policy and funding settings doesn't work, we need to look elsewhere – potentially to alternative organisational or structural solutions.

These could potentially include:

1. **Developing an alternative policy and funding model under the NDIS** designed specifically for early intervention programs meeting specified criteria on outcomes, cost-benefit, financial transparency, and accountability. This would be designed initially to meet the requirements of early intervention services for hearing-impaired children, but would also be a model for other comparable EI programs/providers.
2. **Assigning primary responsibility in this area to the health portfolio** under which current clinical protocols have been developed and which is demonstrably a more conducive environment for the programs provided by evidence-based multi-disciplinary providers. To be successful, this arrangement would require adequate funding and nationally consistent referral arrangements across states and territories (which is a weakness in the current health system).

Parallels with other healthcare models and best practice

To guide this process of review and consideration, we can also look to alternative models of healthcare practice where there are comparable aspects of structure, practice and/or communication.

There are some parallels in the early intervention model for hearing impaired children and the multi-disciplinary rehabilitation teams working in spinal injuries or head injuries. This specifically relates to the close interconnection between members of the team, the team and the patient/client and family, and the team and external providers. Similarly, there are parallels with some Commonwealth health funded centres of national excellence.

Conclusion

Currently, fundamental problems exist in relation to the children's hearing services under the NDIS. These issues present real threats to deaf children's outcomes and to the goal of optimising their lifelong social and economic independence.

Current NDIA initiatives to address these issues, including reference packages and early childhood early intervention access partners, are unlikely to provide definitive or long-term solutions. The root problem is that NDIS policy and funding settings are incompatible with basic requirements of effective early intervention and do not work with complex, expert, multi-disciplinary early intervention programs such as those provided hearing-impaired children.

As at March 2017 only a small number and proportion of NDIS-eligible hearing-impaired children are in the NDIS. There is an urgent need to resolve these matters, if only on an interim basis, before the scheme is rolled out across Australia to the remaining 3,500-4,000 children who are deaf or hearing impaired.

While specific solutions are needed to address some immediate and urgent issues, these will not negate the need to address the broader structural fit and alignment of early intervention for children with hearing loss within the NDIS.

The best way forward is to develop an outcomes-based funding model for hearing-impaired children that is designed to be applicable more widely across the early intervention sector in relation to evidence-based programs achieving real outcomes with a positive cost benefit.