

A CONCIERGE MODEL FOR THE NDIS A NATIONAL SUPPORT PROGRAM FOR CHILDREN WITH HEARING LOSS

THE PROPOSAL

Australia has some of the best systems in the world for supporting children with hearing loss. However, only 50% of children with a permanent hearing loss currently access the specialist early intervention services they require. This results in these children entering school without the language and literacy abilities of their peers. The social and economic losses arising from this leakage exceed \$250 million.

First Voice proposes that the Australian Government pilot a concierge-style model based on the learnings of the successful Queensland Hearing Loss Family Support Service. The pilot program would be conducted in NSW and support families and children in their journey from fitting through to engagement with an appropriate specialist service. The estimated annual cost of the pilot in NSW is \$851,500, with a total cost over three years of \$3.1 million (including evaluation and reporting costs). Based on the Queensland experience, the percentage of children failing to reach a specialist early intervention provider could be expected to reduce from 50% to 25%. A 50% improvement on the current national situation for this cohort could be delivered with an estimated cost:benefit in excess of \$135 million.

BACKGROUND

Hearing loss is one of the first diagnoses of a disability that a newborn child is likely to receive and is the most common disability at birth. In Australia, approximately 1 in 1000 children are identified at birth with a hearing loss. This increases by another 2 per 1000 by the time they reach 5 years old, with 1 in 300 children having permanent hearing loss at school entry. This hearing loss has significant impacts on a child's social inclusion, academic success and future employment prospects. Over the past 70 years, Australia has developed world-leading practices in identifying and supporting these children but, while the universal newborn hearing screening reaches 98% of children, only 50% of children with a permanent hearing loss reach the specialist early intervention providers they need – a provider who delivers evidence-based specialist, targeted, multi- or trans-disciplinary therapy supports for children with hearing loss and their families.

This leakage from the system often results in these children entering school without the language and literacy abilities of their peers, putting them significantly behind in their educational (and then employment) attainment.

CURRENT SITUATION

Children with normal hearing start hearing around halfway through pregnancy, stimulating the particular part of their brain responsible for hearing & listening, i.e. the auditory cortex. As a result, by the time they are born, children with hearing loss are already delayed by five months in key aspects of their brain development. An immediate and specialist response is required to prevent significant lifelong impacts for the child. The key elements of this response are:

1. Rapid detection and diagnosis
2. Early and effective provision and fitting of hearing devices
3. Early and effective provision of specialist early intervention therapy

The system in Australia designed to deliver these elements for a child born with hearing loss is depicted in Figure 1 below. The process relies on coordination between the State health system, Hearing Australia

(part of the Federal Hearing Services Program) and the National Disability Insurance Scheme. Each element of the system functions well, and each leads the world in its effectiveness, however without a system taking overarching responsibility many children do not complete the pathway.

Figure 1: Current Referral System for children born with Hearing Loss



For the two-thirds of children who develop their hearing loss *after* birth, the system is poorly defined and there is no clear referral pathway into diagnosis or from diagnosis. As a result the proportion of these children ‘slipping through the cracks’ is much higher.

While more than 4,000 children aged up to 6 years are supported by Hearing Australia, less than 2,000 are accessing the specialist early intervention services they need, with many children entering school with poor listening skills and spoken language delays that significantly hamper their learning and literacy development impacting school performance, social development and employment.

With an estimated net cost to the community of \$520,000 (\$464,712 in \$2015) per annum for each child not receiving specialist early intervention therapy¹ the social and economic losses arising from this problem exceeds \$250 million¹.

There is a simple solution to this issue.

SOLUTION

Learning from the success of the Queensland Hearing Loss Family Support Service, there is a clear and cost-effective way to address the issue:

- Employ Family Support Officers, responsible from supporting families from the time of diagnosis through to engagement with a suitable early intervention provider, located in paediatric specialist hospitals and Hearing Australia paediatric centres
- The Family Support Officers support families to access Hearing Australia, the NDIS and then their chosen specialist therapy provider, suitable for the goals the family has for their child

The approach addresses the leakage in the system by working with families to link them to their device and funding programs, while guiding them on to an evidence-based specialist early intervention service that meets their needs and reflects their choices.

Outcomes can be measured on engagement levels with specialist services and family satisfaction with those services.

¹ Deloitte Access Economics, Cost-Benefit Analysis of First Voice's Early Intervention Program (2017)

ESTIMATED COST TO GOVERNMENT

The estimated cost to Government for the pilot is \$851,500 per year, with additional funding for evaluation and reporting to provide a 3-year total cost of \$3.1 million:

Role	FTE	Employment and on-costs	Total cost
Family Support Officers	4	\$125,000	\$500,000
Regional Manager	1	\$155,000	\$155,000
Non Salary Costs		30%	\$196,500
Total per-annum			\$851,500
<i>3 year operating costs</i>			<i>\$2,554,500</i>
Evaluation & reporting costs			\$550,000
Total cost of 3-year pilot			\$3,104,500

The national cost of the full program would be \$2.6 million per year:

Role	FTE	Employment and on-costs	Total cost
Family Support Officers	12	\$125,000	\$1,500,000
Regional Managers	2	\$155,000	\$310,000
National Manager	1	\$190,000	\$190,000
Non Salary Costs		30%	\$600,000
Total per-annum			\$2,600,000

BENEFIT TO THE COMMUNITY

The per-child economic benefit from a child with hearing loss receiving timely and appropriate specialist early intervention therapy is approximately \$520,000 (Deloitte, 2017 op.cit., \$464,712 in \$2015). With less than 50% of children with hearing loss accessing the required specialist therapy, the potential benefit from the program exceeds \$275 million.

EVIDENCE THE PROGRAM WORKS

The program has been designed based on the successful Queensland Hearing Loss Family Support Service. This service is offered to the families of all children aged birth to six years in Queensland who receive a “direct refer” result on newborn hearing screening or are diagnosed with a permanent hearing loss.

ALIGNMENT WITH ROADMAP FOR HEARING HEALTH

The Roadmap for Hearing Health was delivered to the Federal Government in February 2019. Strongly supported by the sector, it articulates key initiatives and priorities for the Government. Implementing the Concierge Model will enable Government to address key elements of the Roadmap, specifically:

- Page 5, Priority 7: “There is a smooth transition for clients from the Hearing Services Program (HSP) to the NDIS, with a particular focus on vulnerable clients currently receiving services through the CSO component.”
- Page 14, Key action 2: “Implement a consistent and standard pathway for paediatric referral and services, including a single, national point of referral for children post early-identification of hearing challenges.”

Most importantly, it reflects the objective of ensuring there is no child “slipping through the cracks” as enunciated throughout the Roadmap.

ALIGNMENT WITH THE NDIS PRINCIPLES

The NDIS is based on the following four insurance principles:

- The funding base required is determined by the reasonable and necessary support needs of the participants;
- The NDIS seeks to minimise lifetime support costs by investing in people early to build their capacity and optimise their lifelong social and economic independence;
- The NDIS will invest in research and encourage innovation; and
- The NDIS has the ability to act at the systemic level, as well as fund individual support needs.

Overall, the financial sustainability of the NDIS is predicated both on significantly reduced costs of lifelong support and care (including disability pension payments) through effective, evidence-based early intervention as well as significantly increased national economic benefit through increased employment of people with disabilities.

The program is aligned with these principles. It:

- Ensures that children are linked with early intervention services based on their support needs;
- Minimises lifetime costs by maximising the independence and social inclusion of children;
- Optimises future employment of children with hearing loss, with associated long-term economic benefit;
- Allows rapid adoption of innovation and best practice through supporting families’ choice; and
- Integrates the activities of the Health and NDIS systems to better support the children.

The multidisciplinary service delivery of specialist early intervention services supports each child’s overall development, including those with additional disabilities. The use of educators, speech therapists, auditory verbal therapists, occupational therapists, physiotherapists, psychologists and audiologists with children and their families enables a “whole of child” family-centred approach to be taken and supports the development of the early building blocks and skills for children with additional needs. Further, given the strong networks that specialist early intervention services have throughout the areas in which they operate, they provide a significant support in the cross-referrals of children to other specialist services.

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