

IMPROVING THE NDIS FOR CHILDREN WITH HEARING LOSS - COMPREHENSIVE HEARING INTEGRATION PROGRAM 'CHIP'

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 specialist early intervention services. 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 implement a 'Comprehensive Hearing Integration Program' (CHIP). Based on the successful Queensland Hearing Loss Family Support Service, CHIP would be a national program to support families and children in their journey from diagnosis through to engagement with an appropriate specialist service.

The estimated annual cost of the program is \$3.1 million. 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 situation for this cohort could be delivered with an estimated cost: benefit in excess of \$135 million, representing a benefit: cost ratio in excess of 40:1.

Funding for CHIP would be provided from within the current NDIS ILC allocation. It is proposed to be implemented via a tender, open only to organisation(s) independent from any early intervention provider or Hearing Australia and able to provide expert unbiased and targeted supports and advice for families.

BACKGROUND

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. 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 a specialist early intervention provider – 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.

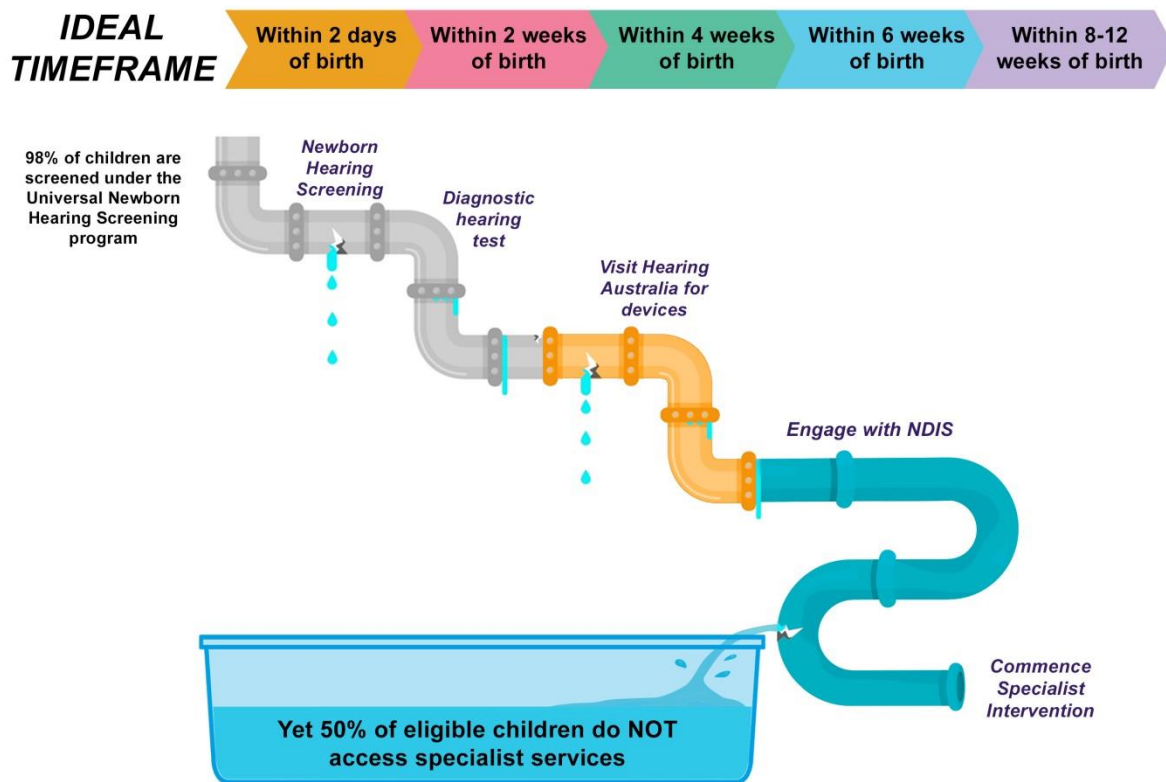
CURRENT SITUATION

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 is depicted in Figure 1, below. The universal newborn hearing screening program leads the world in its reach, screening approximately 98% of all children born in Australia. The pathways, processes and timeframes put in place for the health system to conduct the diagnostic testing and then to refer to Hearing Australia for hearing devices are all an integral part of the system's success. However, while more than 4,000 children aged up to 6 years are supported by Hearing Australia, less than 2,000 are accessing specialist early intervention services, 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.

Figure 1: Current Referral System for Children with Hearing Loss



With an estimated net cost to the community of \$371,000 per annum for each child not receiving specialist early intervention therapy¹ the social and economic losses arising from this seepage exceeds \$250 million.

There is a simple solution to this problem.

REQUEST OF GOVERNMENT

The request of Government is to implement a national 'Comprehensive Hearing Integration Program' (CHIP). Based on the successful Queensland Hearing Loss Family Support Service, the program would support families to access each step of the system, outlined above, addressing the leakage in the system by working with families to link them to diagnosis, device, and funding programs, while guiding them on to an evidence-based specialist early intervention service that meets their needs and reflects their choices. The service delivery will recognise the family-centred care required to support families during a vulnerable time, while ensuring that families have choice and control throughout the process.

Elements of CHIP would include:

- 20 FTE² Support Officers working directly alongside families across Australia, with workforce allocation based on population/demographics, plus a small additional FTE allocation for supervision and management support.
- The organisation(s) responsible for employing CHIP staff should be independent from an part of the system, including any early intervention provider to ensure unbiased and targeted supports and advice for families.
- Based outside any service deliverer (including Hearing Australia) will ensure the support and advice is solely focused on providing informed choice and control for families, uninfluenced by any funding source.

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

2. 20FTE is based on a per-capita basis, based on 1 FTE per 1,200,000 people and derived from the Queensland Hearing Loss Family Support Service model.

- Referrals from the various State/Territory Health screening or diagnosis processes (whichever is appropriate) to ensure family engagement with Hearing Australia, then the NDIS early intervention partner, and then specialist early intervention services. Supports for families would commence from the first point at which a possible hearing loss had been identified, through to three months after the engagement with a specialist early intervention provider.
- The hearing services sector in each State/Territory will form part of the induction, training and support for staff in the CHIP program, ensuring those staff have an in-depth understanding of the service offerings available.
- CHIP would work across all parts of the country, including regional and remote locations to ensure access for all Australian children with hearing loss to the best possible supports.
- As recommended in international protocols (e.g. similar to those of the American Speech-Language-Hearing Association (ASHA) Joint Committee on Infant Hearing Position Statements on Principles and Guidelines on early hearing detection and reporting), these arrangements should be supported by a regime of benchmarks, quality indicators and performance monitoring requirements.

The CHIP staff would:

- Work with and receive referrals from the state-funded health screening or diagnosis services;
- Contact families to help link them with the various agencies and organisations to ensure they obtain the supports they require;
- Facilitate family choice and control by also providing documentation to support decision making, interpreting the offerings and outcomes of the various service providers;
- Support families to engage with each stage of the process, following up after each stage;
- Develop an understanding of the needs, goals and aspirations of each family to help them engage with the specialist early intervention program to best suit their needs;
- Facilitate the effective progression for families through each stage of the system, ensuring all supports are provided within accepted timeframes; and
- Provide feedback to all parts of the hearing services system for children about the family experience in accessing supports.

Estimated Cost to Government

The estimated cost to Government is \$3.1 million per year. This has been calculated from:

<u>Role</u>	<u>FTE</u>	<u>Grade</u>	<u>Assumed salary</u>	<u>Salary cost</u>
Program Manager	1.0	APS level 6	\$100,000	\$100,000
Program Assistant	1.0	APS level 3	\$70,000	\$70,000
Regional Supervisor (QLD/NT; NSW/ACT; VIC/TAS; SA/WA)	4.0	APS level 5	\$85,000	\$340,000
Support Officers	20.0	APS level 4	\$75,000	\$1,500,000
Total	26.0			\$2,010,000
Non-salary employment costs			35%	\$703,500
Travel and miscellaneous costs per person			\$15,000	\$390,000
Total program cost				\$3,103,500

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 \$497,000 (Deloitte, 2017 op.cit.). Of this, approximately \$126,000 relates to direct service provision (excluding the family's own investment), yielding a net benefit per child of \$371,000. With less than 50% of children with hearing loss accessing the required specialist therapy, the potential benefit from CHIP exceeds \$275 million.

With a realistic short-term goal of reducing the leakage to 25%, the benefit from the CHIP would be more than \$135 million per year. Given the estimated \$3.1 million used to deliver the service there would be a return on investment of more than 40:1.

The total number of families to be assisted is approximately 1,500 per year based on the most recent Australian Hearing data:

Table 1 Clients less than 7 years of age who were first fitted with hearing aids by Hearing Australia in 2018

	Birth Year:	2012	2013	2014	2015	2016	2017	2018	Total	
	Age:	<7	<6	<5	<4	<3	<2	<1	Number	%
NSW		59	36	27	29	41	56	98	346	23%
VIC		58	44	41	33	33	82	105	396	27%
QLD		55	47	45	37	24	67	92	367	25%
WA		37	38	21	13	6	26	28	169	11%
SA		12	10	13	3	3	16	18	75	5%
TAS		3	5	3	1	3	6	2	23	2%
ACT		6	3	3	3	3	5	7	30	2%
NT		18	20	19	9	2	4	6	78	5%
National		248	203	172	128	115	262	356	1,484	100%
%		17%	14%	12%	9%	8%	18%	24%	100%	

EVIDENCE THE PROGRAM WORKS

The CHIP has been designed using the highly 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. The stated aim of this service is to support “families all over Queensland who have children with a permanent hearing loss and aims to minimise the time between a child’s diagnosis of hearing loss and families receiving support and services”.

The data support this claim. Even though the majority of leakage occurs in the 5th and final step (engaging with a specialist early intervention provider), at the 3rd step (engagement with Hearing Australia) Queensland has a 20% higher engagement rate than the rest of Australia.

Table 2 Children aged less than 6 years supported by Hearing Australia as a proportion of the population

Non-indigenous people

State	Population <6 yrs	Hearing Australia	Ratio
NSW	570,868	1,085	1.9
VIC	481,642	1,071	2.2
QLD	351,685	869	2.5
WA	197,835	402	2.0
SA	113,397	217	1.9
TAS	32,117	56	1.7
ACT	33,183	88	2.7
NT	13,856	49	3.5
National	1,792,655	3,837	2.1

ABS population data June 2018 (adjusted for percentage of non-Indigenous people, ABS data June 2016); Hearing Australia data December 2018.

Only non-Indigenous people have been included in these statistics for the comparison of the Hearing Australia and population numbers, due to the high rates of chronic middle ear infections in Aboriginal children. Among the five mainland states it is noticeable that Victoria (who has a similar system) is the next best after Queensland. The number in ACT is high due to the overall level of support provided and high in the NT due to environmental factors.

ALIGNMENT WITH ROADMAP FOR HEARING HEALTH

The Roadmap for Hearing Health was delivered to the Federal Government in February 2019. Launched with much applause from the sector, it articulates key initiatives and priorities for the Government. Implementing CHIP 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 CHIP program is aligned with these principles. It:

- Ensures that children are linked with early intervention services based on their reasonable and necessary 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 NDIS also has a number of additional guiding principles, of which the following are most relevant to the CHIP program:

- People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development (section 4(1));
- People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability (section 4(2));
- People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports (section 4(4));
- People with disability should be supported to receive reasonable and necessary supports, including early intervention supports (section 4(5));
- People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity (section 4(8));

- People with disability should be supported in all their dealings and communications with the NDIA so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs (section 4(9));
- Reasonable and necessary supports for people with disability should:
 1. support people with disability to pursue their goals and maximise their independence (section 4(11)(a));
 2. support people with disability to live independently and to be included in the community as fully participating citizens (section 4(11)(b)); and
 3. develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment (section 4(11)(c));
- The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected (section 4(12));
- The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:
 1. promoting their independence and social and economic participation (section 4(13) (a));
 2. promoting choice and control in the pursuit of their goals and the planning and delivery of their supports (section 4(13)(b)); and
 3. maximising independent lifestyles of people with disability and their full inclusion in the community (section 4(13)(c));
- People with disability should be supported to receive supports outside the NDIS, and be assisted to coordinate these supports with the supports provided under the NDIS (section 4(14));
- Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted (section 4(15)); and
- Positive personal and social development of people with disability, including children and young people, is to be promoted (section 4(16)).

IMPACT ON OTHER SUPPORTING DISABILITIES

Hearing loss is one of the first diagnoses of a disability that a newborn child is likely to receive. With the universal newborn hearing screening often occurring within 2 days of birth, the path to a full diagnosis within a fortnight of birth is often achieved. Unfortunately, for approximately one third of children supported by specialist early intervention services hearing loss is not the only disability that will be diagnosed.

While the primary focus of the CHIP would be to provide the pathway to a specialist early intervention service relating to hearing loss, these specialist services have a significant impact on the early development of the whole child. 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. This is particularly true for conditions often associated with a later diagnosis such as Autism Spectrum Disorders.

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.

CONCLUSION

CHIP would enable the Australian Government to deliver a cost-effective national solution through the NDIS that stems a problem and costs which would otherwise compound as children with hearing loss reach school age and beyond.

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