

4 December 2020

Hearing Services Program Review Panel

via hearing-review@health.gov.au

First Voice Submission for the Hearing Services Program Review

Thank you for joining the First Voice Board on 2 December 2020 to discuss the Hearing Services Program Review. Further to that discussion, please find below First Voice's Submission.

As discussed, First Voice's submission largely focuses on our expertise in the Community Services Obligations section of the Program. The submission contains eight (8) recommendations and is supported by evidence cited in the paper and through the attachment outlining key documents that support the claims made. It also includes a case study about how thin markets can be better served, retaining Hearing Australia but focusing on a different approach to supporting each of those different thin markets.

First Voice will provide further examples to follow this formal submission.

Yours sincerely

first voice THE FUTURE IS HEAR

SUBMISSION TO THE REVIEW OF THE HEARING SERVICES PROGRAM

INTRODUCTION

Over the past 70 years, Australia has developed world-leading practices in identifying and supporting children with hearing loss, of which the Hearing Services Program is an integral part. While the Universal Newborn Hearing Screening program reaches over 95% of newborn children, only 50% of children with a permanent hearing loss ultimately reach a specialist early intervention therapy provider - a provider that delivers evidence-based specialist, targeted, multi- or trans-disciplinary therapy supports for children with hearing loss, and their families. There is a role for the Hearing Services Program to address this shortfall and optimise the program's outcomes for clients.

First Voice

First Voice is the representative body for the leading early intervention therapy centres across Australia & New Zealand whose primary focus is supporting families with children who are deaf or hearing impaired and providing them with Listening and Spoken Language therapy services. First Voice members support children with hearing loss and their families to achieve spoken language, mainstream education and social inclusion. Member organisations include Can:Do 4Kids (SA), Hear & Say (Qld), Royal Institute for Deaf and Blind Children (NSW & Victoria), The Shepherd Centre (NSW & ACT), Telethon Speech & Hearing (WA) and the Hearing House (NZ). More information is available at https://www.firstvoice.org.au

The Hearing Services Program

First Voice advocates for the retention of the coverage of the Hearing Services Program (HSP). For the purposes of this submission, the focus of First Voice will be on the Community Service Obligation (CSO) relating to the 0-26 age demographic.

In providing comments on the HSP however, First Voice notes that the various parts of the HSP are discrete market segments within themselves (ATSI, Complex Adults, other CSO 0-6, other CSO 7-26, Voucher program). As such, each should have their own publicly stated outcomes for which providers of any service provision should be held to account, and each should have an identifiable budget allocation. The current arrangement lacks transparency for each cohort; and the focus is on activity or outputs (by hours) rather than driving identifiable outcomes for the community. Delineating these cohorts within the HSP will assist in the alignment of resources and delivery of key government priorities (such as Aboriginal and Torres Strait Islander ear health within the *Roadmap for Hearing Health*), and provide transparency in reporting outcomes specific to that cohort. Key initiatives, such as contracting providers to address thin markets, can then be specifically targeted for that market.

Recommendation 1: Ensure each component cohort of the Hearing Services Program is funded with **outcomes** for each market specified, made publicly available, and with service providers held to account for their delivery.

The paediatrics hearing market

The paediatrics hearing market in Australia is miniscule, services required are highly specialised and it is difficult to ensure rapid response and national delivery of a consistent, high standard – especially for those who live in regional or remote communities.

In Australia, approximately 1 in 1,000 children are identified at birth with a hearing loss. Further children will develop hearing loss in the first few years of life (due to progressive loss, disease, trauma, etc.) and by the time they reach 5 years old and are of school age, approximately 1 in 300 children will have permanent hearing loss. This equates to more than 4,000 children across Australia.

There are additional children who have hearing loss due to middle ear infections (otitis media) which, unless appropriately treated, can lead to permanent hearing loss. This is a major issue especially for indigenous children (with more than 10% of children from remote indigenous communities having chronic suppurative otitis media with less than 10% of children with both ears being normal) that requires a specific social and medical focus.

Under normal circumstances, children begin hearing around halfway through pregnancy. In contrast, by the time they are born, children who are deaf are already delayed by five months in key areas related to oral communication or language development due to the lack of stimulation of their auditory cortex. An immediate and specialist response is required to prevent significant lifelong impacts for the child.

Children diagnosed with hearing loss in both ears (bilateral hearing loss) have been demonstrated to have the most profound deficits in speech, language, literacy and social inclusion. Nevertheless, children with loss in one ear (unilateral hearing loss or single-sided deafness) also suffer significant impacts. While listening through one ear alone can be sufficient when a child is in a quiet environment, the impact of hearing loss often only becomes evident once a child is in a challenging auditory environment such as day care or school. Early investment in supporting children with hearing loss also prevents a significantly larger future cost to the child, their family and to society.

In decades past, support for children with hearing loss was restricted to those with a moderate or worse loss in both ears (normally defined as a loss of more than 40dB in each ear). Children with a hearing loss in one ear (unilateral loss), or children with only a mild loss (21-40dB) were seen as not requiring support.

Extensive research over the last three decades however, has shown that these children do suffer significant functional loss in their communication capacities. This is evident from the first few months of life, where over 40% babies of around nine months of age with unilateral loss had delays in babbling, an important developmental step for spoken language (Kishon-Rabin, 2015¹). This then leads on to significantly worse speech language scores in children and adolescents (Lieu et. al., 2010; Fisher & Lieu, 2014²) and results in significant problems at school (Lieu, 2013³).

A review of the literature on the effects of unilateral hearing loss (Krishnan & Van Hyfte, 2016⁴) found that these children had:

¹ Kishon-Rabin, L The impact of permanent early-onset unilateral hearing impairment in children – A systematic review, International Journal of Paediatric Otorhinolaryngology Volume 120, May 2019, Pages 173-183

² Fisher C, Lieu JEC. Unilateral hearing loss is associated with a negative effect on language scores in adolescents. Int J of Paediatric Otorhinolaryngology 78 (10):1611-1617, 2014.

³ Lieu JEC. Unilateral hearing loss in children: speech-language and school performance. B-ENT 9 Suppl 21:107-115, 2013 ⁴ Krishnan, L.A & Van Hyfte, S. Management of Unilateral Hearing Loss, International Journal of Paediatric Otorhinolaryngology,

⁴ Krishnan, L.A & Van Hyfte, S. Management of Unilateral Hearing Loss, International Journal of Paediatric Otorhinolaryngology, 30 Jun 2016, 88:63-73

- Reduced spoken language competence (25-40% with poorer speech & language skills of a wide variety of domains);
- Potentially reduced cognitive ability (lower performance on complex verbal IQ tasks);
- Reduced educational progress (22-40% needed to repeat a grade at school and 41-54% required an individual education plan to support their learning); and
- Poorer social & behavioural development (20-33% with behavioural problems, continuing into adulthood).

Given the dramatic adverse life outcomes that can arise from all levels of childhood hearing loss, it is absolutely critical that all of these children are provided with the required specialised supports in a timely, effective and accessible way.

The current hearing care system for children

The key elements of an effective hearing care system response are:

- 1. Rapid detection and diagnosis
- 2. Early and effective provision and fitting of Assistive Hearing Technology (AHT); and
- 3. Early and effective provision of specialist early intervention therapy.

Of critical importance is that families with newborns and children with hearing loss have a fast, simple, universal pathway for help, as a diagnosis creates a high degree of stress for parents. More than 90% of these parents have not had experience with childhood hearing loss and so do not know what is required for their child. They need immediate, culturally-appropriate support from an independent professional who can assist them to commence and then navigate the pathway to appropriate support for their child.

The system in Australia delivers these elements to varying degrees. Improvements can be made through changes to the Hearing Services Program.

1. Rapid detection and diagnosis

Rapid detection, diagnosis and intervention are critical when it comes acquiring listening and language skills for deaf and hearing-impaired newborns and children. Every day counts. Minimising the time from onset of hearing loss through to receiving high-quality auditory stimulation (from the combination of an appropriate hearing device and appropriate early intervention) is critical for the successful support of a child with hearing loss. This delay must be kept as short as possible and should be a maximum of 1 month to diagnosis; 3 months to fitting of effective hearing devices; and 6 months to specialist therapy.

Starting with detection and diagnosis, the Universal Newborn Hearing Screening program leads the world in its reach, currently screening approximately 98% of all children born in Australia. The pathways, processes and timeframes are in place for the health system in each State and Territory to then conduct the required and rapid diagnostic testing.

While the introduction of Universal Newborn Hearing Screening has meant that nearly all children born in Australia with a hearing loss are diagnosed within the first few months of life, there is no nationally coordinated approach nor a national database that allows effective tracking at a population level.

In addition, there is no national approach for the detection and diagnosis of hearing loss developing in the first years after birth. As a result, the diagnosis of these children is delayed and they are often not identified until they are having problems at school, if at all.

Recommendation 2: The Hearing Services Program facilitate a national database of Universal Newborn Hearing Screening results.

Recommendation 3: The Hearing Services Program be expanded to deliver a national hearing screening program for children 4-7 years of age.

2. Early and effective provision and fitting of Assistive Hearing Technology (AHT)

The next step is for early and effective provision of AHT through referral to Hearing Australia, in its national capacity as 'First Responder' for the paediatric market. Funded through the Community Service Obligation of the Hearing Services Program, Hearing Australia was created to enable timely, universal and expert access to AHT as the market has not been ready or able to do so.

Following diagnosis, a child needs to be rapidly referred to the required specialised facilities and clinicians. Direct referral pathways and active follow-up (to ensure at-risk families don't fail to attend) are critical for success. While Australian Hearing has established a structured pathway that has resulted in over 90% of children diagnosed at birth having appropriate referrals, a similar, standardised process has not been established for children diagnosed later in life.

Recommendation 4: Hearing Australia retain its role as the sole-funded AHT provider for the 0-6 year old market.

The Hearing Services Program, Hearing Australia, and the National Acoustics Laboratory (NAL) are *critical hearing health infrastructure* for the nation. First Voice members work hand in glove with these essential government providers.

3. Early and effective provision of specialist early intervention therapy

It takes up to 6 years of intensive, holistic communications support *in addition to effective AHT fitting* for a child to develop listening and language skills to take them through the rest of their life. A specialist early intervention provider delivers evidence-based specialist, targeted, multi- or trans-disciplinary therapy supports for children with hearing loss and their families. These are specialist services not-for-profit First Voice members provide.

High-quality access to sound for a child with a hearing loss requires the child to be provided with the correct AHT (specialised hearing aids, cochlear implants, etc), along with management of the devices, child education and carer education. This process is very different in young children than it is with adults, requiring audiologists with specialist paediatric training supported by specialist therapists in specialist facilities.

Even with the best hearing devices available, the sound that children can access through AHT is not equivalent to what they would normally hear. This is due to both the quantity and quality of sound they receive. Children with 'normal' hearing are listening 24/7 – even when they are asleep they are

perceiving sound and their brains are being stimulated. In contrast, children with aids will normally only have them on for a maximum of 12 hours a day (due to taking them off during bathing, sleep, etc).

Normal exposure to sounds and language is not sufficient for a child with hearing loss to develop their language potential. Daily intense and individual therapy must be provided – which is best provided through the child's parents or caregivers. This also provides the critical benefit that the child learns their family's home language, creating a strong and caring family bond.

Parents and carers must be supported and educated in the specialised approaches that they need to use to enable the development of spoken language in their child. This requires an expert integrated transdisciplinary/interdisciplinary service that incorporates clinicians who have specialist knowledge in paediatric audiology, listening & spoken language, and emotional support.

Therefore, a substantial part of the clinician's work is individualised adult education, the level of support required for a child with a mild or moderate hearing loss is not substantially less than the level of support required with a severe or profound loss (the same level of adult education is required for the parents, regardless of the child's level of loss).

The listening and language skills of a child change as they develop, which requires adaptation of the listening and language interventions that the parents need to provide. In addition, the hearing loss impacts on the development of normal social skills and executive functions of the child and additional support is required to assist with these areas. As a result, support over all of the early years of life is required for the multiple challenges and transitions that these children face due to their hearing loss.

Despite the challenges detailed above, and in contrast to the experience of the vast majority of children with hearing loss around the globe (as detailed in published literature), it is feasible for most children with hearing loss to routinely achieve spoken language at the same level as children without any loss.

This is demonstrated by the outcomes achieved by children attending the early intervention programs of the member centres of First Voice. Children graduating from these programs, with all levels of hearing loss (including profoundly deafness), and many with other disabilities or complications, typically develop the same level of language as their normally-hearing peers, with over 90% of children going on to a mainstream class in a mainstream school.

First Voice publishes its speech outcomes through its *Sound Outcome* reports (available at <u>https://www.firstvoice.org.au/reports-papers/</u>), which show that 86% of children in First Voice member specialist early intervention programs reach normative speech outcomes when compared to 84% for the Australian population.

The per-child economic benefit from a child with hearing loss receiving timely and appropriate specialist early intervention therapy is approximately \$497,000⁵ (Deloitte, 2017 op.cit.). Of this, approximately \$126,000 relates to the direct cost of service provision (excluding the family's own investment), yielding a net benefit per child of \$371,000.

^{5.} Deloitte Access Economics, *Cost-Benefit Analysis of First Voice's Early Intervention Program* (2017) <u>https://www2.deloitte.com/au/en/pages/economics/articles/first-voice-early-intervention-program-cost-benefit-analysis.html</u>

Opportunity for a new targeted initiative that encourages the provision of services to vulnerable Australians in 'thin markets'

While more than 4,000 children aged up to 6 years of age are supported by Hearing Australia through the Hearing Services Program, *less than 2,000 of them access a 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 on their school performance, social development and employment opportunities.

In short, 50% of children in need of specialist early intervention hearing care services are at risk of 'falling through the cracks'.

In 2019, Hearing Australia took on 1,323 new children aged 0-5 years of age. With half of those or approximately 650 not receiving specialist early intervention therapy at an estimated net cost to the community of \$371,000 each,⁶ the potential annual social and economic losses arising from this seepage would exceed \$240 million.

There is a simple solution to this problem.

Based on the successful Queensland Hearing Loss Family Support Service (currently the only service of its kind in Australia), a targeted 'national hearing loss family support service' could be implemented to support families to link them to diagnosis, device, and funding programs, and guide them onto an evidence-based specialist early intervention service that meets their needs and reflects their choices. The program would recognise the family-centred care required to support families during a vulnerable time, while ensuring that families have choice and control throughout the process. The independent service deliverer (including Hearing Australia) to ensure the support and advice is solely focused on providing informed choice and control for families, independent of and not influenced by any funding source.

The service 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;
- 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;
- 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

^{6.} ibid

• Provide feedback to all parts of the hearing services system for children about the family experience in accessing supports.

The estimated incremental 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 economic benefit in excess of \$120 million, representing a benefit: cost ratio in excess of 20:1.

Delivery of an initiative of this kind would also deliver a key action in the national *Roadmap to Hearing Health* 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.*"

Recommendation 5: The Hearing Services Program initiate a 'national hearing loss family support service' to support families of children with a permanent hearing loss minimise the time between a child's diagnosis and uptake of the required support and services; ensuring access for all Australian children with hearing loss to the best possible supports.

Recommendation 6: The collection of data 'end-to-end' for the system (from universal newborn hearing screening through to engagement with specialist early intervention) be standardised and publicly reported, with a custodian responsible for the collection of that data (to enable transparency and to measure the effectiveness and efficacy of the system).

If this is of interest to the Panel, First Voice can provide data and further information in support of the national hearing loss family support service initiative, i.e. its 'CHIP' proposal.

Choice and control – understanding the pathways and markets

The issue of choice and control for all parts of the HSP is often one where the discussion is skewed towards adults and approached from an ideological basis, rather one focused on a 'whole-of-system' approach or understanding each market in turn.

First Voice advocates for the retention and strengthening of existing pathways for children aged 0-6. The pathway from universal newborn hearing screening, to diagnosis, to fitting, through to engagement with early intervention is one that must be protected and strengthened and not weakened through any false 'choice and control approach'. Approximately 95% of parents with children with a hearing loss do not have a hearing loss themselves, creating uncertainty and angst in them about what to do next, what services to access, and what is best for their child. To disrupt a successful system for that cohort would undo much of the good work that has been done in establishing our world-leading system for children with hearing loss.

The opportunity for choice and control should come after that first diagnosis, fitting, NDIS access, and engagement with specialist early intervention. It is possible for families to exercise informed choice and control after a period of support (that includes effective and full advice about issues such as device options, including implanted devices; early intervention; school support and/or parental support). This however, must be done with system-based conditions and a multidisciplinary approach to mitigate the long-term risks to children's hearing and development if they are not done well:

- 1. Effective paediatric standards;
- 2. Registration of paediatric specialists to support children;
- 3. Providers being able to provide effective counselling and support of families at the various stages of their child's life to support choices that impact on their development; with
- 4. Outcomes measures established, with clear accountabilities.

The experience from countries such as US, Scandinavia and the UK (where contestability has had a negative impact with regard to access, timely provision of services, expertise provided, and cost of the program that ultimately impacted outcomes) demonstrates the needs for measures such as these.

Recommendation 7: The issue of 'choice and control' is examined for each market segment, based on the needs of the consumer and how services for them will interact within a broader system.

Interactions between the Hearing Services Program and the NDIS

The review of the HSP must be considered in light of how the service delivery under the Program interfaces with other programs, taking a 'whole-of-system' approach. For children, this involves the interface between universal newborn hearing screening, diagnostic services, the NDIS and then early intervention. The need to support the navigation and transition through these various elements of the system for children who are first diagnosed has been discussed earlier in this paper.

In relation to the NDIS, First Voice supports the Scheme's goal to maintain <u>and improve</u> outcomes for vulnerable children and their families. Members are working with the HSP, Hearing Australia, the DSS and the NDIA to fulfil this promise. The role of the HSP, particularly the CSO, should remain separate from the NDIS. Their purposes are different, eligibility criteria are different, key success factors are different, and the outcomes should be different. The previously proposed changes to the HSP and the NDIS for the age demographic (where services currently provided by the CSO component of the HSP would have been taken over by the NDIS) caused significant confusion and concerns about critical elements of the CSO being lost, such as emergency devices provided within 24 hours with service from expert professionals, a national quality assurance approach, plus much more.

The NDIS should be considered an evolving system, one still in its infancy. There continues to be significant disparity in the level of packages provided under the NDIS, negatively impacting on families. First Voice contends that creating any further overlap or joining of the two programs will create greater uncertainty and confusion for the consumer. Instead, an awareness campaign needs to be provided to outline to consumers what each program does, the pathways into each, and what consumers can expect.

Recommendation 8: The Government embarks on a campaign to provide greater clarity around the HSP and its interface with other government programs, particularly the NDIS.

Cost-benefit analysis of First Voice early intervention programs (Deloitte – Access Economics):

https://www.firstvoice.org.au/wp-content/uploads/2016/09/First-Voice-Deloitte-Access-Economics-Cost-Benefit-Analysis.pdf

• First Voice Graduate Outcomes Report:

https://www.firstvoice.org.au/wp-content/uploads/2016/09/First-Voice-Graduate-Outcomes-Report.pdf

• First Voice CHIP Proposal:

https://www.firstvoice.org.au/wp-content/uploads/2020/08/FV-CHIP-Proposal-Final.pdf

Thin Market Example – Telethon Speech & Hearing and

First Voice advocates for the support of thin markets⁷. Each thin market, however, has unique characteristics with different community needs and expectations, as well as different referral pathways, service delivery options and stakeholders. As such, as part of the Hearing Services Program, the CSO should be delivered not by one organisation who asks, "How do we meet the needs in this community?", but rather one who answers the question, "How are the needs of this community best met?". The example below, explores service delivery to the remote community of the term. Western Australia.

Background

First Voice member, Telethon Speech & Hearing (TSH) has a long history of providing supports to children with hearing loss and/or speech and language delays. Outside government services, TSH has the largest number of paediatric audiologists employed by any organisation in Western Australia. It is a registered school, an NDIS provider, and is an audiology provider. It has been a provider under voucher system of the HSP, adhering to all of the requirements associated with such provision. In ear health and audiology, TSH has clinics in Wembley and Cockburn, supports children with hearing loss or ear health issues in 27 schools in Western Australia, runs ear health programs in the Pilbara, Wheatbelt and Kwinana regions of WA. It supports children with all assistive technologies from bone conductors through to mapping for cochlear implants.

TSH has been providing ear health services in the Pilbara of Western Australia since 2011 and developed the Pilbara Ear Health Model of Care in 2015 (refer to <u>http://bit.ly/TSHmodelofcarebook</u>).

⁷ Thin markets can be defined as inadequate service availability resulting in consumers' needs not being met. Thin market categories include geographically remote areas, specialised supports with insufficient supply or low demand, supports for people with complex needs, support for Aboriginal and Torres Strait Islander consumers or those from Culturally and Linguistically diverse backgrounds.

Services – Summary of Model

has no regular Aboriginal Health Service, has a local health service run by WA Country Health Service and has a sole school catering for kindergarten through to Year 12. Employment is largely in industries supporting oil and gas activities (with being the largest employer). The percentage of people in the town who are Aboriginal is %. A large portion of Aboriginal people in the town live in the town who are Aboriginal is %.

In providing services to the community, TSH has an integrated ear health model which can be summarised as:



In short, TSH provides prevention activities, early screening and detection, audiological supports (by highly qualified audiologists), primary health services (by a GP, nurse practitioner and/or ENT), and surgical interventions (by an ENT), as well as post-operative or post-device support through our local staff.

Key Achievements

Appendix 1 summarises some key data in terms of service delivery into Some highlights include:

- 1. *Prevalence* The prevalence of middle ear disease in the community has dropped with the percentage of children under 7 years old who presented middle ear disease dropped dramatically from 51.7% in 2011 to 33.3% in 2016.
- 2. Clinic Attendance TSH has a minimum attendance rate at their clinics of 85% because of the relationships they have developed with communities in the **second** of Western Australia over time.
- 3. ENT Referrals Referral percentages to ENT have dropped from 40.9 to 27.4%
- 4. Community Acceptance Due to its relationships, TSH has been asked by adults in various communities to provide them with ear health services, because of what they have been able to achieve for the children. This has led to a deliberate strategy to support intergenerational change in ear health.

Issues with the Current Model

Upon identification of the need for a device, TSH will refer to Hearing Australia so it can deliver its services under the Community Service Obligation. However, Hearing Australia visits are often based on volume to make it "financially viable" for them and have often not been supported by professionals from their Perth locations. The visit by Hearing Australia will often then happen six months' later, sometimes more (with no visit to **Service**) in 2020, despite TSH having 4 visits to the town plus regular contact with the local health service, school, and others to support them).

The wait has a substantial impact on children particularly in the classroom, so much so that TSH has now started a program with the **second second se**

The Solution

The solution is simple. Under the CSO, Hearing Australia could contract providers who are trained and registered to provide services to ATSI peoples in the regional in which they operate. By doing so, it will:

- 1. Provide a more expeditious service for regional and remote communities, particularly ATSI peoples;
- Reduce the costs for Hearing Australia, by not requiring them to have to fly to and be accommodated in various parts of the country where suitably qualified people can already deliver the service in situ within local communities;
- 3. Align staffing, as outsourcing will reduce the time Hearing Australia staff are taken from their substantive location, resulting in more hours available for other HSP delivery;
- 4. Increase attendance rates where other providers have already established positive community relationships;
- 5. Provide effective support after device fitting as part of an integrated package of care;
- 6. Better achieve the goals of the *Roadmap for Hearing Health*, particularly pertaining to ATSI peoples; and
- 7. Retain or improve standards of service delivery through the monitoring of service provider standards and outcomes.

End.

Appendix 1 – Key Data

1. Children Seen



2. Prevalence of Middle Ear Disease



3. ENT Referral Rates

