About Telethon Speech & Hearing

Telethon Speech & Hearing (TSH) is an iconic and trusted Western Australian organisation. We are a registered charity, not-for-profit organisation, independent school and NDIS provider. For over 50 years we have supported children and their families with hearing loss and/or speech and language difficulties. Our unique, integrated model provides diagnostic, therapy, and support services. This whole of life approach ensures every child receives the highest level of care in helping them to hear, speak, learn and play. TSH offers a range of essential early intervention, clinic-based and school support services to assist children in realising their full potential.

Support of the Hearing Services Program

TSH is very supportive of the Hearing Services Program and makes its submission focusing on its two key areas of service delivery (both of which are thin markets):

1. 0-26 under the Community Service Obligations
2. Services to ATSI members of our community under the Community Service Obligations

It does so noting that the various parts of the HSP are discrete markets within themselves (ATSI, Complex Adults, other CSO 0-6, other CSO 7-26, voucher program). As such, each should have their own budget, and their own publicly stated outcomes that providers of any service should be held to account for.

The current arrangement allows any outcomes for each discrete area to be hidden. Reports are very outputs (hours) focused rather than driving real outcomes within community. Separating the HSP into each area will assist in the alignment of resources with key government priorities (such as ATSI ear health as per the Roadmap for Hearing Health). It will also provide transparency around funding and outcomes specific to that cohort.

In making this submission TSH endorses the recommendations made in the First Voice submission to the Review. TSH's submission should be read in conjunction with that submission and makes the following additional statements.

Objective and Scope of Program

TSH is supportive of the broad objectives and scope of the Hearing Service Program. It could be amended to state:

> *The Australian Government Hearing Services Program (the Program) aims to prevent and reduce the impact of hearing loss by providing eligible people with access to hearing-related services.*

Eligibility for the Program

The eligibility criteria for the Program seem to be appropriate as they currently stand. However, there are opportunities for further improvement of services delivered under the HSP.

Interface with Other Schemes

The current pathway for children upon identification through the universal newborn hearing screening programs is one of the most advanced in the world and should be retained. However, the need for an effective interface with specialist early intervention providers is wanting, with only half of the children eligible for such services being supported by one.

This can be improved by implementing a national program similar to that run in Queensland. 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 on to 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 could be funded by the Hearing Services Program.

It is recommended it be based outside any 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.

This 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;
- 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;
- 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;
- Facilitate the effective progression for families through each stage of the system, ensuring all supports are provided within accepted timeframes;
- Better support access to the NDIS; and
- 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 government's national Hearing Health Roadmap 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.*"

Hearing Loss Prevention

Sadly, there are no nationally consistent programs for children who are not identified through the universal newborn hearing screening or have preventable conductive hearing loss or otitis media.

Recognising that otitis media and other ear health disease which can lead conductive hearing is most prevalent in children under the age of 7, the Hearing Services Program does not provide surveillance or prevention services to all Australian children requiring this support. 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.

State run systems community health systems have a 6-12 month delay in access to audiological services, plus often another two years to access an ENT service (more if you are an Aboriginal or Torres Strait Islander child according to recent Hearing Australia research). The resultant impact on speech and language development, literacy, learning and social engagement is significant.

A national ear screening and pathways program will address one of the most preventable forms of hearing loss - conductive hearing loss in children. According to the World Health Organisation, 60% of all childhood hearing loss is preventable, and according to the ABS 2.9% of all Australian children aged 0-14 have reported ear/hearing problems (8.4% for Aboriginal children). By creating early detection and prevention measures it will positively impact tertiary health care costs and educational outcomes. It will also identify any degenerative hearing loss in children who were not identified in the newborn screening process.

TSH recognises the HAPEE program which has recently commenced for Aboriginal children aged 0-6. This is a good start that will help address issues for a small, but overrepresented cohort. It does not, however, apply to all children.

A screening program for 4 year olds as they enter kindergarten through to 7 year olds will provide the quick identification of ear health issues and hearing loss (sensorineural or conductive) and pick them up in time for their schooling. A national approach will address the ad hoc approach current taken and will focus on all children. Performed at this age, the screening, along with the associated pathways for each community, can address the delay in hearing. This will enable speech and language development, which have a flow on effect on literacy development and learning.

Choice and Control

TSH strongly echoes the call from First Voice and 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 a 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 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.

For children, the opportunity for choice and control should come after that first diagnosis, fitting, NDIS access, and engagement with specialist early intervention. After a period of support (with effective advice about issues such as device options (in full and including implanted devices), early intervention, school support and/or parental support), it is possible for families to exercise informed choice and control. This, however, must be done with conditions 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
4. Outcomes measures established, with clear accountabilities

The experience from countries such as US, Scandinavia, and the UK (where contestability has brought issues, rather than improvements) demonstrates the needs for measures such as these.

Thin Markets

Both of the key markets TSH operates in are thin markets. In addition to the comments made above about services for children, the other key focus for TSH is services for Aboriginal and Torres Strait Islander members of our community.

It is well noted that Aboriginal children are likely to be impacted 10 times more than non-Aboriginal children by ear health related issues. The sad fact is that it is multi-generational. In regional and remote parts of the country (particularly in Western Australia), the localities are separated by vast distances making access to services for local people very difficult with limited (if any) access to technology to support consistent tele-based services.

In WA there are providers who provide ear health supports under various funding guises (philanthropic, WA Country Health Services, and Rural Health West being the main three) in regional and remote areas. Effective ear health and hearing services in these areas are coupled with excellent community engagement, increasing attendance at clinics and building prevention strategies.

For a decade TSH has been providing ear health services to regional and remote communities in Western Australia, primarily to support Aboriginal people. We provide 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. We have a minimum attendance rate at our clinics of 85% because of the relationship we have developed with communities in the Pilbara of Western Australia. It is due to these relationships TSH has developed services for children and adults – a deliberate strategy to support intergenerational change in ear health.

Upon identification of the need for a device TSH will refer to Hearing Australia so it can deliver its services under the Community Service Obligations. The visit by Hearing Australia will often then happen three to six months' later (sometimes more with Hearing Australia not yet visiting parts of Western Australia in 2020), and those visits are often based on volume to make it "financially viable" for them. This wait is too long for any person, particularly for children.

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

1. Provide a more expeditious service for regional and remote communities, particularly ATSI people;
2. Reduce the costs for Hearing Australia, by not having to have them fly to various parts of the country where suitably qualified people can already deliver the service in local communities;
3. Increase attendance rates where other providers have already established positive community relationships;
4. Provide effective support after device fitting as part of an integrated package of care;
5. Better achieve the goals of the Roadmap for Hearing Health, particularly pertaining to ATSI people;
6. Retain or improve standards of service delivery through the monitoring of service provider standards and outcomes.

The case study attached to the First Voice submission will provide an example of how a thin market could be better served.

Recommendations

TSH recommends:

1. The elements of the Hearing Services Program be recognised as discrete markets, and resources and accountabilities be specifically aligned with each discrete market.
2. The Program's purpose be adjusted to explicitly add reference to the prevention of hearing loss.
3. The 0-6 pathway for children with hearing loss, and role Hearing Australia plays within it, be retained.
4. A national hearing loss family support service be implemented to support families navigate the hearing and early intervention system.
5. Children aged 4-7 be better supported in their ear health through a national screening program for early years of schooling.
6. The issue of choice and control be contextually considered for each discrete market, with its implementation for children predicated on maintaining the existing 0-6 pathway, along with reviewing lessons from international changes and putting in safeguards for children.
7. Contracting of locally based services to address thin markets, particularly for ATSI people, be enacted to drive better outcomes.