Royal Institute for Deaf and Blind Children

Submission to

Hearing Services Program Review

Prepared by

Royal Institute for Deaf and Blind Children

[redacted]

Key contact:

[redacted]

Content

About Royal Institute for Deaf and Blind Children

Royal Institute for Deaf and Blind Children (RIDBC) is Australia's largest non-government provider of therapy, education and cochlear implant services for children and adults with hearing or vision loss, their families, and the professionals that support them.

Our Mission is to provide quality and innovative services to achieve the best outcomes for current and future generations of Australians with hearing or vision loss.

We pride ourselves on working in collaboration with families, children and adults to tailor services that support and fit individual needs and life goals.

Our services for children, adults, families, and the professionals that serve them include:

- Assessment and diagnostics
- Early intervention and early learning programs
- Specialist educational programs (i.e., schools, preschools and school support)
- Therapy and re/habilitation services
- Audiology and cochlear implant services
- Research, postgraduate, and professional education (operated in affiliation with Macquarie University).

Our Cochlear Implant Program is Australia's largest and most comprehensive, setting new benchmarks and delivering the highest level of care and support at every stage of the cochlear implant journey.

RIDBC Renwick Centre conducts world-leading research and provides both postgraduate and continuing professional education courses in a range of fields relating to the development and education of children with vision or hearing loss.

RIDBC services are provided to over 8,000 people from twenty permanent sites across Australia, and remotely using technology in rural and regional areas.

For more information about RIDBC, visit www.ridbc.org.au.

Response to the Consultation Paper

1. What should be the objectives and scope of the Program?

Over the past 70 years, Australia has developed a system of world-leading services in identifying and supporting children with hearing loss, of which the Hearing Services Program is an integral part. Universal newborn hearing screening (UNHS) programs operated by the various state and territory jurisdictions now cover more than 95% of all births in Australia, ensuring that children identified with hearing loss and their families are able to engage with hearing services and specialist early intervention therapy providers at the earliest possible time. Early intervention services deliver specialist evidence-based multi- or trans-disciplinary therapy support to children and, importantly, to their families. Since its inception, there has been a critical role for the Hearing Services Program as part of the network of services which, together, have the collective objective of providing the best possible opportunity for normalised developmental outcomes for children who are deaf or hard of hearing.

In this context, a continuing objective of the Hearing Services Program (HSP) should be to ensure that all children and young people who are identified with significant hearing loss are able to receive hearing services (i.e., assessment and the provision of amplification and associated technologies) as a basis for minimizing the impact of hearing loss on their quality of life. Specifically, the HSP should aim to ensure that families of infants and young children are informed about, and directed to, a range of early intervention services (i.e., consistent with the principles agreed with the National Disability Insurance Scheme).

Having noted the importance of services to children (particularly newborn children, it is acknowledged that objectives of the HSP should vary across each of its target cohorts (i.e., the aged, indigenous participants, and other vulnerable groups).

For each of these groups, however, a common objective of the HSP should be to provide timely access to hearing for those identified with hearing loss through the fitting and maintenance of hearing devices and accessories. In this regard, the objective should be to ensure that all such services are based on the best available evidence and that outcomes for each group are identified and assessed to ensure that (a) there are clear benefits for individual clients, and (b) that there is a quantifiable return on public investment in regard improved quality of life and social engagement for all participants.

2. Which consumers should be eligible for Program subsidies?

The current target consumer groups for the CSO program should remain eligible for services under the HSP. The program should continue to be adequately funded to provide services to those groups, namely:

- Children under the age of 26 years
- People eligible for the Voucher Scheme who have complex hearing or communication needs or live in remote areas
- Aboriginal and Torres Strait Islander people over 50 years of age

The current target groups for the Voucher Program for adults should also remain eligible Those groups are:

- People referred by the Disability Employment Services Program
- Pensioner Concession Card holders
- Department of Veterans' Affairs Gold Card holders
- Dependants of persons in one of the above categories
- Members of the Australian Defence Force

3. How well does this Program interface with other schemes?

All Australian state and territory jurisdictions now have world-class newborn hearing screening programs, with population coverage exceeding 95% of births. However, those state-based programs have no formal direct link to the HSP regarding data sharing or assurance of engagement.

On best available evidence, the onward referral of children from UNHS programs to Hearing Australia, and from there to early intervention programs, is very effective. However, the lack of data sharing and the lack of a common identifier for clients of these multiple programs and systems inhibits information flow and the ability to account for any possible loss of engagement at each transition point in the system.

Anecdotally, there are strong and effective links between UNHS programs and Hearing Australia regarding handover of case responsibility. Indeed, most state-based UNHS programs have key performance indicators relating to engagement of children who are identified with hearing loss with Hearing Australia. The effective transition of families from UNHS programs to the HSP (i.e., Hearing Australia) is underpinned by the fact that Hearing Australia is the obligated provider of services nationally and there is a common approach to the interface between the two systems right across the country.

Having noted this high level of engagement and associated low levels of loss to follow up through the transition points, there is still potentially much to be gained through the development of a more effective strategy for data sharing and, in particular, the introduction and mandating of the use of a common identifier for children within the data management systems of UNHS programs, the HSP, and the NDIS. Such a development has the potential to reduce the need for duplicate records about children across the various systems and programs.

The interface of the HSP with NDIS for newly diagnosed children is an important work in progress. There is much to be said for the development and introduction of the streamlined referral pathway between the HSP Paediatric CSO Program, the NDIS, and early childhood early intervention services. However, for children and young adults over 7 years of age, the differing criteria for access to the NDIS and the HSP, and the differing bases for accessing services and supports though each program, make for a difficult environment for families to navigate. The interface between the two programs at these older age levels requires significantly more attention.

4. Does the Program sufficiently support hearing loss prevention?

The recent appointment of a senior executive within Hearing Australia is applauded. However, that activity would appear to be largely independent of any requirement for that to occur under the HSP.

It is noted that the delivery of hearing loss prevention campaigns has been identified as a priority in the Roadmap for Hearing Health. Specifically, the Roadmap calls for the development and implementation of "…a prevention-focused campaign, using effective evidence-based strategies, that provide education on the importance of hearing health, including the potential impact of recreational and occupational noise, and knowledge of the potential impact of unaddressed ear infections, that is both broad-ranging and targeted at vulnerable populations using various formats".

If those ambitions are to be realised then consideration should be given to including specific objectives for such activities, and associated recurrent funding mechanisms, in the Hearing Service Program, and to the concept of obligating a provider (or providers) to deliver those objectives.

5. Are the Program's assessment services and rehabilitation activities meeting consumer needs?

There is no doubt that children who engage with Hearing Australia under the terms and provisions of the HSP are offered an excellent assessment service and generally gain access to appropriate amplification using strong evidence-based strategies for fitting of devices. Indeed, the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study has established the efficacy of the device fitting procedures used by Hearing Australia for all paediatric HSP clients realtive to other internationally acknowledged strategies.

For all children who receive their assessment and device fitting through Hearing Australia under the HSP, the provision of intervention and ongoing habilitation services are the domain of other providers.

It is noteworthy that, with the exception of the streamlined pathway for children identified in early childhood, there is no guided pathway from hearing assessment and device fitting services under the HSP to engagement with early intervention or other providers under the terms of the NDIS or education sectors. The potential consequence of this gap is that consumers (i.e., children and their families) may be poorly informed and at risk of not being able to access the most appropriate or effective services beyond the HSP.

Hearing Australia, as an independent and expert agency with no direct interest n the provision of intervention or other support services, could usefully be tasked under the terms of the HSP to ensure that all children identified with hearing loss are engaged with relevant qualified providers, and that the outcomes of that engagement are tracked and reported upon.

For the voucher-eligible adult population there is little doubt that the HSP provides access to assessment and fitting of hearing aids. However, the program appears to have no mandated requirement to consider outcomes nor to measure the benefits of rehabilitation activities with clients. Indeed, there is no evidence that rehabilitation services are delivered as an element of the HSP. Currently, HSP outcomes for this client group seem to relate predominantly to the number of hearing aids dispensed and not to any improvements in communication abilities or, more globally, to quality of life.

6. Is the Program supportive of consumer choice and control?

For newly diagnosed children through to the age of 7 years, it is entirely appropriate that there be a single obligated provider of hearing services (i.e., Hearing Australia). The designation and funding of a single obligated provider of services ensures that there is a safety net for children and their families and that a focus on quality of outcomes is not compromised commercial imperatives relating to hearing device provision and servicing.

On face value this situation could be interpreted as a limitation of choice. However, there is support (i.e., by services providers and consumers alike) for this position. It is widely acknowledged that the provision of a dedicated provider under the children's HSP has ensured a focus on the unique needs of children and facilitated the development of highly specialised professional skills to meet those distinctive needs.

The results of numerous consultations with consumers and parent advocacy groups for children with hearing loss have consistently shown that, although parents understand the potential benefit of having a choice of provider, they deem there to be greater benefits associated with having a sole obligated provider of services to children. Factors such as the assurance of unbiased information (i.e., unaffected by competitive or commercial interests), and the availability of highly specialised paediatric expertise that comes from large scale involvement in exclusively paediatric service delivery, are features of the current system that consistently rated more highly by families than choice and control when it comes to the provision of hearing services.

The current Department of Health project to develop standards for paediatric audiology is to be applauded. It is the strongly held view of RIDBC, however, that this initiative should not be seen as a strategy for opening the HSP to multiple providers in a contestable framework. The arguments for the continuing delivery of the Children's HSP by a single obligated provider are manifold. It is not within the scope of this submission to make those arguments, but we will be only too pleased to elaborate on those matters if requested.

7. Are the Program's service delivery models making best use of technological developments and services?

The HSP should provide access to a broader range of technology than just hearing aids. It is recognised that implantation of devices is currently beyond the scope of the program, which is appropriate given the National HealthCare Agreement. However, there should not be any systematic impediment to HSP clients who need access to such interventions being referred to and engaged with appropriate services to that end.

Regarding technology such as bone-anchored devices for conductive hearing loss, there are currently significant obstructions because of the gulf between State and Federal Government responsibilities in this area. For eligible HSP clients, the processor is funded by the HSP through Hearing Australia and the implanted elements of the device are funded as episodes of surgery and associated medical care by the various State and Territory health care systems. The divide between these systems and the frequent lack of commitment to by State health systems has a direct impact on HSP eligible clients seeking to access bone-anchored hearing aid technologies and puts them at significant disadvantage.

Provision of access to cochlear implant technology has traditionally been the responsibility of the states, and outside the remit of the HSP. Once again, this is appropriate in the context of the National HealthCare Agreement. However, unlike devices provided through the HSP, most states have a limit on the number of cochlear implants they provide to their constituents. As a result, access for HSP eligible adults with severe to profound hearing loss do not all have the same access to cochlear implants as they do to hearing aids. Therefore, many continue to access new hearing aids through the HSP that are not ameliorating their hearing difficulties to the extent that would be possible through a cochlear implant.

A recently released international consensus paper (Buchman et al., 2020) clearly articulates the advantages of cochlear implant technology for a significant proportion of adults with hearing loss. "Cochlear implants significantly improve overall and hearing-specific quality of life in adults with bilateral severe, profound, or moderate sloping to profound sensorineural hearing loss" (Statement 9, p.4). It is vital that mechanisms be found by which the HSP can make provision for referral to cochlear implant assessment as part of the services provided to clients; consistent with international best practice.

For HSP eligible adult clients (i.e. those over the age of 65) who receive a cochlear implant from a state-based program, there is currently no access to new technology in the form new/replacement sound processors . Therefore, clients who have sound processors that are obsolete, unsupported, damaged beyond repair, or require costly repair, are unable to have those replaced through the HSP. This is in contrast with HSP CSO clients under the age of 26 who can access replacement processors in these circumstances.

The net result of this anomaly is that adult clients with cochlear implants frequently struggle with obsolete sound processors (in some cases up to 15 years old) that are not providing the quality of access to sound that is available through newer devices. The impact of this circumstance is felt in terms of clients' engagement and independence. Further, this obviously creates a two-tiered system for those who were eligible for the NDIS prior to 65 who have lifelong access to upgrades.

Reference:

Buchman, C. (2000). Unilateral cochlear implants for severe, profound, or moderate sloping to profound bilateral sensorineural hearing loss: A systematic review and consensus. *JAMA Otolaryngology-Head and Neck Surgery*. DOI: 10.1001/jamaoto.2020.0998.

8. Does the Program sufficiently support consumers in thin markets?

Because of their community service obligations under the HSP, Hearing Australia has developed a very wide footprint and a system of outreach services that have become a backstop for thin markets. The obligation to provide HSP services to CSO clients where the population is very small has had demonstrable benefits for clients of the HSP in such areas.

Hearing Australia should be adequately funded to continue to provide expert CSO services in these markets.

9. Are there opportunities to improve the administration of the Program?

RIDBC is not able to comment extensively on this question.

It is noted, however, that with increasing number of government schemes and associated providers, there needs to be greater coordination between schemes in order to unburden consumers having to navigate the interface between systems themselves.

A concern regarding program administration relates to current economies associated with volume-based buying of devices. For providers such as Hearing Australia, these efficiencies may be lost if there were to be any move to contestability of the CSO program for children. Any such dimunition of economies would undoubtedly impact the overall cost of the HSP, for little apparent benefit.

10. Does the Program effectively make use of data and information to inform decision-making?

Because of its status as the sole provider of paediatrics Hearing Services, Hearing Australia has an extraordinary data base of information relating to paediatric hearing loss in Australia. As a consequence, with the possible exception of Denmark, Australia arguably has the best data in the world on childhood hearing loss and hearing device usage. Importantly, this information is made available annually in summary form through annual demographic report on children fitted with devices. That report is a vital source of information for the field and for the Government. The data is also used by newborn hearing screening programs, early childhood early intervention agencies and other educational programs . among others. The responsibility to maintain and report on data in this manner should be **an ongoing requirement of Hearing Australia under the HSP**.

As positive as the management and availability of data on children already is, it is noteworthy that there could be a significant enhancement of this data by the development and implementation of a national database for newborn hearing screening. Such a database could be brought under the terms of the HSP as a responsibility of a designated provider (perhaps Hearing Australia or its research arm, the National Acoustic Laboratories) to assist in monitoring the effectiveness of the interface between UNHS programs, the HSP, and the NDIS (i.e., to ensure that no children fall through the gaps between screening, diagnosis, hearing rehabilitation and early childhood early intervention programs). Notably, this need was identified as a key action in the Roadmap for Hearing Health “Enhance national data collection from the UNHS program and departments of education for longitudinal tracking and analysis”.

Beyond the management and reporting of paediatric engagement and device use data, it would appear that the HSP does not have enough data on the **outcomes of the program** to inform both program management and, importantly, Government decisions about program development or enhancement.

Most of the data that is made available regarding the Voucher program, for example, is related to outputs (i.e., vouchers issued, devices fitted, maintenance services provided, etc.). For more effective program evaluation and development there needs to be more information collected on the outcomes of the programs and reported for the benefit of those who use, administer, and fund the HSP. Specifically, there needs to be much more information made available about the nature of the clients who are using the program to ensure that there is a good match between the program's activities, the program's objectives, and the actual needs of the clients that are being served (particularly clients from CALD or other vulnerable groups). Apart from internal use of this data, public availability of deidentified data on the demographics of adult participants in the HSP (as for the paediatric program) would add greatly to research capability and our understanding of multiple issues including, for example, the number of clients who are served by hearing aids that might more effectively be served by engagement with other technologies, including cochlear implantation.

Overall, we would argue that there needs to be more information published on the **outcomes** for all participants in the HSP (i.e., children and young people, indigenous participants, voucher clients, and complex adult clients). That data should include information on longer term outcomes such as level of educational attainment and employment.