

Parent perspectives on the potential sale of Australian Hearing

The views of three organisations representing parents of deaf and hard of hearing children and young people

Our submission regarding the potential sale of Australian Hearing represents the views of three organisations representing parents of deaf and hard of hearing children. These groups are run by parents with the lived experience of raising a child with hearing loss.

Parents of Deaf Children is the peak body for parents of deaf or hearing impaired children in New South Wales. The role of the organisation is to support families in NSW with information, referral and advocacy services.

Aussie Deaf Kids is a not-for-profit organisation providing online information and support to families raising a child with hearing loss in Australia.

Canberra Deaf Children's Association is a non-profit community organisation providing support and information to parents and families on issues affecting deaf and hearing-impaired children.

As parents of children with hearing loss, we want our children to grow up to be able to fully participate in society. In order to do this, they need:

- A family with the capacity to provide them with the language environment and support they will need.
- Communication skills that allow them to learn, make friends, engage with their community and work.
- Access to technology, which allows them to develop the aforementioned communication skills and communicate with their family, their friends, their teachers, their employers and to participate fully within their community.
- Education and socio-emotional support to assist them to successfully achieve the goals they envisage for themselves.

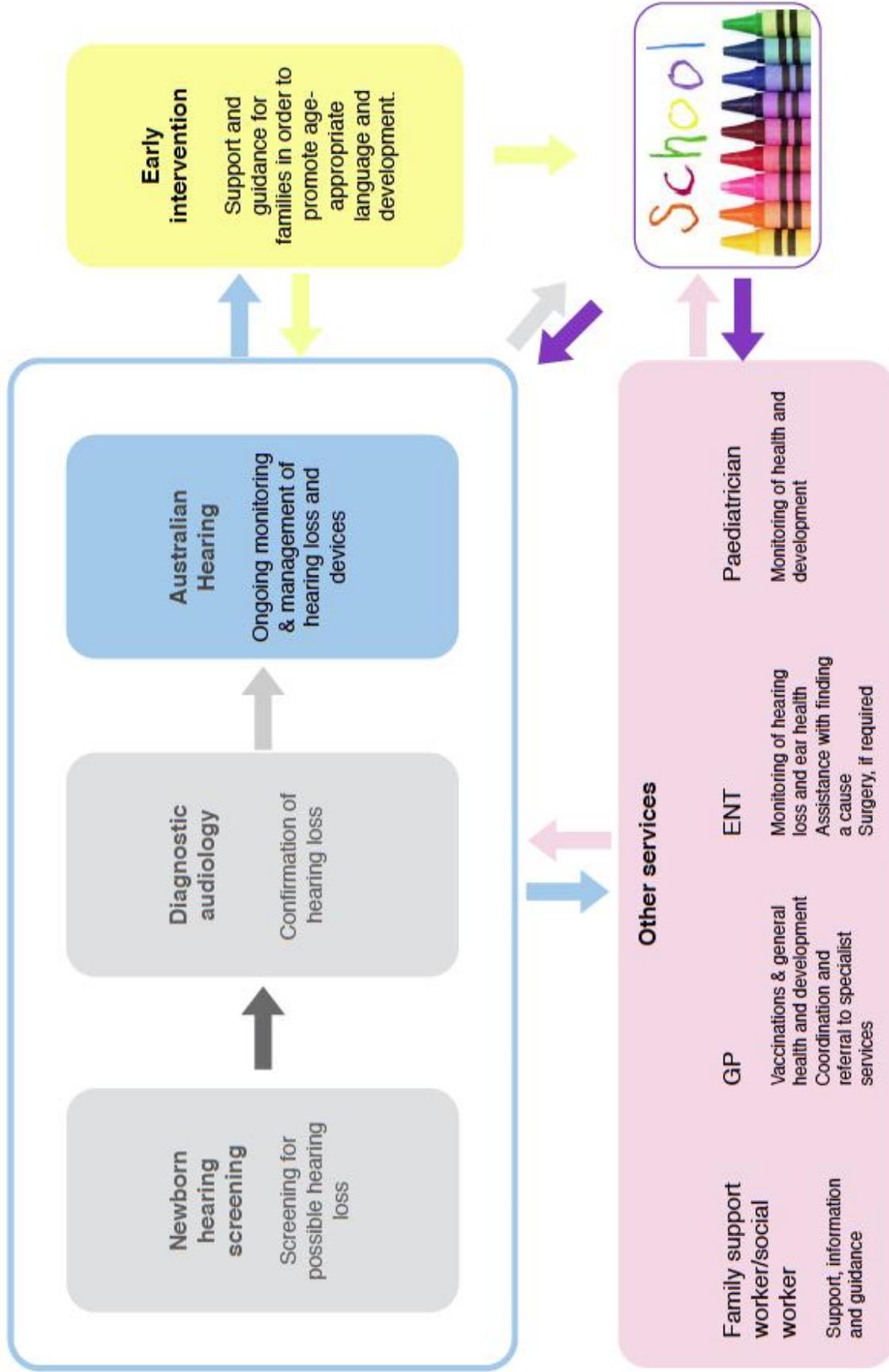
This submission expresses the views and concerns of our members regarding the potential sale of Australian Hearing. It is informed by our experiences as parents of deaf children who use Australian Hearing services. Our children have all levels of hearing loss and may have cochlear implants or hearing aids. Our children may use oral language or sign language or both (bilingual) to communicate.

We will only address the issues as they relate to children and young adults from diagnosis to 26 years of age. This is our expertise - living with and raising a deaf or hard of hearing child in Australia and we believe our views need to be a major consideration when any decisions are made that will affect our lives.

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The pathway from newborn hearing screening



In Australia, the loss to follow up after newborn hearing screening is less than 2 percent. In the US, where pathways from screening to diagnosis to audiological management provide considerable barriers for families, the loss to follow up after a “refer” screen was reported as 36.9 percent in 2012².

Section A: INTRODUCTION

The Australian Government announced the scoping study into the future ownership of Australian Hearing in the 2014 Budget.

“The Government will provide \$11.7 million in 2014-15 for scoping studies into future ownership options for Australian Hearing, Defence Housing Australia Ltd, the Royal Australian Mint and the registry function of the Australian Securities and Investments Commission.

The studies will assess the likely sale environment for each business operation and seek to ascertain the optimal method and timing of sale.”

In this submission we would like to address the issue outlined in the tender documents - *“maintain service and quality levels for AHS customers including in regional and rural Australia.”*

As parents of deaf and hard of hearing children in Australia, this is the critical aspect of the potential sale of Australian Hearing and one causing considerable concern to our members.

The sale of Australian Hearing will have a profound impact on the lives of thousands of Australian children and their families.

Australian Hearing has been providing services to children since 1947. These services have changed the lives of generations of deaf children. Hearing aids and other listening devices provide access to spoken language and help deaf people to communicate with family, friends, colleagues and the community.

The system for deaf and hard of hearing children in Australia is built around the fact that all children, regardless of location, socio-economic background or parental education levels, receive services from Australian Hearing that allow them access to high quality technology that optimises their ability to listen and, in turn, to learn.

The sale of Australian Hearing will not only alter the lives of our children and families, it will put at risk the entire health, education and disability support infrastructure that supports us. Newborn hearing screening, early intervention, education, family support will all require review and changes.

Consequently, the sale will put at risk the future outcomes for Australian children with hearing loss. We have detailed below why families value the services provided by Australian Hearing. We believe that the sale of Australian Hearing has implications for the whole system for deaf and hard of hearing children and their families and it cannot be viewed as a single entity for sale.

Section B: ABOUT HEARING LOSS IN CHILDREN

Almost all children born in Australia are now screened for hearing within hours of their birth.

Approximately 1 per 1000 babies born in Australia is identified with a permanent bilateral sensorineural hearing loss through newborn hearing screening - around 500 babies across Australia each year. Prevalence rates rise as children grow. This may be the result of an illness or accident or because the child has a progressive hearing loss¹.

Australia has a clear pathway from screening to diagnosis to audiological services which has resulted in the lowest loss to follow up rates after newborn hearing screening in the world - i.e. almost every child who receives a “refer” result at newborn hearing screening will continue on to diagnostic audiology and Australian Hearing, if required^a.

Deafness is a low incidence disability but the consequences can have a lifelong impact on language, literacy, educational achievement, socio-emotional development and the ability of the child to lead a productive and independent life as an adult.

Over 90 percent of babies born with hearing loss have parents who can hear. There is no family history of hearing loss and their baby is often the first deaf child they know.

Hearing loss can range from a mild loss to a profound loss. It can occur in one or both ears. The incidence of unilateral hearing loss is similar to bilateral hearing loss in children. Hearing loss can be stable or progressive - i.e. it gets worse over time. About 40 percent of children with hearing loss have an additional need such as vision impairment, cerebral palsy, global developmental delay or autism.

Approximately 11 percent of children using Australian Hearing have one or two cochlear implants. Most children with hearing loss use hearing aids to hear and listen. Most children, irrespective of the device they use, benefit from an FM system at home and school.

Contrary to the view often seen in the media, hearing aids and cochlear implants are not a cure or an instant method of changing lives from silence to sound. They are an aid. They assist a child to access sound and spoken language. If all the services and support required are in place and working well, then the child can grow and learn and become an independent member of the community.

The development of high quality technology and targeted interventions has changed the educational outcomes of deaf children over the past couple of decades. Increasing numbers of deaf children are now achieving similar education milestones as their hearing peers. For these outcomes to occur, the children need:

- Well-supported families who are engaged and able to sustain the work that goes into helping the child to achieve their potential.
- Appropriate high quality listening devices - these include hearing aids, cochlear implants and FM systems.
- Regular and reliable access to audiologists with specific paediatric experience, including working with children with additional disabilities.
- Targeted education services which support the child and family from the time of diagnosis through to adulthood³.

Our members overwhelmingly tell us that they **do not** want the system for providing hearing services for children to change and recent reviews of the service indicate that consumers of Australian Hearing service are very happy with extremely low levels of complaint.

The recent Australian National Audit Office validated this parent feedback. Audit Report No. 32 2013-14 into the “delivery of the hearing Community Service Obligation by Australian Hearing”, stating on pages 15 & 62:-

- “Overall the CSO program is being effectively administered by Australian Hearing in accordance with an MOA developed jointly with DOH. “
- “The level of complaints recorded in 2012-13 for the CSO program was low compared to the number of services provided (122 048) at 0.02 per cent, especially given the diversity of clients and the geographical spread of Australian Hearing’s operations⁴.”

Section C: WHAT DO FAMILIES VALUE ABOUT AUSTRALIAN HEARING?

1. Equity of access

- 1.1. When a child is diagnosed with hearing loss, they will receive free quality hearing aids that optimise their ability to acquire age-appropriate language, irrespective of where they live or their socio-economic status.
- 1.2. Australian Hearing services are available to families across the country - including families in rural and remote areas.
- 1.3. A child's future should not be compromised because the family is unable to afford appropriate hearing aids and other listening devices.
- 1.4. All children receive appropriate paediatric services, including those vulnerable children whose parents are unable to be strong advocates for them (due to factors such as having English as a second language, socio-economic background or education).

2. Reputable provider

- 2.1. At a time when families are most stressed and least knowledgeable, they know that the hearing needs of their baby will be optimised at Australian Hearing Centres. Families can be assured of a reputable provider with appropriate experience, knowledge and skills.
- 2.2. Families know that they will be provided with advice and equipment by Australian Hearing which is not governed by profit, sales or unscrupulous marketing persuading families to purchase products that are not required.
- 2.3. Families do not have to navigate the complexities of an additional system, especially in the early years, when they are still acquiring knowledge and understanding of hearing loss and its impact on their child.

3. Trained audiologists

- 3.1. At Australian Hearing centres families have access to trained audiologists who have expertise in dealing with the complex needs of children and families. Research indicates that outcomes for young children and their families are better when providers have experience working with deaf and hard of hearing children and their families³.
- 3.2. The size of Australian Hearing ensures a consistent standard is maintained and supported across the whole organisation which cannot be replicated by multiple separate organisations, therefore creating difference of service options based on factors other than the client needs
- 3.3. Testing and hearing aid prescription in babies and children is a complex and time consuming process and often requires multiple appointments. It can take many appointments and patience to develop a clear picture of a child's hearing levels

and the structure of the program provided by Australian Hearing allows for this contingency.

- 3.4. Australian Hearing Audiologists have support of experts from the National Acoustic Laboratories and can refer children with complex hearing disorders there for specialist testing. This is extremely reassuring to families with complex needs - world class hearing health care regardless of socio-economic factors.
- 3.5. The comprehensive paediatric program Australian Hearing provides allows the audiologists be exposed to and experienced in:
 - 3.5.1. Testing babies and children
 - 3.5.2. Hearing aid prescription and provision in children
 - 3.5.3. Children with additional needs - around 40 percent of children with a hearing loss have an additional need. This requires additional expertise and understanding for each child and family.
 - 3.5.4. Family-centred services - understanding that supporting the family is crucial to the outcomes of the child.
 - 3.5.5. The changing audiological needs of the child as they grow from babies to young adults - each life stage requires different technology and support systems for the child and family.

These skills provide a high quality service that is paramount to the ongoing development of each child.

4. Evidence-based practice

- 4.1. Australian Hearing has a consistent approach to hearing aid prescription and children are fitted with hearing aids where they are tested. A recent US study indicates the importance of this approach in optimising hearing aid prescription for speech audibility in children. Fitting errors were more likely in locations where children received their hearing aids from a larger number of audiology practices throughout the catchment areas ⁵.
- 4.2. The National Acoustic Laboratories has been at the forefront of research into hearing aid prescription and features that optimise access to spoken language. Children and young people have benefitted from their research and use of the NAL prescription at Australian Hearing centres.
- 4.3. As clients of Australian Hearing many children have been part of the LOCHI study⁶ - the largest longitudinal study of deaf and hard of hearing children in the world - undertaken by NAL. This study has provided evidence for best practice for services for deaf and hard of hearing children around the world.

5. Additional support mechanisms

- 5.1. International guidelines on family-centred services published in 2013 outline the many additional support mechanisms required by families in their journey. Australian Hearing audiologists have been the mainstay for provision of much of this information to families over many years (Moeller et al., 2013).

- 5.2. Australian Hearing provides culturally appropriate service and access to interpreters to ensure families are able to understand their child's hearing loss and its management.
 - 5.3. Children live and learn in many different environments and Australian Hearing liaises with early intervention and education services to holistically care for the child and family
- 6. Repairs and maintenance**
- 6.1. Hearing aids, cochlear implants and FM systems are small, sensitive and fragile - not child-friendly. Despite the best efforts of parents, they are broken or lost. Maintenance support is essential at the hearing services centres.
 - 6.2. Children cannot learn without their listening devices and their needs are quickly met with replacement devices, repairs and loan devices when repairs are lengthy.
 - 6.3. The technicians available at many Australian Hearing centres are experienced and knowledgeable and are often able to repair equipment on the spot. This minimises the time a child is without their device.
 - 6.4. The Cochlear Implant Support Program provides a valuable service to parents whose child has a cochlear implant. Families have ready access to an expert for troubleshooting and replacement parts.
- 7. Economies of scale and cross-subsidisation**
- 7.1. Our children currently have access to the quality hearing devices primarily due to the buying power that Australian Hearing has in the market. If the organisation is sold, this buying power will be eroded, leading to lower quality aids and subsequently less quality access to sound, speech and language for our children.
 - 7.2. Australian Hearing has funded the budget shortfall for the CSO component of the Hearing Services Program from profits realised from providing commercial services to their Voucher clients⁴. This has provided the funding for children's devices to keep pace with changing technology and innovation. If children are to compete in this world, they need access to technology that will facilitate their participation.
- 8. Engagement with parent support groups and consumers**
- 8.1. Australian Hearing has met regularly with parent support groups over many years, listening to their suggestions and acting on these or any issues requiring attention. It is a collaboration based on trust and mutual respect for the knowledge each party brings to the table - Australian Hearing are experts in audiology and parents are experts on living and raising a child with hearing loss.
 - 8.2. The Paediatric Program Advisory Committee, established in 2013, allows for additional collaboration and guidance from consumers - both parents and young adults using Australian Hearing services.

Section D: OUR QUESTIONS FOR THE SCOPING STUDY

How will a privatised system ensure: -

1. All children, including those whose parents cannot be a strong advocate for them, due to factors such as having English as a second language, socio-economic background or education, continue to receive appropriate paediatric services?
2. Families receive independent and unbiased advice about their child's hearing loss, listening device requirements and early intervention needs?
3. Children are provided with free quality listening devices that meet their needs at least until the age of 26?
4. Devices will be updated as technology changes or the needs of the child change?
5. Hearing device maintenance services deliver prompt repair or replacement capability?
6. Access to services is maintained in regional, rural and remote areas? Australian Hearing currently operates many centres in regional areas that DO NOT have specialised Early Intervention for deaf and hard of hearing children. These Early Intervention services maintain that it is not financially viable for them to operate in these areas. How can families in regional, rural and remote areas be assured that future owners of Australian Hearing will not come to same conclusion and consolidate or centralise services in major cities?
7. Parents are not coerced into purchasing devices with features that are not required by the child in that period of their life?
8. Appointment allocation provides sufficient time for the audiologist to test and fit young babies and children with appropriate devices?
9. Audiologists have experience and training to deal with children including children with additional disabilities?
10. Consistency of service delivery is maintained across all service providers or locations?
11. Aboriginal and Torres Strait Islander families, migrant families and Deaf families receive culturally appropriate services and interpreters so they are able to understand their child's hearing loss and needs and make informed decisions?

12. The entire support structure for deaf and hard of hearing children in Australia is built around the services provided by Australian Hearing. How will this be addressed if a sale is to proceed?
13. How will the system be monitored and evaluated? Monitoring must include documenting child and family outcomes, knowledge and skills of the interventionists, and family benefit from services³. Any changes to the system need close monitoring and evaluation to ensure the outcomes of deaf and hard of hearing children and their families are not compromised.
14. Research is continued on providing the best outcomes for children with hearing impairment?
15. Specialist technical support is provided for children diagnosed with complex hearing problems?
16. Engagement and input continues with parent groups so that the service delivery meets expectations?
17. Information interchange between the hearing service provider and early intervention services, schools and medical specialists is consistent and continued?
18. Why are we changing a system that is considered to be the best system in the world for the audiological management for children diagnosed with a hearing loss?

Section E: RECOMMENDATIONS

1. Parents of deaf and hard of hearing children believe that the interests of their child and family are best met through the current Hearing Services model and the proposed privatisation of Australian Hearing should NOT proceed.
2. Parents of deaf and hard of hearing children recommend that the scoping study considers:
 - All the services identified in Section C that MUST be maintained, and
 - How a privatised system can continue to deliver equitable services to families so the outcomes of deaf and hard of hearing children continue to be optimised irrespective of where they live, their level of hearing loss or the devices they use to access spoken language.
3. Parents, parent groups and other consumer organisations who receive services under the Community Service Obligation component of the Australian Government Hearing Services program are consulted at each step in the process leading to the potential sale of Australian Hearing.

Section F: AUSTRALIAN HEARING - SUPPORTING KIDS AND FAMILIES

CAYDEN

“Australian Hearing has been in my family’s lives since our youngest son was diagnosed deaf in 2008, just after he was born. The availability of Australian Hearing provided us with a sense that our child will be supported until he is grown up. The service and initial hearing aids, and later cochlear implants that he received has made it so much easier for us to help develop to his potential and increase the possibility for him to be independent in the future as an adult. This need is amplified as he was later diagnosed with severe autism and severe global development delays, requiring full time care. We hope that the privatisation of Australian Hearing does not increase an already heavy burden on us to provide for his future needs.” Alan - Cayden’s dad



ANNABEL

Fortunately, we were referred to Australian Hearing at the end of our diagnosis appointment...We felt enormous relief knowing that there was a proven system in place to manage Annabel’s audiologic care; we did not feel knowledgeable enough (or indeed, emotionally ready) to investigate other audiology services. Learning about Australian Hearing was our first bit of ‘good news’ in what had been a turbulent and emotional few weeks.

Annabel will turn 3 this September. She is a little chatterbox with age-appropriate speech and language. She demands her hearing aids before her feet hit the floor every morning and is proud to show them off. I am so grateful to Australian Hearing for giving her the chance to hear. Claire - Annabel’s mum





ISAAC

My name is Isaac. I am twelve years old and I am profoundly deaf. I wear a hearing aid and a Cochlear Implant to help me listen and speak.

Being profoundly deaf, I use Australian Hearing as a service. I was diagnosed Christmas Eve 2002 and in the following March, at ten months of age, I got my first hearing aids at the Croydon Australian Hearing centre here in Melbourne. My mum and dad were very excited to have this place to go for support and information about my hearing loss. My parents have leaned on Australian Hearing for all of my twelve years and have become friends with my audiologist too.

Please don't sell Australian Hearing because kids like me need it; parents like mine need the support to get their children the best equipment so they can live better lives.

Being able to hear brings freedom and confidence and the ability to reach our full potential. I can work when I'm older and help the country in the future. I want to be a zoologist and I think with my grades I can do that.

We need Australian Hearing, we are the best country in the world for helping hearing impaired people and if we lose Australian Hearing you will take away from my friends, family and myself the chance of being able to have a great life.

BRIAN

I am profoundly deaf and have worn hearing aids since my diagnosis at 2 years of age. My son is moderately to profoundly deaf and was diagnosed when he was 3 weeks old. Brian's dad is third generation deaf person and wears hearing aids. We wanted Brian to be bilingual and therefore wanted him to be aided as soon as possible.

The first audiologist that managed Brian's case was 'deaf aware' and always ensured that an Auslan interpreter was available for the appointments. When Brian was 18 months old, the audiologist went on maternity leave. We decided to transfer Brian to another centre that is close to our work and that is when we met an audiologist who signs and was always happy to help or provide more information.

Before Brian started school in 2013, the audiologist was great support to our family in terms of managing the FM system and providing information about how to maximise auditory environment in schools. In Brian's class, there was another student who was using an FM system and therefore there were some issues of setting up the right channel so that both students could use the FM. The audiologist arranged on her day off to visit the school and show the teacher and support staff how to troubleshoot.

Our family has always been impressed with the service provided by the audiologists and the fact that they will always try and book Auslan interpreters for the appointments. Diana - Brian's mum



LUCY

We have benefitted from the research that they [NAL] are doing into Auditory neuropathy as protocol for ANSD have changed even in our daughter's short life. The paediatric trained AH staff are great at putting together the puzzle that each little hearing impaired person throws at them. My daughter also has mild cerebral palsy which required regular physiotherapy on top of all the hearing impairment. My daughter is only 3 ½, so we are only at the beginning of the journey. The rawness and sense of grief and loss is gone but when that was there, we certainly needed to know that we were in safe hands. I

certainly didn't need the hard sell of hearing equipment on top of where we were. Scary thought as you are really very vulnerable. Natalie - Lucy's mum



BAILEY

I have a twin brother Jeremy and we are 13 years old. My brother and I are both hearing impaired with Jeremy recently getting a cochlear implant...We have been involved in AHS since we were first diagnosed at 4 years old ... I have a deteriorating hearing loss and that means we sometimes go to AHS up to twice a week. We go there to get our hearing tested and our hearing aids fine tuned and adjusted to depending on our loss. They also provide me with equipment to help me with my education they also provide batteries, all for free. When my

hearing aids need fixing, we take it there and they fix them.

I am really worried if AHS gets sold, then children like me would not have access to the brilliant services that they currently provide. I feel I am very lucky to have all the help through them. It makes me feel sad that we may not have the support in the future and other little children won't have been as lucky as I have been so far. I am also scared that I will just see any audiologist, not one that actually knows me and cares.

I have attached a photo of my brother and myself for you to see that we are REAL children. I am on the right. Bailey - 13 years old

CHARLIE

Charlie has been aided since she was 4 weeks old, She has a severe - profound bilateral loss. Australian Hearing have provided our family with so much support and assistance making a very difficult time in our lives so much easier.

We are concerned that if AH is sold the streamlining of access to professionals and technology may be affected, as well as the possible financial impact to our family and many others.

We feel blessed to have this facility and would be devastated if things change.

Mel - Charlie's mum



DAVID

David was diagnosed severely-profoundly deaf after his newborn hearing screen. We were referred straight to Australian Hearing. In those first busy months, they took care of everything - tested David's hearing periodically, fitted his aids, instructed us in how to use them, and even now, still see us frequently. They even sometimes come to our playgroup to conduct basic tests and fit new molds, so we didn't have to go to their office. At aged one, David was fitted with a cochlear implant, and ever since, Australian Hearing has maintained a thorough communication with the Royal Eye and Ear Hospital to keep everyone co-ordinated. They made our life so easy in that overwhelming time. For the sake of all families dealing with hearing loss, I urge you to give Australian Hearing priority to continue to deliver a high quality of care.

Therese - David's mum



BENTLEY

Our son Bentley was born with Microtia and Atresia. He has no right ear or ear canal and therefore has a unilateral hearing loss. Bentley has been under the care of Australian Hearing since he was a baby. The consistency of care, professionalism, knowledge and understanding provided by Australian Hearing have been invaluable. We feel supported and know that Bentley's hearing and development is their utmost priority. Children with a hearing loss deserve equal access to learning. Our main concern about the proposed privatisation of AH is that hearing services will become profit driven. How can a service provide unbiased support when they are under pressure to meet targets and work within strict budgets? We feel that all children who access this service, including Bentley, will greatly suffer.

Carmen - Bentley's mum



FELIX

We cannot begin to imagine how much more difficult our journey would have been without the services of Australian Hearing. Right when we were dealing with the devastating news of our newborn, Felix, being born deaf, they were there as a central body to assist us in determining the best future for our child. We didn't have to hunt for them. We didn't have to be concerned with their motives, their profitability requirements, or their bias. They were able to direct us to the ongoing services which would suit us best. They don't have to do the bulk of the work to assist Felix as they are not an early intervention service provider, but they guided and supported our family, and continue to do so, with definitive annual testing, supply of technology and spare parts, and unparalleled expertise. Jo - Felix's mum





OLLIE and LILY

Australian Hearing has been in our lives for nearly 17 years now. Ollie first got aided when he was 3 and he is nearly 20 years old now. His younger sister, Lily became a client not long after, when she was diagnosed at 2 years old. She is now 17. In those early years, some weeks we virtually lived at Australian Hearing..

When my son was 15, he did not want to wear his hearing aids – he was at a mainstream school and the only hearing impaired student at the school. He just did not want to be different. I remember that he and I had some difficult weeks – we fought every day about this and our relationship was severely tested.

A visit to his audiologist at Australian Hearing was the breakthrough. They had always got on well and she was able to find a way through it with him. She went through what the problems were and how they could fix them. We left that appointment with a 15 year old who was much happier and who, in my eyes, had started a new phase of life - independence. It was the beginning of him becoming the client. It was also a turning point for me in learning to step away and trust that he will be ok. Trust was the key – I trusted the service and always have, with the hearing health of my children. I have always felt that he would be ok with the safety net of Australian Hearing services in place. Kate – Ollie & Lily's mum



KAITLYN

My daughter is deaf and she can't hear without her hearing aids. She has progressive hearing loss and will one day get a cochlear implant. In America, where I'm from, this costs \$100,000.00. We can't afford that. Not many people can. If you privatise Australian Hearing, you're on your way to an unfair system like they have in the States. It won't happen overnight, but it will become more unequal over time. Australia has the best audiology services for children in the world. Don't change this.

BONNY

I cannot express enough how vital the services Australian Hearing provide have been for me. Because of them, I am fortunate enough to have grown up with access to the best Hearing Aids and FM Systems. Without these services I would not be able to do half the things my hearing friends do - I would have to stay at home and save for thousands of dollars for the inevitable stream of hearing batteries, moulds and hearing tests that is my life.



The services Australian Hearing provide help make what could be a challenging impairment to my life, a mere characteristic of who I am. I certainly would not have had the opportunity to appear on Masterchef The Professionals, nor would I have grown up to have the confidence I do to face the world and fight for who I want to be. I know I am not alone in this.

Bonny - aged 25.

Section G: REFERENCES

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