
SUBMISSION TO THE SENATE INQUIRY

INTO

HEARING HEALTH IN AUSTRALIA

ANZPOD
a coalition of parents of deaf children
across Australia

October 2009

ANZPOD represents families of children who are deaf or hearing impaired around Australia. Members of the group are all parents of deaf or hearing impaired children and represent most of the major parent organisations within Australia. The group is a loose collaboration of parents who wish to make a difference for the parents following in our footsteps. Participation is entirely voluntary and we receive no funding. Our children range in age from 1 to 21 years of age.

The initial focus of this group was to ensure parents of deaf and hearing impaired children have a voice in the development of the National Standards for Newborn Hearing Screening. However ANZPOD also aims to ensure parents of deaf and hearing impaired children have a voice in the development of policy initiatives such as those that may arise as a result of the Hearing Health in Australia inquiry by the Senate Community Affairs Committee.

ANZPOD's submission relates directly to the terms of reference as provided by the Senate Community Affairs Committee.

Within these terms of reference, we seek to address two main areas:

- Universal newborn hearing screening in Australia
- Access to hearing services and technology for all Australians but in particular our children when they turn 21.

In addition, we have briefly addressed the following issues:

- Noise-induced hearing loss
- Employment
- Captions

I. THE EXTENT, CAUSES AND COSTS OF HEARING IMPAIRMENT IN AUSTRALIA

I.1. The extent

Currently one in six Australians has some form of hearing impairment. Data provided by the 2006 Access Economics Report "Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia" forecasts this figure will rise to one in four Australians by 2050.¹ Each of these Australians with hearing loss, does not exist in a vacuum but is part of a wider family unit. Figures that look at relative costs of hearing impairment relate mostly to the individual with the loss only and not at the whole family. So while the extent of hearing loss itself is currently at one in six, the extent of the impact of that individual's hearing loss is much wider.

There is an increasing prevalence of hearing loss with age and this is true for children as well. Australian Hearing reports "In Australia, between 9 and 12 children per 10,000 live births will be born with a moderate or greater hearing loss in both ears and around a further 23 children per 10,000 will acquire a hearing impairment that requires hearing aids by the age of 17 through accident, illness or other causes."²

I.2. Causes

Hearing loss in children can be congenital or acquired. Congenital causes can be genetic or non-genetic in origin. Acquired hearing loss occurs after birth and is usually associated with illness, such as meningitis, recurrent ear infections or injury. Increasingly, young people are exposing themselves to the significant and preventable risk of developing hearing loss from the use of portable stereo players (PSP).

Hearing loss can be sensorineural or conductive in nature. Most children born with a hearing loss have a sensorineural hearing loss as a result of damage to the inner ear or the nerve pathways to the brain. Sensorineural hearing loss is permanent.

Children can also suffer from conductive hearing loss which occurs when sound is not transmitted efficiently through the outer or middle ear.

¹ *Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia*. (2006). Access Economics. Retrieved 07/10/09 from <http://www.accesseconomics.com.au/publicationsreports/getreport.php?report=71&id=81>

² *Hearing loss in Australia - it's more common than you think*. Australian Hearing. Retrieved 7/10/2009 from <http://www.hearing.com.au/upload/media-room/Hearing-loss-in-Australia.pdf>

Conductive hearing loss can often be medically or surgically treated. A significant number of children suffer from conductive losses, often as a result of otitis media. It should be noted that chronic otitis media is a significant issue in the Aboriginal and Torres Strait Islander populations and often times a major cause of hearing loss in these communities.

1.3. **Costs**

The financial burden of hearing loss has been well documented by the Access Economics in their 2006 report – costs largely attributed to lost productivity in the adult years.

Families receive financial assistance for their child with a hearing loss through:

- **Hearing services**
Hearing services for children under 21 are well supported by the federal government. Our children have access to a full range of hearing services through Australian Hearing until age 21. This system uses technology, such as hearing-aids, that enables our children to use their residual hearing and assist them to develop speech and language skills.
- **Carer Allowance**
Most families rely on financial assistance provided by government, such as the Carer Allowance and Child Disability Allowance, to help meet the additional costs of raising a child with a hearing loss. Although these allowances do not come close to covering all the relevant expenditure, ANZPOD welcomes this support and recommends that it should continue.

The financial costs of living with lifelong deafness are enormous – hearing aids and cochlear implants are high-end technology and are, therefore, very expensive. Added to this are the costs of necessary devices such as FM systems and specialised alarm systems – smoke detectors, doorbells, alarm clocks etc. None of these attract tax-deductibility status nor are there any subsidies available despite the fact they are essential for ‘normal’ day-to-day living.

Some children require services from Allied Health providers, for example, speech pathology, physiotherapy and occupational therapy, to help manage their hearing loss. These families may be eligible for Medicare rebates for these services, however, rebates are limited to a total of five Allied Health services per calendar year. Families may also recoup a small

percentage of the fee from private health insurance.

The hidden cost with respect to hearing impairment is hard to quantify. The ability to communicate is the very essence of being. Poor communication skills very often means poor literacy and numeracy skills, poor educational achievements, poor employment prospects, limited income, social exclusion and a high incidence of mental and physical health issues.

2. **IMPLICATIONS OF HEARING IMPAIRMENT ON INDIVIDUALS AND THE COMMUNITY**

2.1. **Individual implications**

For the vast majority of deaf and hearing impaired children, the ability to communicate is solely dependent on the use of hearing augmentation devices – hearing aids and cochlear implants. Life without these devices is impossible. Education, social interaction, sport, daily life in general – all that the ‘normal’ hearing world takes for granted – becomes almost impossible for our deaf and hearing impaired children if their hearing aids or implants are not working properly or are missing. These devices represent an essential part of their ‘being’. They are excellent users of their state-funded devices – their hearing aids do not end up in drawers unused.

Our children are fortunate to have access to hearing health services until age 21 through Australian Hearing. The present system (world’s best practice) sets out to provide our children with the opportunities to be become fully functioning and contributing members of society only to trip them up at the final hurdle. Once they turn 21, this service is no longer available to them. Newborn hearing screening and free access to hearing services, hearing aids, cochlear implants and other assistive devices means that our children grow and learn in an environment where they are dependent on technology. At 21, many of them are still studying or starting out in the workforce, and they are faced with the prospect of having to find appropriate audiological services who understand congenital hearing loss and also fund the purchase of private health insurance, hearing aids and cochlear implants.

One of the members of ANZPOD cites her own personal story:

“I have 5 children all of whom have been afforded the same educational and social opportunities. They have all attended university and have

opted for different career paths. My deaf 21 year old son, however, must always factor extra 'disability' costs into his life – he must always have funds available for regular audiological and ENT assessment, hearing aid maintenance and replacement, hearing aid batteries and essential safety devices. It will always cost him more than his siblings to live and work 'normally'.

ANZPOD member, Jo Quayle, voiced the concern of parents and young adults alike at the 5th National Deafness Sector Summit in 2008, “Productivity and social inclusion for young deaf and hearing impaired people can’t happen if they can’t afford to replace or repair their hearing aids.”

2.2. **Community implications**

As parents of deaf children, we are very aware of the economic, educational and social effects of hearing loss. With increasing numbers of children being diagnosed as newborns and intervention provided at a younger age, we are encouraging these children to communicate and interact with the use of technology in the form of hearing aids, cochlear implants and other assistive devices. These individuals form their identity while wearing fully supported technology until age 21 when they become ineligible as previously highlighted.

Hearing aids and cochlear implant speech processors are extremely expensive and they do not have lifetime guarantees. They break down and need to be repaired and ultimately need to be replaced. At the age of 21 there are not many who can afford maintenance expenses of this magnitude. Some are still students, some have had only limited years in the workforce – if their devices break down or fail completely, their capacity to afford repairs and/or replacement is severely limited. Without these devices, it is almost impossible to study or work and therefore the capacity to earn the funds to repair/replace the devices let alone to provide for all other living expenses is almost non-existent. We also know of many individuals who are only able to afford one hearing aid, which is not adequate for their hearing needs. Where is the social justice ideal of equity of access for all when individuals are forced to make do with only one hearing aid because they cannot afford a second one?

The social costs of living with lifelong deafness are immeasurable – social isolation, limited access to captioned television, movies, public broadcasts (especially emergency broadcasts) just to name a few. If our deaf

and hearing impaired children cannot afford the costs of repair/ maintenance to their devices then the social costs are compounded. Ultimately the cost to the community at large is enormous – rather than independent, tax-paying contributors to society, they become social welfare recipients.

Hearing impacts on the whole family not just the individual with the loss. There is a higher level of marriage breakdown where parents are dealing with the emotional and financial implications of raising a child with a disability. Similarly siblings of children with a hearing loss often resent the extra time and attention provided to their sibling which can lead to behavioural issues. The family as a whole needs to be supported throughout the journey with access to appropriate counselling at any point in time being a priority for families. This issue will be further discussed in terms of reference 3.2 - “Adequacy of access to assessment and support services”.

3. THE ADEQUACY OF ACCESS TO HEARING SERVICES

3.1. Adequacy of access to hearing services and hearing technology

As previously noted there are issues of access to hearing services for children who have been supported through Australian Hearing from diagnosis until they turn 21. After turning 21 they cease to be eligible to access this service.

There are two main issues for our children when they turn 21:

3.1.1. Finding appropriately trained audiologist

Our children need to find an audiologist in the private sector who understands the issues of congenital deafness and has the knowledge and skills in the complexities of their needs. Most private audiologists are experienced in acquired hearing loss and the appropriate audiologist is almost impossible for our children to find.

An additional problem is that many private hearing clinics are staffed by audiometrists who are not university trained and do not understand congenital hearing loss. We are concerned that uninformed young adults may receive advice from these clinics which is inappropriate and potentially costly for our children.

3.1.2. Cost of ongoing technology needs

- **Hearing aids** – these costs around \$3,000 each. Most of our children wear two hearing aids. A rebate is available from private health insurance but is only available on the extra cover and goes no way near meeting the cost of the hearing aids. Membership of a health insurance fund is also income-dependent – students and low-income earners are the least likely to be members of Health Insurance funds. Regardless of this, the rebate for hearing aids and speech processors is extremely small and is no incentive to join a fund.
- **Ear moulds** – hearing aids attach to ear moulds which fit into the ear canal. These need to fit well, otherwise the hearing aid produces feedback which is unpleasant for everybody. Ear moulds also deteriorate over time. The cost of replacing an ear mould is between \$75 and \$150.
- **Hearing aid batteries** - batteries cost around \$1 each and last approximately two weeks.
- **Repairs** – this depends on the nature of the repair but can be several hundred dollars.
- **Cochlear implants** – Implantees with private health insurance can claim an upgrade on their processor but those without private insurance will need \$8000 for a single processor. Many of our children now have two cochlear implants. We understand that two thirds of adult implantees are not privately insured.
- **Cochlear implant batteries** – each processor requires three heavy duty batteries which last 2 days. This is a cost of around \$60 per processor per month.

As one of our members highlights:

“Of course we all know this one but for my daughter – 1 implant 1 hearing aid = \$16,000 plus FM=\$1,000 + batteries \$500 so at 21 she will require (on today’s rates) a job which give her approx \$6,000 a year to maintain her battery addiction, and be able to put away money to upgrade in 3 years. That’s without any technology issues that require servicing and a fee for that. All of this is without having a life.... Study, work and social life would all be affected.”

In the United Kingdom, the National Health Service (NHS) provides hearing aids at no cost to those that require them . “NHS hearing aids, new earmoulds, tubing, batteries and repairs are free. On average, they last about five years. If you lose your hearing aid or damage it, you may be asked to pay towards the cost of repairing or replacing it.” ³

Currently audiological services are not available on the Medical Benefits Schedule. Medicare rebates for such services would assist in the financial costs associated with lifelong deafness.

Recommendations for former child clients of Australian Hearing Preferred option

All former child clients of Australian Hearing over the age of 21 continue to be included in their Adult Eligibility list. This could be done via a voucher system where the individual could choose their provider of choice and receive their hearing aid at no cost, in the way that pensioners currently are entitled to a voucher to cover the costs of purchasing hearing aids. Vouchers should cover the cost of the aids which includes features that are clinically warranted for that individual – not just one model fits all. Individuals can choose to top-up aids with additional features if they wish and pay the gap. Similarly cochlear implant upgrades and repairs could also be funded under a voucher system.

Second option

All former child clients of Australian Hearing over the age of 21 be permitted to continue to be serviced by Australian Hearing until they reach a certain income threshold. For those young adults who also have HECS repayments, this threshold may need to be adjusted upwards to ensure an appropriate living wage.

Third option

Tax rebates on hearing services, hearing aids, cochlear implants and assistive listening devices. Assistive listening devices such as FM’s, flashing door/smoke alarms, home loop systems etc should be tax deductible for all age groups. Parents should be able to claim for dependants.

³ *How do I get a hearing aid through NHS?* NHS Choices. retrieved 07/10/09 from <http://217.64.234.89/chq/Pages/894.aspx?CategoryID=68&SubCategoryID=157>

3.2. **Adequacy of access to assessment and support services**

The Prime Minister recently announced the introduction of universal newborn hearing screening throughout Australia by 2011. Newborn Hearing Screening is an initiative whole-heartedly supported by parents. The potential for improved outcomes for our children in terms of language development and the flow-on effects for education and socio-emotional development is an exciting and welcome prospect.

As parents of deaf and hearing impaired children, we want to ensure that newborn screening programs meet the needs of all families throughout the country, irrespective of the extent of the child's hearing loss, their geographic location or their ethnicity. We believe that current early diagnosis and referral services do not acknowledge the parent expert and do not fully reflect families' needs.

In July 2009, we outlined our vision for newborn hearing screening programs in a document titled "Quality Standards for Newborn Hearing Screening Services – supporting families" which is attached.

In brief, we believe that newborn hearing screening programs will meet the needs of families and improve outcomes for our children if:

- While acknowledging the important role played by professionals, parents need to be an integral part of the planning and decision-making stages of program development. Development of services should be the result of parent-professional partnerships.
- All babies in Australia have access to newborn hearing screening which is timely and minimises stress and disruption to the family
- The choices made by families need to be informed, meet the needs of the child and family and reflect their desires, beliefs and values. This requires accurate, reliable and unbiased information and appropriately trained professionals who support the notion of informed choice for families.
- Parents need family-friendly services which empower families and help them develop new strengths and competencies which meet the ongoing needs of their growing child.

Recommendations for universal newborn hearing screening

These are outlined in the attached document "Quality Standards for Newborn Hearing Screening Services – supporting families."

Assessment of hearing loss is only the first step; it is the intervention program that follows that makes the difference in the life of the child with a hearing loss. Intervention includes a range of services such as audiological, family, early learning and medical support. As part of any newborn screening program, there needs to be high quality, evidence based, early intervention programs that are available to all families on an individual needs basis. Empowering parents by providing them with information about all possible educational methodologies means little, if those same programs are not readily available. Early intervention services must provide personnel that have both the training and expertise to be able to deliver the program and ensure satisfactory outcomes for families.

When families first learn of their child's hearing loss, it can be a very difficult and emotional time. At that point, families need access to a range of support services, including meeting other parents who have children with a hearing loss, meeting Deaf and hearing impaired adults, and access to counselling services. Parents and families all cope in different ways with the diagnosis of a child with a hearing loss and as such counselling services need to accommodate those differences. Families need to be able to access counseling services at any point in the journey, not just in the early years.

4. **ADEQUACY OF CURRENT HEARING HEALTH AND RESEARCH PROGRAMS**

For many parents it is a difficult decision to choose specific interventions. This is in part due to a lack of detailed and easily accessible information that relates to outcomes demonstrated by specific intervention methodologies. Research into educational approaches and their outcomes is an area that needs further investigation.

ANZPOD awaits with interest the outcomes of the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study currently being conducted by the research arm of Australian Hearing - National Acoustic Laboratories.⁴

⁴ Further information on the study, which began in 2005, can be found at www.outcomes.nal.gov.au

5. **ADDITIONAL POINTS FOR CONSIDERATION**

The major focus of ANZPOD's submission has been across two main areas that we feel most strongly about as parents of deaf and hearing impaired children. However, there are others areas that we believe also need to be a focus of the Senate Committee Inquiry and would like to briefly make reference to them here.

5.1. **Noise induced hearing loss**

Hearing loss can also be acquired later in life. We believe that for over one third of people with hearing loss, excessive noise is responsible for at least part of this loss. Excessive noise is present in many situations. Some of the more common sources include industrial machinery, nightclubs, movie theatres, lawn mowers, low flying jet aircraft and loud impulse noise, such as an explosion or gunfire. The effects of excessive noise on hearing are permanent.

Most developed countries, including Australia, have Occupational Health & Safety legislation designed to protect hearing in the work place. However, in some industries such as farming, hearing protection regulations are difficult to enforce. Furthermore, there seems to be little awareness in the general community of the risks associated with recreational noise, particularly amongst children and young adults. The "it won't happen to me" attitude prevails.

As parents of deaf children, we are very aware of the economic, educational and social impacts of hearing loss. We are particularly concerned at the number of young people who are exposing themselves to the significant and preventable risk of developing hearing loss from the use of portable stereo players (PSP).

In recent years sales of personal music players, which include mobile phones with such functions, have soared. The risk of noise induced hearing loss increases when PSP are used in environments where users raise the listening level to mask out background noise, such as on public transport.

There is ample scientific evidence that regular exposure to noise intensity above a level of 85 decibels (dB), can permanently damage hearing. For some people, hearing damage occurs at 75dB. The maximum volume setting on some personal music players can generate up to about 120dB, the equivalent of an airplane taking off nearby. According to a European Commission report in October 2008, around 10 percent of

listeners risk permanent hearing loss or damage by listening to loud music every day for five years.⁵

In recent weeks, the European Commission ordered all makers of portable music players to add a default volume setting of around 80dB and a health warning to all new devices within the next two years. The new standard default setting on devices will not prevent users from overriding the default settings and pumping up the volume, but there will be clear warnings so they know the risks they are taking. The EC is also calling on standards bodies to change industry wide technical safety standards for other mobile devices to include the 80dB default setting.⁶

Recommendation for noise-induced hearing loss

ANZPOD recommendation is that the federal government introduces similar regulations in Australia.

5.2. Employment

An issue that affects both our children as they get older and adults with acquired hearing loss, is gaining employment. Employment levels are lower in those with hearing loss than their hearing counterparts. Part of this is the result of employers being wary or unsure of the implications of employing someone with a hearing loss.

The federal government funds a workplace modification scheme which is run through JobAccess. This scheme “aims to make accommodating employees with disability in the workplace easier.”⁷ Employers must employ a person with disability for at least eight hours a week in a job that is expected to last for at least three months and employees have to meet the eligibility criteria.

The information provided on the JobAccess website is very employer orientated. However the deaf person has to first secure a job. Employers

⁵ *Scientist warn of health risks from exposure to noise from personal music players.* (2008). Europa. Retrieved 07/10/09 from <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/08/1492&format=HTML&aged=0&language=EN&guiLanguage=en>

⁶ *Consumers: EU acts to limit health risks from exposure to noise from personal music players.* (2009). Europa. Retrieved 07/10/09 from <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/09/1364&format=HTML&aged=0&language=EN&guiLanguage=en>

⁷ *Workplace modifications.* JobAccess, Australian Government. Retrieved 07/10/09 from http://www.jobaccess.gov.au/JOAC/Workplace_modifications

must pay for the modifications up front and then apply for reimbursement. A far better alternative would if a young person could take information to a job interview which details their specific needs, e.g. modified telephone/alarm equipment and a guarantee that these needs will be met under the scheme. This way the young person can be assessed on their ability to perform the job and not their inability as perceived by an uninformed employer.

5.3. **Captions**

Many individuals with a hearing loss (including our children) rely on captioning to enable them to fully access the information being presented. Captions are used in television, movies and public broadcasts. Many people are working to improve captioning levels within Australia and move towards equity of access for Deaf and hearing impaired Australians.

Of particular importance to our children is the use of captions in schools. Captions provide a vital access tool for our children to ensure their inclusion in classroom activities using electronic media. Without captions, they do not have the same access to the curriculum as their hearing peers.

We applaud the Accessible Education Database being launched by Media Access Australia in late October 2009 and hope there will be a time when all electronic media needed by our children at school is available with captions.

The producers and distributors of movies, or the television stations themselves don't always realise the impact that captioning their programs can have. They often have little idea of just how many Australians have a hearing loss and how they could widen their viewer audience by providing captions. Continued awareness campaigns targeted at producers, distributors and television station directors, and the wider community will help to educate every one of the benefits of captioning.

Equally a lot of people with a hearing loss do not know that they can speak up and highlight instances of lack of captioning and have their voices heard. An education campaign targeted towards people with a hearing loss, advising them of ways to bring attention to lack of captioning is also a necessary awareness campaign.

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