Parents of
Hearing
Impaired
South
Australia

SUBMISSION TO THE INQUIRY INTO HEARING HEALTH IN AUSTRALIA
SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

Submitted by Parents of the Hearing Impaired of South Australia Inc

Parents of the Hearing Impaired of South Australia Inc (PHISA) is a voluntary organisation formed by a group of concerned parents of hearing impaired children in 1977. PHISA is a family support network run by parents, providing advocacy, empowerment and friendship. Our mission is to support parents in their journey to maximise the outcomes for their child/ren who are deaf and hearing impaired.

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

1. the extent, causes and costs of hearing impairment in Australia;

1.1 The Extent

Currently there is one in six Australians with some form of hearing impairment. Data provided by the 2006 Access Economics Report "The Economic Impact and Cost of Hearing Loss in Australia" project that this figure will rise to one in four Australians by 2050. Figures that look at relative costs of hearing impairment relate mostly to the individual with the loss only and do not consider the wider context of family of the person with a hearing loss. Hence whilst the extent of hearing loss itself is currently at one in six, the impact of that individual's hearing loss is much wider than that.

1.2 Causes

There are many differing causes of hearing loss, resulting in different types of hearing loss. Some children are born with a hearing loss which may occur as a result of a genetic issue, the result of a maternal infection or birth problems. Some childhood illnesses (eg meningitis) also result in hearing loss. There are high numbers of children that suffer conductive losses, often as a result of otitis media, or other issues with the Eustachian tube. 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.

Hearing loss can also be acquired later in life as a result of damage caused by excessive noise. Excessive noise is present in many situations.

Accidents or injuries to the ear can also result in hearing loss. Similarly there is also a degree of hearing loss that is the result of the ageing process rather than from a specific accident or injury. Whilst many of these causes of hearing loss occur later in life after the individual has developed spoken language, the effects can still be devastating and result in isolation and withdrawal from friends and family.

1.3 Costs

The Access Economics study (2006) states that "In 2005, the real financial cost of hearing loss was $11.75 billion or 1.4% of GDP". However these "costs conservatively do not include costs of otitis media which can be substantial in some sub-populations, such as Aboriginal children".

The bulk of this cost was attributed to loss of productivity, where many of those with hearing loss were not gainfully employed due to their hearing loss. If the ultimate goal is reducing lost productivity, then quality intervention programs are the key. Newborn screening only identifies the presence of a hearing loss; it is the quality of intervention that follows on from that which impacts on the ultimate outcomes in adulthood.

Similarly for later onset hearing loss, quality intervention needs to be in place to maximise outcomes for all individuals with a hearing loss. The better we support those with a hearing loss and their place in the workforce, the less cost from lost productivity. Another issue that relates to the costs to Australia as a result of lost productivity for individuals with a hearing loss is the individual cost of purchase, repair and maintenance of hearing technologies.

The next largest cost, in the Access Economics study (2006), was that of informal carers, ie family members attending appointments with the person with a hearing loss to facilitate communication with doctors or other professionals. This cost was averaged out based on carer hours of around 5.7 hours per week. For parents of young children with a hearing loss, the amount of hours spent attending audiology appointments, driving to and from such appointments, visiting other specialists would well exceed that number of hours of caring a week. For those parents that qualify, there is assistance towards some of these costs through Carers Allowance and Child Disability Allowances. These allowances do not meet all the costs of raising a child with a hearing loss but PHISA is appreciative of the existence of these benefits and believes they should continue to be provided to parents.

Many of the additional services costed in this study were from allied health services eg speech pathology, audiology etc. Hearing Health Care services are provided by both Commonwealth and State agencies and public and private entities with there being no co-ordinated program of care. Monies may be more cost effectively used if there is a co-ordination in the care programs offered and a level of accountability required to be demonstrated by such programs receiving public funding.

The hidden cost with respect to hearing impairment is that of depression and related mental health issues. 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. <u>Implications of hearing impairment for individuals and the community.</u>

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 devices such as hearing aids and cochlear implants. Life without these devices is impossible. Things that the hearing world take for granted, for example education, social interaction, sport etc become almost impossible for our deaf and hearing impaired children if their hearing aids or implants are not working properly or are missing.

In Australia, children are fortunate to have access to hearing health services until age 21 through Australian Hearing. 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 develop in such a way as to be dependent on technology. At 21, many of them are still studying or starting out in the workforce, and they are faced with trying to find a suitably qualified audiologist who understands congenital hearing loss. They need to fund both the costs of their hearing aids, cochlear implants and repairs and also the costs of taking out private health insurance to help cover some of these costs. The financial costs of living with **lifelong** deafness are enormous. People living with a hearing loss also face 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.

One person tells his story:

My name is Alexander Phillips and I'm 21 years old. I was born with a profound hearing loss when I was 15 months old. I was fitted with hearing aids in both years shortly afterwards. After little success, I went to an Ear Nose and Throat surgeon who informed my parents that Cochlear Implants were being implanted in Melbourne. I was implanted at 3.5 years of age and had great success with it. I went to kindergarten and by the time I was 5 years old I was ready for mainstream school. After roller coaster ride through high school I successfully completed year 12 with enough marks to get into university. I went to the University of Adelaide and studied a Bachelor of Economics. I finished my Bachelor degree in 2008 and continued my studies by enrolling in a Master of Accounting & Finance, again at the University of Adelaide. I hope to finish next year.

Throughout the whole process, I attended the Cora Barclay Centre from the age of 12 months. I have received a range of services from them including Auditory-Verbal Therapy, audiology services, speech lessons and visiting school support. If it was not for the Cora Barclay Centre, I would not have been able to successfully go to a mainstream school and finish or even go to university.

When I was growing up the costs of my hearing aids, FM equipment, Cochlear Implant, Cochlear Implant processor and services were covered by both private health insurance and the Australian Government through Australian Hearing. Private health insurance covered repairs and upgrades of my Cochlear Implant processor which is usually every 5 years. Australian Hearing also provided me with free upgrades to my Cochlear Implant processors which have cost between $8,000 and $10,000. In addition to these services, Australian Hearing provided me with batteries which are fairly specific and very expensive relative to other batteries. Furthermore, some of my old Cochlear Implant processors have required services and repairs every 3-6 months. My audiologist informed me that a service of a Cochlear Implant processor typically costs anywhere between $300 and $600 and that the cost of batteries cost around $1,000 a year per processor.

As I got older, especially as I was reaching 21, I became more and more aware that when I turned 21 I would largely be on my own in terms of covering costs of ongoing maintenance to my Cochlear Implant processor since almost all of Australian Hearing services stop at the age of 21. Before I turned 21, I have always been very concerned about the ongoing maintenance costs of my Cochlear Implant processor, especially the cost of batteries. I haven't incurred any huge costs to date which makes me very fortunate as it is unusual to go more than 6 months without requiring a Cochlear Implant processor service. However, I still do worry about something happening to my processor and as a result I try and be extra careful with it. Since I am a university student with very little income, I know I would not be able to cover the cost of any service should my processor require one. People who are deaf find it far more difficult to secure part-time and permanent employment than do people with normal hearing, and there are a number of jobs commonly filled by uni students from which we are precluded because of the difficulty of hearing, such as bar work and restaurant service. Consequently, I would have to turn to my parents if my processor broke down and the idea of that makes me feel very uncomfortable and have a sense of belittlement. However, unlike many people, I do have parents who have the resources to assist me. For instance, at my church there is a mother of two kids in her mid-thirties who has a hearing loss in both ears and requires the use of hearing aids in both ears. While I was having a conversation with her recently, she told me she hasn't been wearing hearing aids for many years because she hasn't been able to afford hearing aids since the age of 25. At the age of 18 a person is legally an adult and generally at this age people begin to learn to be independent. After finishing year 12, I had such a great feeling of satisfaction of how much I achieved after

being born with no hearing and going through all the challenges a hearing impaired person faces and conquering those. I felt much more independent after year 12. Given that I know I'll have to rely on my parents for financial support in relation to my Cochlear Implant, I feel as though I have lost a sense of independence.
I personally believe that 21 is too young an age to be cutting of services for the hearing impaired especially as a lot of people at this age are studying at university or TAFE or have a job with little income. Although, I have to say I have been very fortunate in having good contacts in the hearing impairment community who can give me great advice and to still be able to receive audiology services from the Cora Barclay Centre.

2.2 Community implications

With increasing numbers of children being diagnosed as newborns and intervention provided at a younger age, we are setting these children up to 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 cochlea implant speech processors are extremely expensive and they do not have lifetime guarantees. Many of those who are under 21, can not 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.

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. These issues are even further magnified when those over 21 are unable to afford to replace/repair hearing aids/cochlear implants and so can not function in the work place, home and family life. Ultimately the cost to the community at large is enormous – rather than independent, tax paying contributors to society they become social welfare recipients.

Hearing loss 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 through out the journey with access to counselling at any point in time being a priority for families.

At the other end of the spectrum employment levels are lower in those with hearing loss than hearing counterparts. Part of this is the result of employers being wary or unsure of the implications of employing someone with a hearing loss. What is required is the education of employers and providing them information and an understanding of what is possible. Learning from those employers that are already successfully integrating employees with a hearing loss is a great place to start.

3. <u>the adequacy of access to hearing services, including assessment and support services, and hearing technologies;</u>

3.1 the adequacy of access to hearing services

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

Our children need to find an audiologist in the private sector that understands the issues of congenital deafness and has the knowledge and skills to meet their needs. Most private sector 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.

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. Most students or new to the work force 21 year olds can not afford to pay for private health insurance.

Ear moulds – hearing aids attach to ear moulds which fit into the ear canal. Ear moulds also deteriorate over time. The cost of replacing an ear mould is between $75 and $150. Hearing aid batteries cost around $1 each and last approximately two weeks or in the case of cochlear implant batteries each processor requires 3 specific batteries which last about 2 days, so the cost for implant users is about $60 per processor per month. 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. Cochlear implantees also need replacement microphone covers, coils and battery holders.

In the United Kingdom, the National Health Service (NHS) provides hearing aids to those that require them at no cost as part of the NHS system. There is also no age limitation on eligibility for this service. From the NHS Choices website (http://217.64.234.89/chq/Pages/894.aspx?CategoryID=68&SubCategoryID=157)

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. "

PHISA's recommendation is that all former child clients of Australian Hearing over the age of 21 continue to be included in their Adult Eligibility list.

With regards to other costs, PHISA's recommendation is that there is tax rebates on hearing services, hearing aids, cochlear implants and assistive listening devices. In the case of parents with dependant children, they should be able to claim a tax benefit for the costs of assistive listening devices for their children.

For those individuals who acquire their hearing loss later in life, the costs of deafness are significant.

PHISA's recommendation is the adoption of a model similar to the UK NHS system where by hearing aids are provided at no cost to individuals that require them.

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.

3.2 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. Newborn Hearing Screening commenced with a pilot program in SA 2002 and then was subsequently rolled out across the state by February of 2006.

Recent evaluation of data from SA by PHISA has shown some issues within Newborn Hearing Screening in SA, which is fundamentally related to inadequate resourcing of the program. When PHISA requested input from families who have been through the program, there were some complaints about lack of access to screening in rural/remote areas of SA. If the Prime Minister seeks to introduce screening Australia wide, then this needs to include all Australian born children, not just those born near major metropolitan hospitals and facilities. This means a serious commitment to ensuring that there are sufficient financial resources allocated to the SA program to enable screeners in the non-metro areas to be recruited, trained and supported on an ongoing basis.

PHISA's recommendation is that all babies in Australia have access to newborn hearing screening which is timely and readily accessible.

An example of issues faced by parents is incorrect information being given out by a screener to the family. In one case the parent was told the baby most likely had a profound hearing loss, which is not something that can be determined by the basic newborn screen. Later when it was determined that the baby's hearing loss was not actually profound and that the screener should not have told the parent that, the mother was extremely angry. In fact she was so disillusioned with the screening process as a result of this, that she denied permission for her subsequent child to be tested under the newborn screening program. Again this issue relates to the provision of inadequate resources to the screening program, with out adequate resources the program can not provide sufficient training and ongoing monitoring and support of screeners in the performance of their role.

PHISA's recommendation is that funding be allocated to ensure sufficient numbers of fully trained and supported screeners are available to provide a newborn hearing screening program in SA.

The provision of a newborn screening program in SA means that hearing losses previously undetected in babies are now being diagnosed. These include hearing losses like unilateral losses (one ear only), or bilateral (two ears) mild or moderate hearing losses. Prior to newborn screening these children's losses would go largely undetected until pre-school or school age testing in most instances, if at all. As a consequence the many providers across all of the intervention services, including audiologists, have never had to provide an intervention service to children with these levels of losses, instead their focus has been more on the severe to profound level of loss. Given that these children are now being identified, it is totally reprehensible not to afford access to intervention, including counselling, for the parents of these children with lesser losses. At the time of diagnosis these parents only hear that their child has a hearing loss. The level of loss means nothing to them and they need to be afforded the same level of counselling and support in those early times and as parents of children with more significant losses.

The SA protocol indicates that all children with a diagnosed permanent hearing loss (irrespective of level of loss) should be referred to Australian Hearing (AH) and the Department of Education and Children's Services (DECS). However as recently presented at the Australasian Newborn Hearing Screening Conference in Adelaide earlier this year, the data showed that too many were children were not being referred. So instead of reaching AH in a timely fashion there were some instances where children did not get to AH until 93 weeks after diagnosis! Clearly the benefits of any newborn screening program are severely reduced if children are lost in the system for such long periods of time. PHISA believes that part of the problem with this situation is that there is no governance of the process from diagnosis through to the family choosing an early intervention provider and there is no regular auditing against developed protocols to ensure provider adherence to the protocols, ie no-one is watching the shop.

PHISA's recommendation that in each state, it becomes the responsibility of the state screening program to oversee the governance of the passage of parents through the screening process up to and including selection of an early intervention provider.

In SA that would be the Child and Youth Health (CYH) Universal Newborn Hearing Screening Program. Part of the role of the governance organisation would also be ensuring that regular audits of provider adherence to protocols be carried out to ensure that families re receiving best practice as laid out in the newborn screening protocols.

PHISA would like to see as part of the national approach that each state program allocates appropriately trained caseworkers to each family at the point of diagnosis.

These case workers would have no affiliations with any of the audiology providers, cochlear implant teams or early intervention providers; they would be a completely independent person. Their role would be to assist families in the facilitation of moving through each stage of the process until that family chooses an early intervention provider. This could include helping them access counselling services, accessing deaf and hearing impaired adults, or other support organisations such as PHISA. Similarly these case workers would be well placed to provide valuable information relating to how effectively protocols are working for the families.

PHISA's recommendation is that funding be provided to ensure counselling services are available to parents of newly diagnosed children as part of the screening program.

There is a lack of counselling services for families in the current SA screening program. It is well documented in the research that parents all react and cope differently with the diagnosis of a hearing loss in their child. Most have no prior knowledge or familiarity with deafness and feel lost and isolated at that time. Part of the national approach to newborn screening as per the Prime Minister's announcement, needs to be the inclusion of sufficient resources to allow each state screening program to have counselling services available to parents from the point of diagnosis for as long as they need it.

In SA PHISA is very fortunate to have the support of the screening program staff and others who seek to include parent representation in the planning and decision-making processes. This is not the case with all programs or all programs in all states. 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

PHISA would also recommend the following in regards to screening programs

- The choices made by families need to be informed and meet the needs of the child and family. This requires accurate, reliable and unbiased information and appropriately trained professionals.
- 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.

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. What is required is high quality; evidence based early intervention programs available for families to access. These programs need to have personnel that have the training, expertise and qualifications required for this role. All early intervention programs (including audiology) should have as a fundamental part of their program, the empowering of parents. Parents are the best placed to make decisions about their child, and as such should be the keepers of all information as it relates to their child.

PHISA's recommendation is that professionals should not be gate keepers of information but rather should be providing parents with all the information and empowering them to make their own informed choices.

Within SA there have been some moves by professionals to deny parents their right to a service provider of their choice. PHISA's position has always been about the parent's right to make that choice. If there is more than one option available to parents that can provide the required service, then it must be up to the parent to make that choice. Where we have medical personnel declining to treat children based on the fact that their parents have not chosen the professionals preferred provider, then we have serious issues. Professionals have no right to interfere with the parent's choice in this matter and to seek to do so must be very close to an ethical breach of their professional standards.

Parents within SA have enormous hurdles to climb over on their way to choosing a school and subsequent deafness provider. Within SA parents are often misled with inaccurate information about which provider can support them in which schools, whether or not they qualify for transport assistance if the best school placement is not their local school and similar issues. There is no comprehensive documentation of policies in regards to these matters, or if there is, it is not available to parents or parent organizations like PHISA.

PHISA's recommendation is that there be a comprehensive policy document available to parents that relates to school choices, deafness providers that can provide a service in those schools, and transport assistance criteria and requirements.

For many parents the additional funding for their child with regard to their hearing loss differs between private versus public schools as a result of state based versus commonwealth based funding. There needs to be funding transparency so parents know exactly how much funding is being allocated to a school or other service provider, for their child. A child's deafness does not change based on whether the child is in a public or private school.

PHISA's recommendation is that funding for children with a hearing loss be based on the level of loss, (and any delays they may have) and that the amount allocated is the same irrespective of school placement.

It is then up to the parents where t hey place their child and in negotiation with the school and any other providers, how that money is spent. There is already a precedent for this in the Federal Governments Autism initiative where parents have access to a voucher style system and can then choose their provider from a list of suitable operators.

4. Adequacy of current hearing health and research programs, including education and awareness programs

4.1 Adequacy of current hearing health and research programs

For many parents it is a difficult decision in trying to choose a specific intervention methodology. This is in part due to a lack of detailed research that relates to outcomes demonstrated by specific intervention methodologies. Research into educational approaches and their outcomes is an area that needs further investigation. Within research findings and approaches there must also be a transparency with regards to the qualifications of the professionals working with the child in each program that is used for research programs.

Submission prepared by Naomi Higgs for PHISA.
Naomi Higgs
3 David St
Coromandel Valley
SA 5051