The Shepherd Centre

Giving deaf children a voice

SENATE INQUIRY INTO HEARING HEALTH

SUBMISSION

A) Terms of Reference

B) The Shepherd Centre's Submission

October 9th 2009

SENATE INQUIRY INTO HEARING HEALTH – The Shepherd Centre

The Shepherd Centre is a not for profit organisation started 39 years ago and is only 28% government funded, the rest is raised by fundraising.

Our Vision

To enable children who are deaf and hearing-impaired to develop spoken language so they may fully participate in the hearing world and in so doing reach their full potential**.**

Our Mission

To assist children who are deaf and hearing-impaired achieve spoken communication within the family, the educational setting and within the wider community by involving parents and the community in the education and development of the child.

To develop the skills of the parents and carers, by providing an intensive infant and preschool program, so that children may acquire speech and language, principally using their residual hearing with the use of appropriate listening devices (e.g. hearing aids or cochlear implants).

To develop language, listening, speech and social skills to facilitate integration of the child with their hearing peers at the earliest possible opportunity and ensure integration continues throughout life.

SENATE INQUIRY INTO HEARING HEALTH

A) Terms of Reference – General Comments

This is a very broad area of disability and the terms of reference covers all ages. Given the special needs of particular service recipient groups, the Committee may consider delineating special groups within the terms of reference to ensure their needs are addressed.

Age categories and their special needs

The Committee could consider looking at the needs of:

- infants 0-4 years (preschool),
- children 5-12 years (school)
- teenagers 13-18 years (high school)
- young adults 18-25 years (vocational development stage)
- adults 25-65 years (adult life) and
- seniors 65 years plus.

These categories have been defined using key educational, vocational and health/age-related milestones.

Current Structure

Various parts of the industry are currently structured to serve three groups: all children 0-21 years, adults and adult pensioners. This is driven by legislation around funding across public and private sectors. Service delivery is as follows;

- Children 0-21 years are seen free of charge by Australian Hearing (AH) for their amplification (hearing aid) or by AH and Cochlear Implant programmes for those with Cochlear Implants. Cochlear implants are funded by state government and private health funds.
- Once recipients reach the age of 21, government support is withdrawn and they move into the private market until they are pensioners.
- If/when recipients become pensioners (at any age) they are again supported fully by AH. AH is funded in two ways by the federal government which is discussed below.

Hearing needs are very aligned to school and work in the early years and quality of life in later years. This is not to discount the enormous social impact hearing loss has if it is not treated and managed to a persons wellbeing and their social network.

Levels of hearing loss

For children and adults the level of hearing loss they have obviously affects the impact on their lives and the treatment and pathways they need to consider. In children the approaches to hearing loss treatment vary according to the level of loss as it does with adults.

There are particular issues emerging in relation to funding of services to:

- Fully implement Universal Newborn Hearing Screening (state funding)
- Children identified with hearing loss at birth and support for families in terms of counseling (not funded)
- Infants adequate and timely access to Cochlear Implants as determined for unilateral or bilateral implantation (state funded)
- Early intervention services funding (limited state funding and relying on fundraising)
- Children with unilateral and mild hearing loss identified at birth, new area of diagnoses flowing from Universal Newborn Screening (not covered by AH federal funding)

- Children who need devices other than hearing aids or cochlear implants (not adequately funded by AH's funding)
- Young adults with hearing loss establishing their career and life (not funded by state or federal government)
- Adults with severe to profound losses and the funding of treatment (adults have very limited access to state funding for Cochlear Implants)
- Indigenous services are discussed later.

Accessibility - Rural Services, Indigenous Australians, Low Income groups, Non English Speaking Backgrounds, Prisoners, Refugees,

There are a number of factors that limit access to hearing services, which should be assessed. These factors include people who:

- Live in a rural or remote location
- Have a low income
- Come from a culturally or linguistically diverse background
- Are in the justice system and
- Are refugees.

Under each Term of Reference the needs of these groups will need assessment.

Funding and Affordability

The Office of Hearing Services (OHS), which is part of The Department of Health and Aging, has a determining influence on the whole industry, both public and private, by what it does and what it does not do. Its impact cuts across all areas of the industry from manufacturers of hearing devices to private hearing services providers.

The industry is also funded both federally and by state funding which is quite complex.

Office of Hearing Services

OHS provides AH with funding for its operations as follows; capped funding for Community Service Obligation clients or all children, adults with severe loss and Indigenous clients; and Voucher funding for eligible adults (pensioners).

Capped funding is always problematic when client numbers rise (adults) and technology advances (for all clients). However our universal coverage of children on a standardised national platform by AH has been praised world wide and is seen as an ideal situation. The funding however needs a different formula. As childhood deafness is a relatively stable figure this is not an expensive refinement.

OHS also provides Voucher Funding to eligible providers in an open market including AH which covers a basic screening, the provision of hearing aid/s and some follow up free of charge to all eligible clients (Department of Veteran Affairs and most Centrelink pensioners). OHS seems to have a very large investment in resources that check eligibility for the service. This is prudent but perhaps overly resourced.

Savings could be made by accepting pensioner's cards as proof of eligibility at the point of service delivery. Hearing checks and hearing aids are not a service people will rush to defraud. While a verification system is required, there appears to be a disproportionate focus (and infrastructure) within OHS on eligibility checking.

The other area of savings is in take-up and usage of hearing aids. Pensioners are tested and take a free hearing aid and then don't wear it. It is estimated between 20 to 30% of people fitted with hearing aids do not wear them. It may be advantageous to break the Voucher into two, for example screening and then treatment. An active decision to seek treatment may mean the client is more motivated to wear hearing aids.

Many of the refinements needed in funding levels for children are quite affordable given the basic services are currently well provided. The number of children with hearing loss is quite stable and so the demand is predictable.

The demand in the adult population is growing exponentially with age and therefore funding and servicing will be an increasing financial burden. For this reason streamlining and effective use of existing funding needs to be established to enable the unfunded growing adult needs to be met.

Service Providers and Qualifications

Qualifications of hearing aid service providers in the government sector is regulated, however, the private sector is not. In the Early Intervention and Education area there are gaps in the training of people who teach hearing impaired children.

Technology

Technology is playing such a significant role in mitigating hearing loss including advancements in Cochlear Implants, captioning and classroom amplification systems. The Committee may find it useful to be briefed on technologies that mitigate hearing loss and support people with hearing impairment and research directions being developed. The Hearing CRC and the National Acoustics Laboratories which are part of AH can provide the overview for much of the hearing amplification technology and the Deafness Forum for the support technology.

COMMENTS ON SPECIFIC TERMS OF REFERENCE

a) Work has been done on these areas by the National Acoustics Laboratories, Hearing CRC, Access Economics report and government agencies.

b) It should be remembered that for children it was not that long ago that children who were deaf were called deaf and dumb because they could not speak properly.

c) The Shepherd Centre will put in a submission that addresses issues relating to the diagnosis and early intervention for children aged 0-5 years. Australia has a strong international standing in this field. We are close to being a world leader in our Universal Newborn Hearing Screening, followed by diagnosis, treatment through AH and if needed Cochlear Implants. There are however areas of unmet need which can be improved at little relative cost. The situation with adults is probably not as strong.

d) There are emerging special needs for education about the damage iPods can do to teenagers and young adults' hearing.

e) The issues surrounding Indigenous communities' hearing health have to be addressed in parallel with the strengthening of a range of primary health care issues that produce middle ear infections in this community. They also have obvious access issues in relation to geography and cultural and social conditions. This area is of great concern, has enormous social impact and is not easily resolved. However there are some interventions that can assist hearing and health outcomes.

THE SHEPHERD CENTRE

History of The Shepherd Centre

The story of The Shepherd Centre began in 1970. It was a dream realised for Dr Bruce Shepherd and his late wife Annette. Both of their children were born profoundly deaf and at that time there was no suitable program in Australia for teaching deaf children to speak. The Shepherds believed that given the opportunity and with training, children who are born deaf or hearing-impaired should be able to take their place in the hearing world.

After a long and intensive search, the John Tracy Clinic in Los Angeles was used as the model for teaching. The Shepherds believed this method best encompassed the educational and family ethos they wished to emulate. With just five families, The Council for Integrated Deaf Education, later becoming The Shepherd Centre for Deaf Children and their Parents, was established.

The Shepherd Centre - Our Philosophy and Approach

The Shepherd Centre program, structured around typical child development sequences, is based on family involvement and parent and professional teamwork. It is family focused.

We assist children who are deaf or hearing-impaired to use their residual hearing to learn the skills they need to acquire speech and language and to enable them to live comfortably in the wider community. These skills will enable the adult who is deaf or hearing-impaired to have choices in lifestyle, occupation and mode of communication.

Intensive early intervention, focusing on listening and speaking, is designed to meet this aim. The Shepherd Centre provides services which enable families to gain the knowledge, understanding and confidence needed as the primary decision-makers, caregivers and teachers of their own children.

Mindful of the special needs of the families of children who are deaf and hearing-impaired, The Shepherd Centre offers guidance and support both on an individual and family basis as well as in group settings. Assistance and knowledge is offered so that parents may make appropriate decisions and choices about amplification and hearing devices for their children.

- The Shepherd Centre (TSC) provides an Early Intervention program, teaching children who are deaf and hearing-impaired to listen and speak using their residual hearing with the use of an appropriate listening device such as hearing aids and Cochlear Implants

- The family-centre approach ensures that parents or caregivers are given the necessary skills to work with their children in developing spoken language
- The Shepherd Centre program is for infants and pre-school aged children with the aim of enabling them to attend their local primary school with their hearing peers and reach their full potential in the hearing world
- For some of the families attending The Shepherd Centre, deafness may be one of several special needs for their child. Our teaching staff has a diverse range of specialist skills and is able to confidently work with families to help each child reach their full potential
- We provide our Early Intervention Services at no charge to the families. We rely on the vital support and generosity of the community to continue our work
- We have farewelled over 1,000 families after they graduated from our Early Intervention Program and moved on to mainstream schooling
- There are currently over 200 families who access our services in our five centre's across NSW and ACT, and our Residential Program
- The Shepherd Centre has an international reputation as a centre for excellence and this is reflected in the diversity of families enrolled in our correspondence program, both Australia-wide and internationally
- In the last decade, enrolments in our programs have more than doubled.

The Shepherd Centre is a not-for-profit organisation with five centres across New South Wales (NSW) and the Australian Capital Territory (ACT) with approximately 40 staff. Services are also provided to families in outside of the metropolitan areas through the rural and remote program. Currently, 190 families are seen through the early intervention program and 55 children through who are school aged and use services of the First Sounds Cochlear Implant program (a joint initiative with Sydney Children's Hospital, Randwick). We are also part of the Six Centre Alliance; a group of oral early intervention programs across NSW and New Zealand.

B) Submission to Senate Enquiry into Hearing Health in Australia – The Shepherd Centre

Early Intervention Program for children with hearing loss 0-5

Introduction

This submission, addressing the relevant Terms of Reference of the Senate Inquiry into hearing Health in Australia, is focused on early intervention and the needs of the paediatric population with significant hearing loss, our area of expertise. These concerns may be perceived to be relevant to The Shepherd Centre in NSW and ACT only, however the issues pervade each state, and thereby have national importance.

Terms of Reference

a) The extent, causes and costs of hearing impairment in Australia

For information regarding this area, refer to:

a) OHS Department of Health & Ageing
b) Australian Hearing
c) National Acoustics Laboratory, Chatswood NSW
d) Access Economics Report 2006
e) Ear, Nose and Throat specialists
f) Other government agencies

b) The adequacy of access to hearing services, including assessment and support services, and hearing technologies.

Universal Newborn Hearing Screening (UNHS)

Current Situation

UNHS is active in a number of states in Australia. Within those states the age at diagnosis for hearing loss has decreased from 18 months to 4 weeks and the age of hearing aid fitting has decreased from 22 months to 3 months of age. This process allows typical development of the auditory pathways that would otherwise be compromised; known as auditory deprivation (Kuhl, 2004: Tsao, Liu, & Khul, 2004).

Much of the auditory processing is laid down in the first year of life (Khul 2004). Without diagnosis of hearing loss, the fitting of appropriate hearing technology and Auditory-Verbal Therapy early intervention, this critical period of learning is missed. As result the development of good speech and oral language skills can be significantly compromised.

While we have a gold standard for newborn screening in NSW and Queensland, this standard is not replicated throughout the states. Universal newborn screening is unavailable in some states and different screening protocols are used from state to state, some of which will not detect all hearing losses.

Required Situation
UNHS needs to be available nationally with a gold standard screening and diagnostic protocol.

Recommendation
A national universal protocol for newborn hearing screening with the gold standard process of the double Auditory Brainstem Response (ABR) process and otoacoustic emissions (OAEs). Use of OAEs as the initial test will miss some children with lesser degrees of hearing loss and possibly children with greater hearing losses with the additional complication of auditory neuropathy.

Unbiased Support for Newly Diagnosed Families

Current Situation
Families faced with the prospect of their child being diagnosed with a hearing loss, rarely have the professional support of counselling. Nor do families who have had a diagnosis made and require assistance in choosing an early intervention program. While Australian Hearing provides some assistance, this is largely left to the parents.

Families have reported that when they do seek assistance, the person they speak to has an agenda regarding communication mode or a bias toward a program. This does not make the process easy for parents and does not allow them to make informed decisions.

Required Situation
Families of newly diagnosed children with hearing loss require unbiased support throughout the process of screening, diagnosis and early intervention selection. Critical support times include:

- the time between receiving the referral results and the diagnostic appointment at the hospital (at birth)
- after the diagnostic appointment at the hospital or diagnostic centre (some weeks later)
- after diagnosis when parents are processing technological information in addition to finding the right early intervention support for their child and family (after seeing AH).

Recommendation
Funding be made available for families of children with a new diagnosis of hearing loss (whether the diagnosis occurs through the screening process or at a later age) that provides counselling and unbiased support at several stages of the process of screening and diagnosis.

Early Intervention Outcomes

Current Situation
Early Intervention teams work with families to ensure their child reaches their full potential. For many children with a hearing loss, that includes the development of normal speech and spoken language skills; and attending mainstream schools (unless there are other cognitive or development issues).

Over the past two years the outcomes of children at The Shepherd Centre have been carefully assessed and treated.

These results are outlined in Table 1. In addition to this over 90% of students attend mainstream schooling following graduation from The Shepherd Centre program.

Table 1: Outcomes of children at TSC with English as a first language & normal cognition.

	2008	2009*
Language	66% (*n*=76)	61% (*n*=64)
Vocabulary**	67% (*n*=39)	74% (*n*=23)
Speech**	26% (*n*=27)	55% (*n*=22)

* 2009 stats current to August 2009
** *n* is smaller children can only be formally tested at 3 years of age on these tests

In the typical population of children with normal hearing and cognition, 16% will have delayed speech and/or language. This means that 84% will be in the average or above average range. Given the statistics for typically developing children, the results of children with hearing loss at The Shepherd Centre are very good. It should be remembered that despite early intervention and good hearing technology, hearing is still very difficult for these children.

These outcomes are the result of continuous improvement processes and accountability. However, this transparency is not available across all early intervention programs.

Required Situation

All early intervention programs should be accountable for outcomes. Data on children from newborn screening onwards, including outcomes, should be kept nationally.

Recommendation

A national data base would not only capture data on all Australian children diagnosed with hearing loss and follow their progress longitudinally; it would also provide information regarding centre outcomes, which may assist parents in making a choice regarding a program. Moreover, the processes of those centres may be used as a blue print for other centres.

Funding of Early Intervention

Current Situation

The cost of the early intervention program at The Shepherd Centre excluding the fundraising costs, is approximately $13,000 per child per year, which equates to $65,000 for their entire early intervention years if the child is diagnosed with hearing loss at birth and receives early intervention until the age of five years. With the current numbers in our program this costs over $2.M and may next year reach $2.6M for our organisation alone. Over 72% of the income needed to cover the costs associated with early intervention at TSC is largely obtained through fundraising activities at TSC. With the Global Financial Crisis, raising these funds has become increasingly difficult.

Early Intervention programs for children with hearing loss in NSW are closing permanently (St Gabriel’s School for the Deaf; St Dominic’s School for the Deaf). In addition several are closing their books for the short term due to the increase in numbers and no funding support. In NFPs the economic environment has significantly affected income they rely on. If this trend continues children will be unable to get services in NSW.

Should this be left unaddressed, more early intervention services for children with hearing loss will close, limiting options for families. Moreover, the demands on those services that survive will be enormous and will likely compromise the outcomes of the children. Poor outcomes in early intervention will increase the burden on the education system as children will require more support as they struggle with the curriculum. In turn, the burden will be greater on the social security system, as employment options will be limited to those who have struggled at school.

Required Situation
An urgent increased in financial support to early intervention programs so that optimal outcomes can be maintained.

Recommendation
A similar financial program for children with hearing loss, to that of children with Autism is required. The Autism package allows a substantial annual payment to follow the child to the early intervention program of the parent's choice. This is a Voucher type system.

Cochlear Implant Funding

Current Situation
Today, bilateral cochlear implantation is standard and best practice for children with severe-profound hearing loss. However funding is capped in some states, which leads to waiting lists for those families without private health insurance. Waiting lists can very from several months to more than six months. Waiting for cochlear implantation has detrimental effects on early communication development. Even three months in the life of an infant can see many milestones pass.

The benefit in implanting as young as possible is evident in some of our statistics. Of the children in our programme implanted under 12 months of age, over 70% of children have normal speech and vocabulary and over 65% of children have normal language skills. Since 2006, the average age at implantation for children less than 1 has decreased from 9.5months to less than 6 months, despite the age at which they started early intervention being the same (2 months).

Required Situation
Funding needs to be available so there is no likelihood of waiting lists for cochlear implantation as required be it unilateral or bilateral.

Recommendation
Uncapped Paediatric cochlear implant funding is required to ensure children with severe-profound hearing loss have the best outcomes possible.

c) The adequacy of access to hearing services, including assessment and support services, and hearing technologies

Cochlear Implant Funding
As stated above uncapped paediatric cochlear implant funding is required to ensure children with severe-profound hearing loss have the best outcomes

possible. Waiting for cochlear implantation has detrimental effects on early communication development. Given the benefits of implanting under 12 months of age or as soon as possible, it is recommended that funding be available as clinically indicated and waiting is avoided.

Counselling Services
As stated above counselling services in the early screening and diagnostics process is needed as babies are diagnosed with hearing loss. A state-by-state service needs to be established for families of children with a new diagnosis of hearing loss (whether the diagnosis occur through the screening process or at a later age) that provides counselling and support at several stages of the process of screening and diagnosis. Families of newly diagnosed children with hearing loss require unbiased support throughout the process of screening, diagnosis and early intervention selection.

Critical support times include:

- the time between receiving the refer results and the diagnostic appointment at the hospital
- after the diagnostic appointment
- after diagnosis when parents are processing technological; information in addition to funding the right early intervention support for their child and family.

Access to hearing Services after the Age of 21 years

Current Situation
As our school aged children with cochlear implants reach 18 and then 21 years we are concerned about their access to services to support their use of hearing technology. There is no financial support for this group after they leave Australian Hearing at 21 years and their needs in terms of hearing aids and Cochlear implants are very expensive. This will have a significant impact on tertiary education and employment for this group of people.

Required Situation
A program that provides affordable and subsidised hearing aids/ cochlear implants and advice is required from 21 to at least 25 years of age. Financial support at this level will be cost effective because with hearing technology support they can afford they are employable and are unlikely to require the support of government befits.

Recommendation
A program that provides affordable and subsidised hearing aids/ cochlear implants and advice for adults after the age of 21 years.

d) The adequacy of current hearing health and research programs, including education and awareness programs

For information on adequacy of research in the field, refer to:

g) National Acoustics Laboratory, Chatswood NSW
h) The HEARing CRC Ltd, University of Melbourne, Victoria

e) Specific issues affecting Indigenous communities

Current Situation

The conductive issues for the Indigenous population are well known with Government Departments funding many programs to address this. Australian Hearing also have programs in this area and would be a good referral source for information.

The greatest issue is affecting Indigenous children is access to programs. The Shepherd Centre does not see a representative sample of indigenous children with the sensori-neural hearing loss that other children have.

Required Situation

Access to suitable early intervention programs for Indigenous children with sensori-neural hearing loss

Recommendation

A joint plan between Indigenous groups or the Aboriginal Medical Service and early intervention programs, to facilitate support for these children in the most appropriate and culturally sensitive manner.

Summary of Recommendations

- A national newborn hearing screening program with a gold standard screening of double ABR as is carried out in NSW.
- Establishment of a state-by-state service for families of children with a new diagnosis of hearing loss that provides counselling and unbiased support at several stages of the process of screening and diagnosis.
- A national data base to capture longitudinal data on all Australian children diagnosed with hearing loss.
- A financial program for children with hearing loss in early intervention, that is similar to that of children with Autism. This would provide a substantial annual payment to follow the child to the early intervention program of the child's choice.
- Uncapped Paediatric cochlear implant funding to ensure children with severe-profound hearing loss are implanted at the earlier opportunity as recommended by a paediatric cochlear implant team, and in turn have the best spoken language outcomes possible.
- A program that provides affordable and subsidised hearing aids/ cochlear implants and advice for adults after the age of 21 years.
- A joint plan between Indigenous groups or the Aboriginal Medical Service and early intervention programs, to facilitate support for these children in the most appropriate and culturally sensitive manner.

Anthea Green
Chief Executive Officer

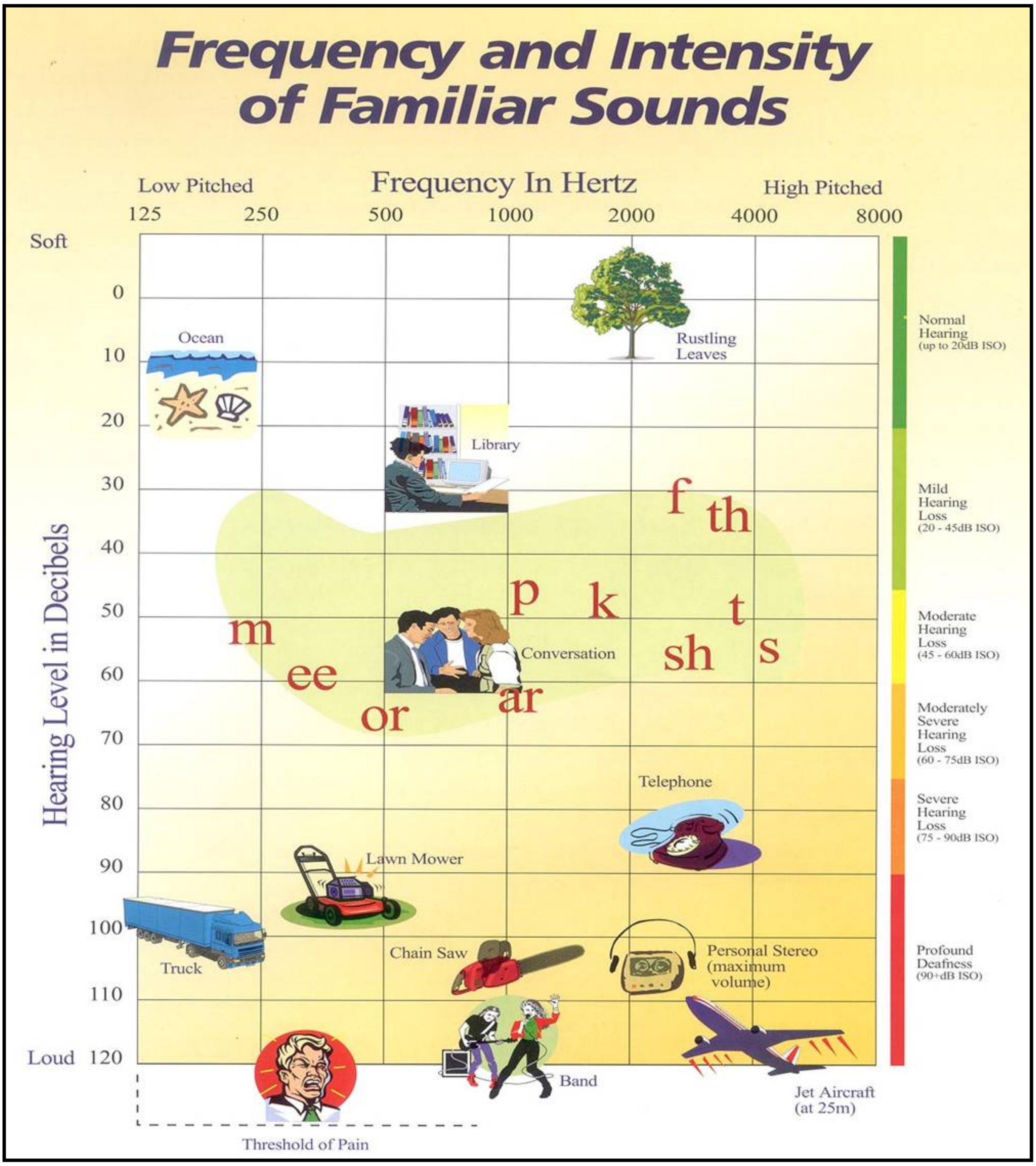
The Shepherd Centre
PO Box 871
STRAWBERRY HILLS NSW 2012
Phone: 61 2 9351 7888
Fax: 61 2 9351 7880
Email: anthea.green@shepherdcentre.com.au

References:

- Access Economics (2006) The economic implact and cost of hearing loss in Australia, Access Economics PTY LTD, ACT, Australia
- Kuhl, P.K. (2004) Early language acquisition: Cracking the speech code. Neuroscience, 5, 831-843
- Tsao, F.-M.Liu, H.-M., & Kuhl, P. K. (2004) Speech perception in infancy predicts language development in the second year of life: A longitudinal study. Child Development, 75,(4), 1067-1084

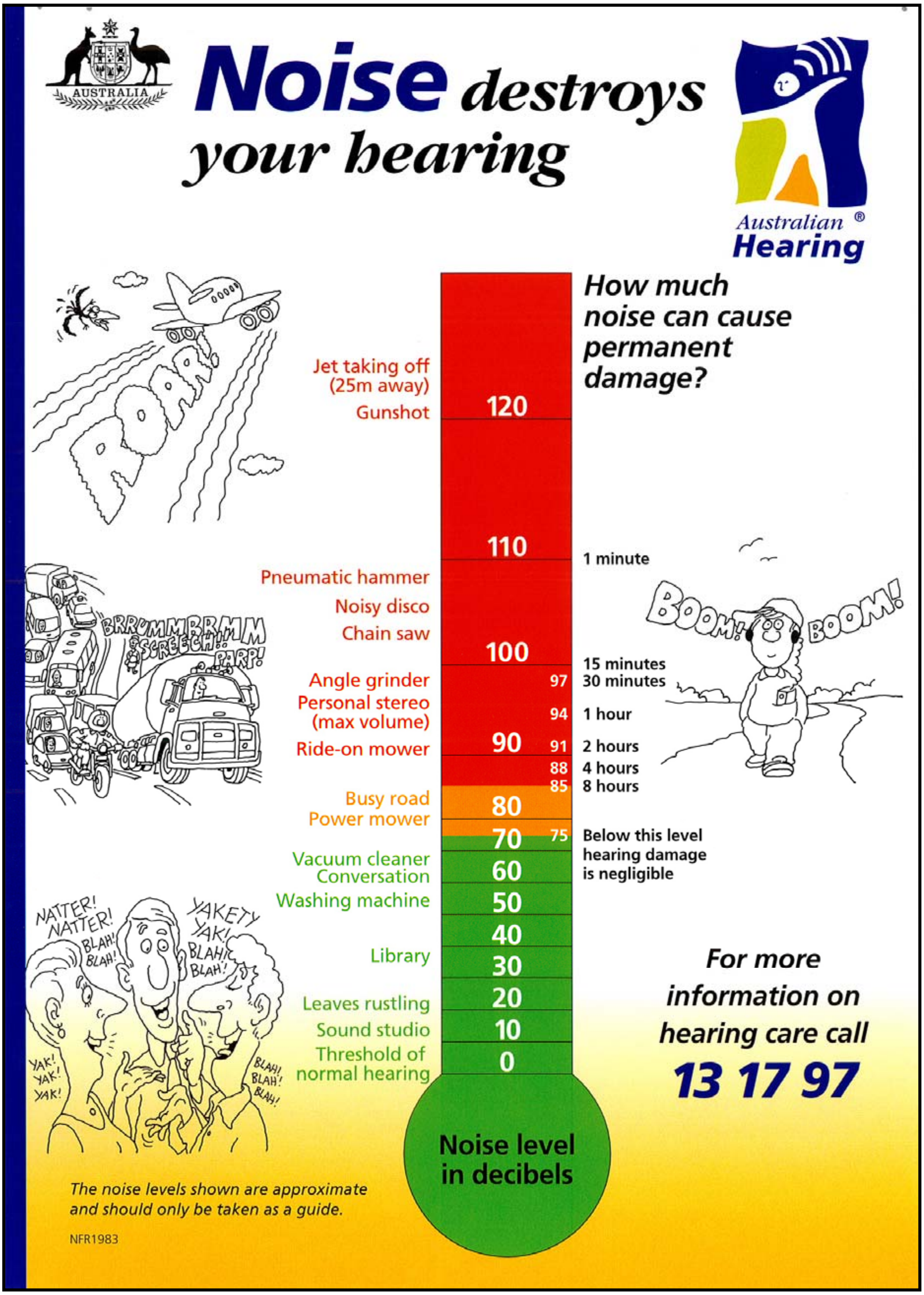
Attachment A: Sounds we can hear at different frequencies

Reference: Australian Hearing www.hearing.com.au



Attachment B: Noise and hearing loss

Reference: Australian Hearing www.hearing.com.au



AUSTRALIA

Noise destroys your hearing

Australian® Hearing

How much noise can cause permanent damage?

Jet taking off (25m away) Gunshot	120		
	110		1 minute
Pneumatic hammer Noisy disco Chain saw	100		15 minutes
Angle grinder Personal stereo (max volume)		97	30 minutes
		94	1 hour
Ride-on mower	90	91	2 hours
		88	4 hours
		85	8 hours
Busy road Power mower	80		
	70	75	Below this level hearing damage is negligible
Vacuum cleaner Conversation	60		
Washing machine	50		
	40		
Library	30		
Leaves rustling	20		
Sound studio	10		
Threshold of normal hearing	0		

Noise level in decibels

For more information on hearing care call

13 17 97

The noise levels shown are approximate and should only be taken as a guide.

NFR1983