

# **Submission to Senate Community Affairs Committee**

## **Hearing Health in Australia**

October 2009

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Though endowed with a passionate and lively temperament and even fond of the distraction offered by society, I was soon obliged to seclude myself and live in solitude...if I appear in company I am overcome by a burning anxiety, a fear that I am running the risk of letting people know my condition...such experiences have almost made me despair, and I was on the point of putting an end to my life – the only thing that held me back was my art'.

(Ludwig van Beethoven, Heiligenstadt Document, 1802) – on going deaf

A note on our terminology: throughout this document you will find references to Deaf, deaf, hearing impairment, hearing loss, and deafness.

Where Deaf is used with a capital D, it is referring to those members of the Deaf community who share a common language and culture. In Australia, that language is Auslan (Australian Sign Language).

Hearing impairment can be anything from mild to moderate to severe to profound. The impact differs for each person and may be due to when their hearing loss occurred, their educational, employment and social experiences, or other factors. Hearing impairment, hearing loss, deaf and deafness are used interchangeably.



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## 1. Executive Summary

Deafness Forum of Australia welcomes the Inquiry into Hearing Health in Australia. The Inquiry represents an important opportunity to understand the costs and impacts of hearing loss and the solutions that people who are Deaf, deafblind, have a hearing loss or a chronic disorder of the ear are seeking.

We encourage the Senate Community Affairs Committee to consider the issues and decisions that will shape how hearing health services are provided in Australia into the future – not just the short term, but 5, 10, 20 and 50 years from now.

Currently, one in six Australians has some form of hearing impairment and this is projected to increase to one in four by 2050.

There is an essential inequity in Australia in the way hearing loss is regarded and funded compared with other health conditions e.g. vision impairment. Hearing health care is not considered by the government to be a primary health care area. Aids are not treated as essential medical equipment. Rather, Deaf and hearing impaired adults are expected to budget for and purchase aids and equipment as if they were discretionary consumer items.

Aids are not a luxury good. Hearing loss can isolate and marginalise people and is associated with other health and mental health issues, and can be the cause of a shift to a lower income bracket because a person may be unable to achieve higher levels of education, and/or to hold higher paying employment. Equipment may be vital, such as a special alarm clock, through to life-saving, such as a special smoke alarm, but the individual bears the additional cost associated with their disability.

The United Nations Convention on the Rights of Persons with Disability includes obligations specific to particular aspects of inclusion and participation, including personal mobility, including facilitating affordable transport and affordable access to mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, and access to interpreters and communication assistance.

Affordability and availability of services, and accessibility of goods, services and premises are of key concern to people who are Deaf, deafblind, have a hearing impairment or a chronic disorder of the ear, and with the ageing population this will become even more vital.

Current Government spending \$62

per person with hearing loss



Economic **cost** (impact) to
Australian society
\$3314

per person with hearing loss

Government Spending compared to economic cost (impact) of hearing loss



## 2. Summary of recommendations

Recommendation 1: health expenditure (early identification and appropriate management, as well as supports in workplace and education etc) on hearing loss be increased, to minimise secondary effects.

Recommendation 2: access to resources (aids and equipment, interpreters, telecommunications, captioning, rehabilitation, counseling and more) must be improved.

Recommendation 3: improving educational outcomes for children who are Deaf or hearing impaired through better access to interpreters, soundfield systems, captioning and more teachers of the deaf.

Recommendation 4: Recommendation 4: Choices and other independent parent resources and information should be available at time of diagnosis.

Recommendation 5 Parent and consumer involvement in family-centred standards relating to newborn hearing screening and the following period for the child and family.

Recommendation 6: Improve government workforce programs for people who are Deaf, deafblind, have a hearing impairment or a chronic disorder of the ear through:

- Real time captioning in the workplace, which is of benefit to Deaf and hearing impaired people, as well as people for whom English is a second language
- Ongoing interpreter assistance for Deaf employees throughout their working life
- Access to programs to people with hearing loss in the workplace, including technology solutions (such as captioned telephone) with government funding.

Recommendation 7: incentives for occupations such as Auslan interpreters, relay officers and stenocaptioners, to fill the skills shortages in these areas (and meet demand into the future).

Recommendation 8: legislation to ensure communication access in the built environment.

Recommendation 9: government subsidy program for communication access.

Recommendation 10: Government to release the long-awaited report on media access for people who are Deaf or have a hearing impairment.

Recommendation 11: Implement communication accessible transport standards.



Recommendation 12: accessible tourism including financial assistance to purchase equipment.

Recommendation 13: As per Access to Premises, all government and business premises should have best practice communication access in place including the display of the International Deafness Symbol to indicate access availability of this access.

Recommendation 14: expanding the National Auslan Booking Service (NABS) to other vital services than private medical services, for example, legal appointments.

Recommendation 15: expanding NABS to improve access for hearing impaired people, for example access to real time captioning for medical and/or for legal appointments.

Recommendation 16: The Commonwealth's Hearing Services Program should be modified and funding should be provided to enable access to the hearing services voucher scheme for

- any Australian who is on a low income or is a full time student.
- any Australian with a severe hearing loss or complex needs
- those with mild to moderate hearing loss who on professional audiological recommendation could benefit from provision of hearing aids/rehabilitation who are able to qualify as low-income.

Recommendation 17: research and active measures to improve mental health for people with deafness.

Recommendation 18: better aged care standards to ensure that hearing loss, which affects around 90 per cent of residents, is adequately catered for, through visual smoke alarms, captioned televisions, appropriate volume control phones, and other relevant mechanisms in accommodation.

Recommendation 19: Universal Newborn Hearing Screening implemented and standardised through all states and territories.

Recommendation 20: Choices to be more accessible online.

Recommendation 21: Hearing loop maintenance schedules be legislatively linked to fire alarm testing regimes.

Recommendation 22: a national campaign on hearing health, and noise injury awareness, developed and delivered with consumer input.

Recommendation 23: campaigns for specific target groups, especially young people going on to risky occupations for noise injury such as farmers, TAFE students.



#### 3. Introduction

Hearing, vision and touch enable us to interact with our environment at all levels. Of the three primary senses, hearing is the foundation sense used for communication between people. A loss of hearing acuity fundamentally changes the ability of the individual to communicate, and through this, limits their ability to interact with society. This has social and economic consequences both for the individual and for society.

Famous deafblind advocate Helen Keller once said "blindness separates a person from objects and deafness separates them from people". While there are many tools, technologies, techniques and supports that can assist people with all levels of deafness to be socially included, these are not always affordable, accessible or available to all.

Deafness Forum of Australia welcomes the Inquiry into Hearing Health in Australia. The Inquiry represents an important opportunity to understand the costs and impacts of hearing loss and the solutions that people who are Deaf, deafblind, have a hearing loss or a chronic disorder of the ear are seeking.

We encourage the Senate Community Affairs Committee to consider the issues and decisions that will shape how hearing health services are provided in Australia into the future – not just the short term, but 5, 10, 20 and 50 years from now.

#### 3.1. About us

Deafness Forum is the peak body for deafness in Australia. Established in early 1993 at the instigation of the Federal government, the Deafness Forum exists to improve the quality of life for people who are Deaf, deafblind, have a hearing impairment or a chronic disorder of the ear. We do this across all areas of deafness and hearing health, through:

- Education and information
- Systemic advocacy
- Consultation
- Recommendations to government on policy and legislation.

Deafness Forum members, whose views are incorporated into this submission, include:

- Numerous Better Hearing Australia branches, including Better Hearing Australia (National)
- Most State-based Deaf societies
- SHHH Australia groups (Self Help for Hard of Hearing People)
- CICADA groups (Cochlear implants)



- Deafness Councils
- Deafness Foundation
- Many service provider associations such as Deaf Children Australia, Audiology Australia, Australian Communication Exchange, and
- Many individual consumers.

#### 3.2. Our consultation process for this submission

We have consulted with our members in all states of Australia to gather feedback on this topic to inform our submission. Some specific comments have been included throughout the paper to illustrate particular points. Our responses represent a large number of comments received from individuals and organisations in the deafness sector, combined with our own deductions from our systemic advocacy work, and based on our continuing engagement with members.



#### 4. Our comments

## 4.1. Extent, causes and costs of hearing impairment in Australia

4.1.1. Extent

#### Current extent

Hearing loss is the second most prevalent chronic disabling disorder, after musculoskeletal disorders such as arthritis. As such, it is more prevalent than any of the other national health priorities.

Currently, one in six Australians has some form of hearing impairment. 1

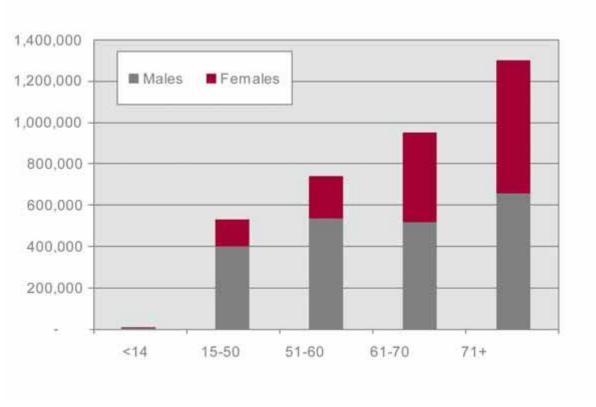


Figure 1: People with hearing loss in Australia, 2005 <sup>2</sup>

In 2005, there were an estimated 3.55 million Australians with hearing loss. Figure 1 (above) highlights the increasing prevalence rates with age.

<sup>&</sup>lt;sup>1</sup> Access Economics Listen Hear! The economic impact and cost of hearing loss in Australia, February 2006, p41 <sup>2</sup> ibid p33



- Of these 10,268 were children aged up to 14 years (0.29% of the total) and 3,534,963 were adults 15 and over
- 49.5% were of working age (15–64 years)
- 64% of people with hearing loss were aged over 60 years with 37% aged 70 years or more.

#### Projected prevalence

Australia's population is ageing. Over the next 40 years it is projected that the number of older people aged 65-84 years will more than double and the number of very old people aged 85 and over will increase by more than  $4\frac{1}{2}$  times. (Wayne Swan speech, 2009) <sup>3</sup>

Prevalence rates for hearing loss are strongly associated with increasing age, rising from less than 1 per cent for people aged younger than 15 years to **three in every four people aged over 70** years.<sup>4</sup>

The prevalence of hearing loss in Australia is projected to increase (from one in six) to one in four people by 2050<sup>5</sup>. Accordingly, it is imperative that the needs of this large and growing sector of society are satisfactorily planned for, and met.

The prevalence of hearing loss is projected to increase from 21.0 per cent (one in five) in 2005 to 31.5 per cent of all males (nearly one in three, largely as a result of demographic ageing) in 2050.<sup>6</sup>

#### *4.1.2.* Causes

Hearing loss can occur at any age.

Pre-natal causes of hearing impairment include in-utero infections and genetic elements, with either partial or complete hearing loss at birth and/or stable or progressively deteriorating over time.

Post-natally, hearing impairment can result from accidents, illness, drug toxicity and excessive noise exposure. Such losses will also vary in degree and stability of hearing levels.

Exposure to excess occupational or recreational noise is a known cause of hearing loss. Despite laws in place to limit noise exposure in the workplace and in the environment, noise continues to account for 37% of all hearing loss. Tinnitus (in a non-medical explanation: constant or intermittent noises in the ear, such as ringing or chirping or buzzing) is strongly associated with noise induced hearing loss and is

<sup>6</sup> Ibid p7

<sup>&</sup>lt;sup>3</sup> Wayne Swan speech to the Australian institute for population ageing research Sydney 18 September 2009 <a href="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm&pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm&pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm&pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm&pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm&pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm%pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm%pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm%pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm%pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm%pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx?doc=speeches/2009/025.htm%pageID=005&min=wms&Year=&DocType="http://ministers.treasury.gov.au/DisplayDocs.aspx

<sup>&</sup>lt;sup>4</sup> Access Economics op cit p5

<sup>&</sup>lt;sup>5</sup> Ibid p41

<sup>&</sup>lt;sup>7</sup> Ibid p79



common from military service, farm work, and machinery use. The incidence of hyperacusis (non-medical explanation: reduced tolerance to normal sounds in the environment) is very high among people who have tinnitus; 40%–86% of those who have tinnitus also have hyperacusis.<sup>8</sup>

Of growing concern is noise induced hearing loss associated with the use of personal music players. This can be known as "older ears on younger bodies" – a trend that's been building since the debut of the Walkman. <sup>9</sup>

#### 4.1.3. Costs

Costs vary with age and management requirements.

However, early identification and appropriate management of hearing impairment at any age is highly **cost-effective** in minimising secondary effects. When identification and management are both early and appropriate, the need to provide remedial programs for avoidable secondary problems will be reduced or even eliminated.

Despite the above, health expenditure on hearing loss is less than 1 per cent of the total expenditure on the national health priority areas.

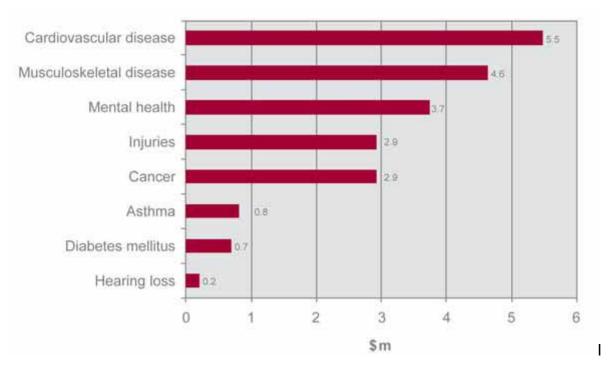


Figure 2: Hearing loss, health expenditure compared to National Health Priorities 2001<sup>10</sup>

<sup>&</sup>lt;sup>8</sup> Wei Sun, 2009 <a href="http://www.asha.org/publications/leader/archives/2009/090901/090901g.htm">http://www.asha.org/publications/leader/archives/2009/090901/090901g.htm</a>

<sup>&</sup>lt;sup>9</sup> "Docs Ring Warning Bells on Earbuds" September 2005 www.4hearingloss.com/archives/2005/09/docs\_ring\_warni.html

<sup>&</sup>lt;sup>10</sup> Access Economics op cit p48



#### In 2005, the real financial cost of hearing loss was \$11.75 billion or 1.4% of GDP.

This figure represents an average cost of \$3,314 per person per annum for each of the 3.55 million Australians who have hearing loss or \$578 for every Australian. The financial cost does not take into account the net cost of the loss of wellbeing (disease burden) associated with hearing loss, which is a further \$11.3 billion.

The largest financial cost component is productivity loss, which accounts for well over half (57%) of all financial costs (\$6.7 billion). Nearly half the people with hearing loss are of working age (15-64 years), and there are an estimated 158,876 people not employed in 2005 due to hearing loss. The productivity cost arises due to lower employment rates, and higher rates of earlier retirement, for people with hearing loss over 45 years and subsequent losses in earnings.

People aged over 65 years constitute half of people with hearing loss but receive less than one third (29%) of the health system expenditure (\$40 per person per annum).

Health expenditure on hearing loss is less than 1% (0.9%) of the total expenditure on the national health priority areas, and only 0.35% of total allocated recurrent health expenditure in Australia. Using the prevalence of diseases reported by the Australian Institute for Health and Welfare<sup>11</sup> (AIHW) for 2001 and allocated recurrent health expenditures from AIHW<sup>12</sup> for 2000-01 it can be seen that, compared to the then expenditure of \$62 per person with hearing loss per annum, we spend far less:\$62 per person with hearing loss. 13

By comparison, based on health data adjusted for expenditure not allocated by AIHW, the allocated health costs (expenditure) arising from hearing loss are estimated to be \$287.8 million in 2005, or an estimated 0.034% of GDP. 14 This equates to an expenditure of \$62 per person with hearing loss per annum.

If more government funding was spent on aids, education, counseling and rehabilitation, we out to you that the economic cost of productivity and carers would diminish.

<sup>&</sup>lt;sup>11</sup> Australian Institute of Health and Welfare (2004) Australia's Health 2004 - the ninth biennial health report of the Australian Institute of Health and Welfare Cat No AUS 44 p389

<sup>&</sup>lt;sup>12</sup> Australian Institute of Health and Welfare (2005) Health system expenditure on disease and injury in Australia, 2000-01 Cat No HWE 28.

13 Access Economics op cit p48

<sup>&</sup>lt;sup>14</sup> Ibid p48



# Government **spending** \$62

per person with hearing loss



# Economic **cost** (impact) to Australian society \$3314

per person with hearing loss

Figure 3: Government spending compared to economic cost (impact) of hearing loss

In summary, it COSTS our society \$3314 per person with hearing loss, and we SPEND \$62 per person with hearing loss.

No wonder people with hearing loss think more should be done. That is what we think too.

Quite clearly, if more money was spent on interventions and support, the cost could be ameliorated in terms of improved productivity.



Recommendation 1: health expenditure (early identification and appropriate management, as well as supports in workplace and education etc) on hearing loss be increased, to minimise secondary effects.

# 4.2. Implications of hearing impairment for individuals and the community

#### 4.2.1. Individual implications

The impact of hearing impairment varies with degree of loss, age of onset, and provision of timely and appropriate management. At any age, time is of the essence. If identification and management is delayed in infants, delays in language acquisition can be expected. For older children, there may be educational delays. For young adults, with low educational achievement there will be consequent limitation to employment and career opportunities. For older adults, enforced early retirement is common. In yet older adults, hearing impairment can be misdiagnosed as early signs of dementia.



The experience of the post-lingual loss of one's hearing is invariably a negative one. The primary loss, plus dawning awareness of the many losses it sets in train, can produce **states of shock, grief and depression**. While this may be obvious in cases of sudden loss of hearing, it cannot be assumed that those with progressive losses have achieved adjustment and acceptance. Frozen states of sadness or anger can often persist and painful grief can be precipitated by sudden confrontations with the accumulating losses. Impacts can include:

- Negative effects on employment and prospects
- The necessary relinquishment of some aspirations for the future
- Disruption of everyday communication
- Withdrawal from previously valued activities
- The vanished pleasure in favourite music or sounds
- Cessation of easy participation in casual conversations
- Changes in relationships.

Some deafened people find themselves withdrawing into a restricted lifestyle, miserably devoid of many of the activities, pleasures and rewards that they previously enjoyed. Others find some acceptance in a modified lifestyle. And yet others manage to navigate through the necessary accommodations and rebuild a satisfying life.

The determinants of the outcomes, is basically **access to resources**. First among the necessary resources are personal ones such as such as healthy self-esteem and resilience and preparedness to persevere in seeking help. Other important resources are socially conferred ones such as power and status and financial assets. Access to counseling, advice and technology is a key resource, as is a supportive family and friendship network. Absence of discrimination and preparedness by the community to provide necessary accommodations to assist communication is vital.

## The current scarcity of resources in the Australian community sets a ceiling on the adjustment of all deaf people.

'An invisible condition without external evidence such as signing, places people who are hard of hearing in limbo. They do not belong to Deaf communities and they are often estranged from the hearing community of which they had been a part.

(Rocky Stone, the founder of the American organization, Self Help for Hard of Hearing People (SHHH))





Recommendation 2: access to resources (aids and equipment, interpreters, telecommunications, captioning, rehabilitation, counseling and more) must be improved.

It seems that for many people hearing loss involves feeling a need for concealment, an apparent fear that if people know, they will judge you to be inferior. It has been described as trying to avoid a 'stigmatized identity' 15.

Many hearing impaired people expend a lot of energy in concealing a status that is experienced as shameful. In order to seek the assistance that would improve communication and reduce the disabling effects of impaired hearing they have to agree to take on this status and stigmatized identity, and many seem to judge that it is not worth it.

When cool logic is applied to this attitude it does seem foolish. However, evidence of stigmatization of hearing loss in the community is not hard to find. There is a fear that revealing a hearing impairment can limit employment or social opportunities. Deafness has long been associated with stupidity, with incompetence, with difficulty and inconvenience, with aging – a diminished identity in itself. It is the butt of jokes and mockery in social situations or in entertainment. It invites irritation and suspicion. 'She hears when she wants to', 'He won't make an effort', 'She won't use a hearing aid' are all depressingly frequent accusatory statements made to or about the hearing impaired.

The question 'Are you deaf or something?' is rarely either delivered or received as an enquiry prompted by genuine desire to assist! Ironically, of course, the very efforts the hearing impaired person makes to conceal his problem can feed the stigma of social ineptness or give rise to a new accusation 'She won't admit that she is deaf!'

Given the losses involved in losing one's hearing, and the possible acquisition of an inferior identity, it would not be surprising to find that **problems with emotional health is frequently a consequence**. Much research has demonstrated this to be true, for example Herbst and Humphrey 1980, Kerr and Cowie 1997, Thomas (1984) Kramer et al 2002.

#### Co-existence with other health problems

Hearing loss has been described as an under-estimated health problem<sup>16</sup>. Adult hearing loss is associated with an increased risk for a variety of health conditions including:

- Diabetes (Wilson et al, 1992; Mitchell, 2002)
- Stroke (Mitchell, 2002)

 $<sup>^{15}</sup>$  Hétu, R. (1996). The stigma attached to hearing impairment. Scand Audiol, 25 Suppl 43, 12-24.

<sup>&</sup>lt;sup>16</sup> Wilson D, Xibin S, Read P, Walsh P, Esterman A (1992) "Hearing loss – an underestimated public health problem" *Australian Journal of Public Health*, 16:282-286.



- Elevated blood pressure (Wilson et al, 1992)
- Heart attack, particularly those rating their hearing as poor (Hogan et al., 2001)
- Psychiatric disorder, particularly those rating their hearing as poor (Hogan et al., 2001)
- Affective mood disorders (Ihara, 1993; Mulrow et al, 1990)
- Poorer social relations (Mulrow et al, 1990)
- Higher sickness impact profiles (physical and psycho-social (Bess et al, 1989)
- Reduced health related quality of life, particularly those with more severe hearing loss<sup>17</sup>.

Perhaps the most common, but nevertheless usually overlooked, health consequence of hearing impairment is fatigue, and then the ill health that constant fatigue can produce. The exhausting process of communication for a hearing impaired person, all that listening, concentrating, checking out clues, guessing, contrasting it with the experience of those with normal hearing takes its physical and emotional toll.

Accidents from failing to hear warnings or approaching dangers, or depression-related suicide, must also be counted as possible consequences.

Remembering Helen Keller observation that deafness separates you from people (leading to social isolation), current research shows depression to be a significant risk factor for heart disease. The Australian National Heart Foundation recently reported that depression and social isolation doubled the risk.

'Depression and social isolation are just as likely to cause coronary heart disease as smoking, high blood pressure and high cholesterol.' 18

#### Relationships

While it is clearly true that having a supportive spouse, family or friend is a vital resource in managing life with hearing loss, sadly hearing loss can **put those relationships under great strain.** Relationships that were once equal can become distorted as the hearing partner gets pulled into the role of 'carer' taking over all interactions with the world. Misunderstandings can constantly arise. Children can slip into the habit of communicating mainly with the hearing parent. Family gatherings can be spoiled by the isolation of and resentment by the hearing impaired family member who sees but can no longer participate in the easy chatter going on around them. Previously close relationships with grandchildren can become distant as the grandparents can no longer hear their high-pitched voices. Friends can start to leave

 $<sup>^{17}</sup>$  Wilson DH (1997) Hearing in South Australia: Disability, Impairment and Quality-of-life, PhD Thesis, University of Adelaide.

<sup>18</sup> Report on World Conference on Health in The Age, 28 April 2004



hearing impaired people out of activities where they know they would have difficulty hearing.

Deafness is essentially interactive. It is an experience which is necessarily shared with others. The closer the relationship, the stronger the impact of hearing difficulties. <sup>19</sup> These impacts included:

- Reduction in frequency of interaction, less intimate communication, less everyday companionship
- Reduction in the content of communication, restricting communication to more important matters, because of the effort required
- Misunderstandings due to not answering, responding inappropriately, asking for repetitions.

A number of researchers have studied relationships and the widespread conclusion is that both partners are negatively affected when one acquires a hearing loss. One has the actual hearing loss, while the other has a 'vicarious loss'.<sup>20</sup>

From the hearing impaired man:

'I lost my hearing then I lost my wife. She doesn't realize what it is like for me' From his hearing wife:

'I sometimes get so angry with him. Sometimes just watching him makes me feel terrified and helpless. And then I feel so alone'

#### **Employment**

Anecdotal accounts and many studies indicate that hearing loss – even a moderate loss - can and often does have a major impact on the individual's employment status. It is a commonplace observation that hearing impaired people are frequently unemployed or underemployed, or, when employed, experience much stress and social isolation from co-workers. Some relinquishment of career ambitions may be realistic and perhaps unavoidable, but more accommodating attitudes and practices by employers would remove many of the barriers to successful employment of hearing impaired people.

In the 1990s, I personally was informed verbally that I would not be recommended for a position at N.S.W. school which had a deaf unit attached to it, on the grounds that I was too deaf to teach. Yet some months later I was asked to do relief work as an itinerant teacher, doing exactly the same work. I believe that this was discrimination on the grounds that authorities did not wish to employ me due to possible ramifications with superannuation and health benefits. (Maureen, 45, NSW)

<sup>19</sup> Hetu, R., Jones, L., Getty, L. (1993). The impact of acquired hearing impairment on intimate relationships: implications for rehabilitation. <u>Audiology</u> 32: 363-81.

<sup>20</sup> Harvey, M. (2000) Vicarious Hearing Loss: A Spouse's Tale. Hearing Loss Jul/Aug 2000 8-14



#### Some research findings include<sup>21</sup>:

- Individuals were usually reluctant to disclose their hearing difficulties to their employer or co-workers, fearing dismissal, negative stigmatization, or loss of potential career advancement.
- Even when the worker's hearing loss is identified, accommodations that could significantly alleviate the effects of communication difficulties are not typically made.
- High levels of psychological stress and general feelings of incompetence were frequently reported as the workers with hearing loss felt they needed to overcompensate to ensure others did not view them as less capable at carrying out their job.
- Some workers reported staying at unsatisfying jobs because of the fear of not being able to find another job and because of the psychological stress involved in the job search and interviewing process and having to reeducate others at work about one's hearing loss.
- Some reported leaving their job, or retiring early due to their hearing loss and psychological stress experienced on the job.

#### A 1998 Australian study concluded that:

'Deafened adults are disadvantaged with regard to education and access to paid employment, particularly those with more advanced hearing loss. Those who have jobs may not enjoy the same level of career progression as those who can hear. Educational and employment disadvantage results in adverse economic position for deafened adults. Access to medical and rehabilitation services greatly enhanced the likelihood of deafened people retaining employment'<sup>22</sup>

#### 4.2.2. Community implications of hearing loss

The implications of hearing loss need to be considered in terms of community cost. Throughout life, at any age, delayed identification and poor and/or delayed management will result in totally avoidable costs.

With prevalence and severity increasing with increasing age, we clearly cannot afford unnecessary early retirements, or mismanaged older people who are confused not by dementia, but rather by not hearing adequately. From the community perspective, investment in timely and appropriate individual hearing management programs is clearly an economic, as well as a moral, imperative.

<sup>21</sup> Stika, C.J. (1997). Living with Hearing Loss-Focus Group Results Part11: Career Development and work Experiences <u>Hearing Loss Nov/Dec 1997</u>:29-32

Hogan, A., Taylor, A. &Code, C. (1989) Employment outcomes for deafened adults with cochlear implants. Australian Journal of Rehabilitation Counselling (Feb)



#### Children and education

We believe that education is the building block for the rest of your life and as such as an absolutely imperative area to address.

Well-managed and supported hearing impaired children who achieve ageappropriate language skills – whether spoken English, Auslan (Australian Sign Language) or other – can be educationally mainstreamed and subsequently take up employment to their appropriate potential, saving significantly at all of levels of government expenditure.

Some babies are born with a hearing loss. Others acquire a hearing loss during their childhood due to:

- A genetic or syndromic progressive hearing problem
- Disease such as meningitis
- Chronic otitis media (especially with indigenous children from 0-12months of age) or
- A myriad of other causes.

Children who are Deaf or hearing impaired are not a homogenous group, although there are some things they have in common. Some of the commonalities are the many factors that impact upon their learning needs, such as:

- Possible difficulties with processing language including the existence of a diagnosed disability such as an intellectual disability.
- Many children start school with poor English language not only because of their deafness or hearing loss but because the language spoken in the home is a language other than English. With the culturally diverse population in Australia for many families the home language is not English. Early intervention therapy usually occurs in the home language as it is important to have a first language base.
- Some Deaf families may use signed English word order accompanied by speech (Total Communication), Auslan, visual cues, or any combination of these. This has implications about the type of programs that need to be implemented, as well as impacting the introduction of reading and writing in English.
- Cultural issues connected to the family, as well as Deaf culture which may or may not be part of the family dynamic.
- Lack of adequately trained and resourced teachers of the Deaf, particularly in rural and remote areas.
- Not enough early intervention programs, especially in rural areas.



- In remote indigenous communities there are no early intervention programs, and yet 80% of children will acquire a hearing loss in the first few months of life.
- Poor transport options to appropriate schools that can provide good support.
- Installation and maintenance of classroom (soundfield) amplification systems has been sporadic. A soundfield system is an amplification system which provides an even spread of sound around the room. Such a system allows all the students to hear equally well wherever they are seated and whichever direction the teacher faces. A large number of research studies have demonstrated that students with fluctuating mild to moderate hearing loss such as indigenous populations benefit significantly with these systems<sup>23</sup>. One of the reasons for low prevalence was that schools or education departments needed to fund installation of these systems from existing budgets.
- Not enough accessible material for Deaf or hearing impaired students especially captioned DVDs. Research has shown that captioning of educational materials not only improves communication access for deaf and hearing impaired but also improves literacy for all students.
- Not enough involvement of deaf role models (oral or signing).



Recommendation 3: improving educational outcomes for children who are Deaf or hearing impaired through better access to interpreters, soundfield systems, captioning and more teachers of the deaf.

Whether there has been an Early Intervention program or not, many parents have experienced bias in the support they were offered, or the information they needed.

"I was in Hobart on the weekend for the Australian and New Zealand Educators of the Deaf Conference and two parents from rural Victoria gave a talk on their experience of early intervention services. At the end of the talk there was not a dry eye in the house. Their story involved a tale of vast travel, misinformation, stress, heartache and, dare I say, neglect. It was a tale of apathy, lack of responsibility and total ignorance of need from the government and indeed the service providers." (Teacher of the Deaf, NSW)

This is not an isolated incident. It occurs far too often in rural and regional Australia.

<sup>&</sup>lt;sup>23</sup> Dillon, H. 2009 <a href="http://www.hearing.com.au/upload/sound-field-systems-helping-close-the-gap-in-">http://www.hearing.com.au/upload/sound-field-systems-helping-close-the-gap-in-</a> classrooms.pdf





Australian Hearing provide an excellent publication for parents called Choices which is written in an unbiased manner and consults with all services and consumer groups to make sure they are all equally represented.

However Choices is not available at the time of diagnosis so parents are left without knowledge, understanding or support until they can schedule their first appointment after diagnosis.



Recommendation 4: Choices and other independent parent resources and information should be available at time of diagnosis.

Greater parental involvement and decision making, and the provision of unbiased information at the time of diagnosis, is important.



Recommendation 5 Parent and consumer involvement in family-centred standards relating to newborn hearing screening and the following period for the child and family.

#### Workforce issues

In 2005 an estimated 1.76 million Deaf and hearing impaired Australians were of workforce age. However, their overall participation rate and the proportion in full time employment are considerably lower than for hearing Australians.

Around 160,000 Australians leave the workforce each year because of their deafness.

Waiting until their jobs are in jeopardy is waiting too long, and places them in a difficult position. If support were available before their job was in jeopardy, everyone's life would be easier.

Without financial assistance for personal hearing aids and cochlear implant speech processors, real time captioning in the workplace, ongoing access to interpreters in the workplace or other accessible technology (such as volume control phones and hearing loops for meeting rooms) how can Australians who are Deaf or have a hearing impairment participate?

Discrimination on the basis of disability is against the law. But without adequate support in the workforce, why would an employer hire someone with greater support needs, with greater costs to the employer? For example, to bring in interpreters for weekly section meetings at up to \$120 per hour is a considerable expense for a small business, one which government programs does not go far enough to cover.



For meetings over 2 hours' duration, two interpreters are required for OHS reasons, making a cost of up to \$240 per hour.

And for Australians with a hearing impairment, who need real time captioning at weekly meetings, there is no assistance.

I had to leave my job as I could no longer cope with struggling to hear what was being said in meetings. (Margaret, aged 62, Melbourne)

People with hearing/deafness disabilities have difficulty in seeking and gaining employment, and in gaining promotions. Often, due to their disability, they are underemployed and have low incomes, limiting their ability to purchase hearing aids and other assistive devices. Also in this situation are the long term unemployed people in the catch 22 situation of being unable to gain employment because they do not have a hearing aid, and unable to afford an aid because they are not employed.

At the age of 46 I was in my office, I was having a conversation with one of my PhD students, and I realised I was not hearing what she said. It was quiet, I had my hearing aid up, I could not hear a lot of what was being said. And so I thought, "OK, this is time to retire". Professor Jennie Brand Miller, NSW



Recommendation 6: Improve government workforce programs for people who are Deaf, deafblind, have a hearing impairment or a chronic disorder of the ear through:

- Real time captioning in the workplace, which is of benefit to Deaf and hearing impaired people, as well as people for whom English is a second language
- Ongoing interpreter assistance for Deaf employees throughout their working life
- Access to programs to people with hearing loss in the workplace, including technology solutions (such as captioned telephone) with government funding.

There is a shortage of trained, qualified personnel to provide services to people with deafness. As our population ages, people's working habits are changing and they leave the workforce or reduce their hours to care for ageing parents. This is further draining the pool of workers, including those who work to provide services for the Deaf and hearing impaired.



Recommendation 7: incentives for occupations such as Auslan interpreters, relay officers and stenocaptioners, to fill the skills shortages in these areas (and meet demand into the future).



#### Access to premises, transport, and the built environment

For people who are Deaf or have a hearing impairment, access means communication access.

Hearing (communication) access, according to the Disability Discrimination Act, is a right that people who are Deaf or have a hearing impairment should have - as does any citizen with "normal" hearing. It is evident that most people are unaware of their obligations, under the Act, and fail to provide hearing augmentation in many areas related to daily living.

Just some of the situations where lack of access has been identified are:

- Justice system
  - O Deafness Forum would like to see the Federal, State and Territory Attorneys-General put in place programs designed to ensure full and equitable access to all Courts in Australia for all people who are Deaf or have a hearing impairment, using their preferred methods of communication.
- Security screening points and entry to secure facilities, where a security guard may say something and not be heard (eg passing though a metal detector)
- Events and meetings
- Entertainment of all kinds
  - Today's technologies make providing captions for theatre, cinema, free to air television, pay television, DVDs, online material cheaper than ever before.

My friends have stopped asking me to go to the movies with them because I can't hear what is being said at our local cinema, and they don't want to drive all the way to George St to go to the movies. Ruth, aged 67, Parramatta

- Hotel/motel and similar accommodation
  - O People who are Deaf or have a hearing impairment pay the same rates as hearing people for a hotel or motel room. But usually they cannot access the same facilities that others take for granted: the TVs are not caption-capable, the phones do not have volume control or there is no TTY, there are no suitable smoke alarms. In house movie systems usually use a different remote control that has no button on it to switch captions on, even if the TV is able to display captions.



How soundly would you sleep in your hotel room if you knew you would not be woken if the fire alarm went off? Bill, 50, Sydney

Imagine returning to your hotel room after a hard day at work interstate. You just want to relax and watch the news. The sound on your TV does not work. Wouldn't you be frustrated? That's the experience of most Deaf and hearing impaired when they stay at a hotel. Having captioned TV allows me to relax and enjoy my stay like other hearing people. Jim, age 65, Canberra

- Tourist destinations eg theme parks, museums
  - Many of Australia's iconic tourist destinations are inaccessible to people who are Deaf or hearing impaired. Live performances at places like the Australia Zoo in Queensland should have captioning and an area with an audio loop so all can enjoy the proceedings.
  - There are 3.55 million Australians who are Deaf or hearing impaired, and they along with their families may enjoy travel within Australia. There are also many more Deaf or hearing impaired overseas tourists who come to Australia expecting the same level of access to tourist sites as they can experience in Europe, UK and USA but they are quite disappointed at the reality when they get here.
  - Physical access (for example, wheelchair access) to tourism facilities has become an accepted norm and is included in the planning of most tourism destinations. It is time for communication access to be recognised and included in the concept of access.
- Information provision on transport conveyances and at transport terminals
  - Travel can be difficult and even dangerous for people who are Deaf or have a hearing impairment. At the very least, it is inconvenient when announcements are made over PA systems with no corresponding visual announcement (such as captions or scrolling text)

One watches other passengers cocking their heads to hear the announcements, then reacting (rolling their eyes or tut-tutting or making mobile phone calls), and if one is confident, chooses a friendly-looking passenger to ask their advice. (However, sometimes it feels risky to make known one's hearing-impaired status known to strangers.) If there are no other passengers in the carriage or station whom I feel comfortable approaching, I can only hope the cause of the disruption



is nothing life-threatening, and that the delay will not be so long as to cause me to miss a critical appointment. (Jill, 42, Melbourne)

- Shops, offices and similar facilities
  - In the UK the government provided a money back scheme for business to install hearing loops at counters and other sites.
- Sport and fitness centres
- Education (at all levels)
- Hospitals and nursing homes.

To provide adequate communication access for people who are Deaf or hearing impaired a combination of the following list is indicative of what is required:

- Real Time Captioning used in meetings, events in sports stadiums such as concerts.
- Audio Loops operating at service counters, transport platforms etc.
   There are now audio loop systems available that can be moved from counter to counter no installation required. Great for banks
  - In the UK, induction loops are specified in the DDA. RNID uses "mystery shoppers" to test the induction loop systems throughout the country. Barclays Bank will be adding induction loops at all branches.
  - Sweden mandates an induction loop, infrared or other arrangement in churches.
  - Switzerland also includes churches in their mandate as well. Induction loops must be tested after installation. What a sensible approach.
  - O Any service desk or information desk should have at least one audio loop installed to assist a hearing impaired person make an enquiry. If the building or office has regular verbal announcements these should also be provided in some visual format. All Australians have the right to access their government and other public areas. Government offices and public buildings should be showcasing best practice in the area of access as they are using taxpayer's funds.
- Auslan Interpreters to be provided in the workplace, at meetings, conferences, theatres, court rooms. Address workforce issues, training and government programs relating to interpreters
- Captioning facilities should be available on TVs in hotels/motels and other accommodation, wherever there is a verbal announcement being made such as places of transport.



- Volume control phones or captioned telephones should be available in the workplace, hotels/motels and other accommodation, public telephones, emergency phones in lifts.
- Fire/smoke alarms the current audible alarms are not suitable for Deaf and hearing impaired. Those that are suitable for people with a hearing loss are considerably more expensive than audible alarms.



Recommendation 8: legislation to ensure communication access in the built environment.

Recommendation 9: government subsidy program for communication access.

Recommendation 10: Government to release the long-awaited report on media access for people who are Deaf or have a hearing impairment.

Recommendation 11: Implement communication accessible transport standards.

Recommendation 12: accessible tourism including financial assistance to purchase equipment.

Recommendation 13: As per Access to Premises, all government and business premises should have best practice communication access in place including the display of the International Deafness Symbol to indicate access availability of this access.

Recommendation 14: expanding the National Auslan Booking Service (NABS) to other vital services than private medical services, for example, legal appointments.

Recommendation 15: expanding NABS to improve access for hearing impaired people, for example access to real time captioning for medical and/or for legal appointments.

# 4.3. Adequacy of access to hearing services, including assessment and support services and hearing technologies

#### 4.3.1. General comments

Hearing healthcare services are fragmented between Commonwealth and Statebased agencies, and between the public and private sectors. There is no coordinated overall hearing healthcare program across Australia. The education sector is also strongly involved in the remediation of hearing loss. A more fundamental problem arises in that, although Australian Hearing Services (a Commonwealth statutory authority) has been established to provide hearing healthcare services to children, pensioners and ATSI peoples, hearing health care is



not considered to be a priority health care area. Hearing aids are not treated as essential medical appliances, reflected in the differential services provided under auxiliary cover by private health funds for hearing services and appliances.

#### 4.3.2. Access to hearing services



The Commonwealth Hearing Services Program is an outstanding program which provides a world class service to eligible clients: a child under 21 years of age or adults on an age, disability or veteran's pension.

However, this leaves a lot of people who are Deaf or have a hearing impairment in the general population (eg of working age) who receive no funding to access services and technologies that will enable them to communicate. The Hearing Services Program also has some anomalies by not providing replacement speech processors to eligible adults with cochlear implants. They will provide maintenance for speech processors but not replace the device. These cost \$8,000 to replace and many of these deaf clients have speech processors that are old and no longer repairable.

My friends are saving up for an overseas trip. I am saving up for my next hearing aids (Kirsten, aged 23, Canberra)

Medicare provides rebates for optical services provided by optometrists, but there is no similar equivalent rebate for services provided by audiologists (university qualified allied health professionals). The benefits payable via private health insurance (that many Australians cannot afford) are extremely small by comparison with the actual costs of hearing aids.

Deaf or hearing impaired adults on low incomes who are not eligible for the Commonwealth's Hearing Services Program are usually unable to afford the often costly hearing health services and/or hearing aids. This is due to a combination of the relatively high costs of aids and the association fitting and rehabilitation components, the exclusion of audiological services from rebates under the Medicare program (unlike a similar sensory impairment in vision impairment), and limited rebates from private health insurers (especially compared to similar aids such as eye glasses). Needless to say, people on low incomes, students and apprentices are also less likely to have private health insurance.

There are some instances of State-based assistance however this is inconsistent across States. The only other known avenue for access to assistance is through some hearing aid banks conducted mainly by volunteers from self-help consumer groups, university audiology clinics, and public hospitals in some States. These provide second-hand, re-fitted hearing aids but they too have their limitations as only behind-the-ear aids can be offered. By the time they are available as pre-used aids, they often have passed their use-by date. Costs may also be incurred to fit and program the device and the re-programming requires specific software for the brand and type of aid.



Paying \$9000 for 2 hearing aids is a decision akin to purchasing a second hand car. My private health insurance only gives me back \$500. As a self-funded retiree, why can't I get something back from the government after all my years in the workforce? John, 62, Mullumbimby

Deaf or hearing impaired adults unable to afford hearing health services can suffer severely disadvantaged lives. Their ability to participate in training or employment, family or social life will be limited and their impairment places them at high risk of developing emotional health and interpersonal problems arising from communication difficulties and social isolation. Provision of some assistance for hearing health and aids would be economically beneficial to the nation if it enables such people to keep, resume or find employment (and thus pay income tax), as well as being personally beneficial for them, their families, friends and employers.



Recommendation 16: The Commonwealth's Hearing Services Program should be modified and funding should be provided to enable access to the hearing services voucher scheme for

- any Australian who is on a low income or is a full time student.
- any Australian with a severe hearing loss or complex needs
- those with mild to moderate hearing loss who on professional audiological recommendation could benefit from provision of hearing aids/rehabilitation who are able to qualify as low-income.

Wilson et al (1992) have identified personal and economic costs of hearing loss. They state that, in 1989, Australia paid out \$70 million in Workers Compensation costs for hearing loss; but this may be only the tip of the iceberg when it is considered that the hearing-impaired occupy more hospital bed days, incur more hospital visits, and have greater limitation of activity due to chronic conditions, than the normal population. They also suffer clinically significant psychological disturbance three times more than the general population, and experience greater levels of anxiety, stress, and fatigue, which may predispose them to other health problems. Research indicates that hearing impairment is a risk factor for cognitive decline in older people and that it may exacerbate the symptoms of dementia.<sup>24</sup>



Recommendation 17: research and active measures to improve mental health for people with deafness.

Although audiological services are available for older people who receive a pension through the Office of Hearing Services, it is established through research that the majority of older people with hearing impairment (>50%) do not attend for

<sup>&</sup>lt;sup>24</sup> Wilson D, Xibin S, Read P, Walsh P, Esterman A (1992) "Hearing loss – an underestimated public health problem" *Australian Journal of Public Health*, 16:282-286.



conventional audiological services. Reasons for this include a lack of awareness about available hearing services, unwillingness to acknowledge hearing problems, and reluctance to accept hearing aids as a method of treatment (Hickson & Worrall 2003).

The prevalence of hearing loss in older people living in aged care facilities is even higher than in the rest of the community, affecting more than 90% of residents (Worrall, Hickson & Dodd, 1993). Research data on the relationship between hearing impairment and dementia, indicates that hearing impairment is a risk factor for cognitive decline in older people and that it may exacerbate the symptoms of dementia. (Peters, Polter & Scholar, 1988; Uhlmann, Laarson, Thomas, Koepsell & Duckert, 1989).

Despite this, the vast majority of older people living in aged care receive no treatment or support for their hearing difficulties, and staff members are frequently unaware of the hearing problems that residents have. (Burnip & Erber, 1996).



Recommendation 18: better aged care standards to ensure that hearing loss, which affects around 90 per cent of residents, is adequately catered for, through visual smoke alarms, captioned televisions, appropriate volume control phones, and other relevant mechanisms in accommodation.

It is a recurrent cost every four to five years for the replacement of a hearing aid. I really need two, but at \$4,000+ for an aid, I function on a single hearing aid, which I use for approximately 18 hours of every day. Without the aid, I hear absolutely nothing as I have a severe to profound loss, as a result of pre-lingual measles. Added to this is the cost of batteries and it is expensive having to pay for having what is termed a disability.

Maureen, Victoria

In the rural sector, South Australia has reported the findings of a five-year project, where approximately 90% of farmers were identified as being at risk of noise-induced hearing loss. 60-80% of farmers between the ages of 30 and 70 were found to have significant hearing loss, which could be attributed to exposure to farm noise. Farmers exposed to noise induced hearing loss have a 50 per cent chance of developing noise induced tinnitus as well as the hearing loss.

Access to hearing services in rural Australia is highly fragmented and variable, both in terms of scope of services and coverage. In broad terms there are two systems - publicly funded and for-profit.

#### 4.3.3. Assessment services

The Commonwealth-funded Hearing Services Program with its clearly defined responsibility for children under the age of 21 years who need hearing devices, and for means tested pensioners, is an excellent program for those diagnosed with hearing loss.



However, with few exceptions, and given no Medicare rebate for services provided by audiologist, for the remainder of the population primary hearing health is presently a state responsibility. Given Australia's vast and varied geographic spread and scattered population, any state-wide hearing health guidelines must be based on adequate area-by-area demographic detail, and should remain sufficiently flexible to adapt to the differing needs of the various health regions. This pre-supposes appropriately located, staffed, equipped and funded audiology units to identify, manage and where appropriate, refer on to other appropriate services, people of all ages and abilities from their surrounding community, for whom hearing is a question.

Unfortunately, this is a model yet to be attained. In fact, it appears to be going backwards rather than forward. For example, in the 1970's, Victoria established a state-wide demographically-based network of audiology units of this nature. In NSW audiology units were situated more by happenstance, with fewer in country areas. More recently, however, in both NSW and Victoria, instead of augmenting these services, audiology units providing unique identification and non-medical hearing management services for all ages and abilities for local communities where no alternatives exist in either the public or the private sector, have progressively been closed. These closures are occurring in both metropolitan and rural areas. As noted in the sections above, despite apparent short-term cost-savings, this has major economic implications in terms of delayed identification and of subsequent increased management costs.

Newborn hearing screening is still not universal in Australia. In those areas and communities where newborn hearing screening is available, it has had a very positive impact in the community (both amongst parents/families and professionals) in raising the awareness of potential hearing loss in infants.

Research, clinical practice and experiences reinforce the tenet that children who enter early intervention before six months of age will have the greatest opportunity to achieve their fullest potential across all developmental domains. The most effective way of detecting infants with hearing loss early enough to promote the best possible outcomes is through universal neonatal hearing screening for all newborns.

"I wish we had found out sooner. I can not waste any more time - he is so behind already." Dad of three year old Jayden who is hard of hearing, Melbourne.

The failure to deliver a universal Newborn Hearing Screening program would result in unfavourable outcomes for Deaf and Hearing Impaired children in terms of communication skills, educational achievement, mental health and quality of life, not to mention the substantial costs to the government and the community as a whole.

Deafness Forum supports partnerships between governments at all levels to ensure a comprehensive delivery of the Universal Newborn Hearing Screening program and other early intervention services. This should mean greater certainty and consistency for parents. We are aware that there is already significant progress towards this, but more can done.





Recommendation 19: Universal Newborn Hearing Screening implemented and standardised through all states and territories.

Prevention, early detection and early intervention should result in vastly improved outcomes for Deaf and hearing impaired children in terms of communication skills, educational achievement, mental health and quality of life. This then would ultimately translate into substantial cost savings, both to the government and the community as a whole.

This is not universal as was promised. In the Wodonga area the initial screening has just been introduced. However, the second phase of assessment of the child is carried out at Shepparton due to the lack of trained professionals and counsellors. The Albury / Wodonga area has a greater population than Shepparton and services a wider region, yet we still do not have adequate access to proper screening facilities, or an ongoing Paediatric Audiologist.

Children with cochlear implants need to travel to Melbourne or Sydney to receive services. Why is there no outreach program for these recipients? Unfortunately, from my experience, the implant centres attach the implant, but then fail to deliver adequate backup with the speech and hearing components that will enhance the child's ability to achieve maximum use of the cochlear technology.

Early childhood services are limited on the Victorian side of the border due to finding people prepared to travel to the regional areas.

Mollie, Victoria

Once a hearing loss or deafness has been identified there must be effective early intervention programs implemented in response. Parents of children who are Deaf or have a hearing impairment do not always have access to the information they need to make an informed decision regarding their child's schooling. In order for parents to make an informed choice of schooling for their children it is essential that they should have all options explained to them clearly and in a non-biased way.



Australian Hearing do provide an excellent publication for parents called Choices which is written in an unbiased manner and consults with all services and consumer groups to make sure they are all equally represented.



Recommendation 20: Choices to be more accessible online.



#### 4.3.4. Support services

At any age, appropriate services are clearly essential to ensure that newly diagnosed individuals and/or parents of young hearing impaired children are supported in selecting the rehabilitation/habilitation services most appropriate to their need, and also to ensure that such devices as cochlear implants and hearing aids are fully and appropriately utilised. As such, these services are extremely cost-effective. Adequacy of support services presently varies widely from excellent to non-existent.

However, it is obviously NOT cost-effective to have to provide support services for remediation of unnecessary secondary handicaps that may well result from delays in initial identification of hearing impairment and in subsequent delayed commencement of appropriate management.

#### 4.3.5. Hearing technologies

The question of affordability of hearing devices for those not eligible for the Commonwealth Hearing Services Program remains problematic. For example, the unique Australian Hearing CSO hearing services program provides (and appropriately encourages reliance on) hearing devices for hearing impaired children resident in Australia from birth/age of identification until they reach 21 years of age. Subsequently, this group in particular tends to be totally dependent on such aids to remain employed tax-paying citizens, yet purchasing new aids can be prohibitive. It is in both their interest, and the economic interest of the community at large, that an appropriate way to address this dilemma is devised and introduced as soon as possible. See previous recommendations.

While hearing technologies are vital, they do not provide access for everyone. Other equipment and services are also required to enable a person with hearing impairment (with or without hearing aids) to be socially included.

For example, captioning on television and in cinemas is increasingly available. While this is commendable, there are other areas where more communication access is required: technology to provide communications access such as induction loops and CART (Computer Assisted Realtime Captioning) is not new, but is still far too seldom available.

Additionally, people with hearing aids or cochlear implants may find they have to purchase additional insurances to cover hearing aids and cochlear implants if they are lost or broken. Currently most insurers will cover personal items like iPods, but not a cochlear implant processor, which is \$8,000 to replace, and vital for many to be able to participate in daily life.



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

#### 4.4.1. General comments

Although there is general acceptance that preventive measures – such as good education, ear protection and information about how to preserve hearing and how to avoid noise-induced hearing loss when working in noisy environments – should be readily available and provided as the norm in industry, the approaches to dealing with hearing conservation vary between States/Territories, and there is no consolidated Australia-wide awareness or public health program. This contrasts with skin cancer or other health conditions where there is a large role for prevention activities.

#### 4.4.2. Hearing health and research programs



Australia is fortunate to have the world-renowned National Acoustic Laboratories programs contributing to research across the range of hearing health issues. For thirty years, world-leading cochlear implant research has emanated from the Bionic Ear Institute, the University of Melbourne and the Hearing Co-operative Research Centre. Increasingly,

universities around Australia, in particular those offering post-graduate professional training in audiology, are contributing to this body of knowledge.

#### 4.4.3. Education and awareness programs

With regard to the general community, there is still much that needs to be done. The need for communications access is noted above and community education regarding this is essential.

Too often, lack of awareness leads to underutilisation of installed systems (such as loops) which is not only unfortunate for those missing out on the benefits they can provide, but can lead to their removal. Too frequently, installed systems such as induction loops are not maintained, and when needed, found to be non-functioning.



Recommendation 21: Hearing loop maintenance schedules be legislatively linked to fire alarm testing regimes.

Community education programs for managing hearing issues particularly in older populations, and in potentially noise exposed populations (either leisure or work-related) are also very much needed. To be successful however it is essential that these must be evidence-based. Presently, there is some work being done in these areas. If any real progress is to be made there needs to be more work done, both in developing Australian programs, and in evaluation for their suitability in the Australian context, of programs developed overseas.



The opportunities for exposure to leisure noise are increasing. Noise-induced hearing loss is an injury, yet it is not included within the aspects of injury covered under the current National Health Priority targets.

The World Health Organization states noise can cause hearing impairment, interfere with communication, disturb sleep, cause cardiovascular and psycho-physiological effects, reduce performance, and provoke annoyance responses and changes in social behaviour. <sup>25</sup>

Tinnitus is also a significant issue and 90 per cent of people experiencing tinnitus also suffer from hearing loss.

Recent research in the UK indicates that 90 per cent of young people experience the signs of hearing damage after a night out. <sup>26</sup> In the US, this has been called a "hearing loss epidemic"<sup>27</sup>. There is no reason to believe the same is not happening here in Australia. In fact, recent Australian research confirms this. <sup>28</sup>

Hearing loss has recognition as an Occupational Health Priority, but the problem has many causes and consequences. Wilson et al (1992) state that a comprehensive approach to hearing loss requires that it be recognised as a public health issue as well.

Indeed it deserves to be a national health priority. Currently 37 per cent of hearing loss is due to noise injury – in theory, this is entirely preventable.

Whilst hearing loss is suffered by a large number of Australians and costs a great deal in economic and social terms, there are demonstrable opportunities for primary and secondary prevention initiatives. Initiatives can be demonstrated in the strategies to address the risks of smoking - why not similar initiatives to address the risks that result in damaged hearing? While there is divided opinion about the efficacy and efficiency of public health campaigns, a good example might be the RNID (UK) "Don't Stop the Music Campaign". Overseas countries have legislated noise levels for example Germany<sup>29</sup>, UK<sup>30</sup>, Switzerland<sup>31</sup>.

Economically and socially, and in relation to health outcomes, Australians would benefit from increased efforts to prevent avoidable hearing loss, and to treat existing hearing loss.

Changes to Occupational Health and Safety legislation have meant a focus on reducing workplace noise. However it is apparent that there is still along way to go. As recently as the 2001/2002 year, it was costing the NSW Government (through

<sup>&</sup>lt;sup>25</sup> World Health Organization Fact Sheet Nos. 258, 300

<sup>&</sup>lt;sup>26</sup> RNID, August/September 2007

<sup>27 &</sup>quot;Hearing loss epidemic approaching" April 2009 <a href="http://www.press.hear-it.org/page.dsp?page=6292">http://www.press.hear-it.org/page.dsp?page=6292</a>

<sup>&</sup>lt;sup>28</sup> Going deaf 2008 <a href="http://www.abc.net.au/rn/lifematters/stories/2008/2239117.htm">http://www.abc.net.au/rn/lifematters/stories/2008/2239117.htm</a>

Noise to be turned down 2007 <a href="http://www.hear-it.org/printpage.dsp?printable=yes&page=5537">http://www.hear-it.org/printpage.dsp?printable=yes&page=5537</a>

<sup>&</sup>lt;sup>30</sup> Legislation to protect hearing 2007 <a href="http://www.hear-it.org/page.dsp?page=5522">http://www.hear-it.org/page.dsp?page=5522</a>

Ears of disco goers to be protected 2007: <a href="http://www.hear-it.org/page.dsp?page=5503">http://www.hear-it.org/page.dsp?page=5503</a>



WorkCover claims) over one million dollars every week for just for hearing loss claims (\$55,303,000 per annum).

The latest statistics from the 2007/2008 year show a cost of \$39,032,000 per annum in hearing loss claims (just over \$750,000 per week).<sup>32</sup>

When you consider that these figures are from NSW alone, and only formal claims are included (contractors, sub contractors and the self employed - such as farmers would have to look after themselves), the dollar cost to the community is pretty staggering. Some years ago, 1996 WorkCover changed the eligibility to at least a 6% hearing loss before a claim can be submitted, which had the effect of temporarily reducing the dollar amount paid out.



Recommendation 22: a national campaign on hearing health, and noise injury awareness, developed and delivered with consumer input.

Recommendation 23: campaigns for specific target groups, especially young people going on to risky occupations for noise injury such as farmers, TAFE students.

#### 4.5. Specific issues affecting indigenous communities

Indigenous communities have their own unique problems. Hearing problems in these communities will not be resolved independently of many other health and lifestyle issues. To be successful, programs must be developed in consultation with appropriate community members.

Indigenous Australians, especially children, are reported as having ear or hearing problems at twice the rate of non-indigenous children, primarily due to the high rates of otitis media. In the Northern Territory it affects at least half of all aboriginal children and a quarter of adults. Around 9,000 of the current NT indigenous population, as a result, will be seriously disadvantaged throughout their lives. Different studies have found rates of hearing loss up to 70%. "Learning Lessons", a report on indigenous education in the Northern Territory, stated that in one classroom 90% of children had no eardrums. In these circumstances, unless educational programs are developed to cope with hearing loss, it is a complete waste of time for children to attend school without appropriate support.

A Damian Howard background paper (Indigenous hearing Loss and the Criminal Justice System) states that, "At least 70% of Indigenous adults have some degree of hearing loss and at least 40% have auditory processing problems. Studies which have found even greater levels of hearing loss among Indigenous inmates suggest a clear association between hearing loss and involvement in the criminal justice system." He later states, "One study in a Darwin prison found 90% of Indigenous prisoners had some degree of hearing loss." There is a definite link between

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Indigenous hearing loss and coming into contact in some way with a criminal justice system. <sup>33</sup>

We defer to indigenous ear specialists in this area and do not have specific recommendations. Our own funding levels do not allow us to pursue this vital area.

#### 5. Conclusion

Given this vast array of possible negative consequences for people with hearing impairment, there is an urgent need for affordable and equitable hearing health services to address their needs. Funding for hearing health for adults is basically inadequate in Australia and hearing impaired people are left feeling they have really drawn the short straw in the competition for financial support as their health needs are largely under-supported.

Specifically, what is required is

- Affordable access to hearing assessment by audiologists. Why such assessment is considered a personal expense when other assessments of medical conditions are funded under Medicare is an anomaly that must be corrected.
- Affordable access to hearing aid and cochlear technology. Hearing aids are extremely expensive and many people simply cannot afford the hearing devices necessary for communication to lead fruitful lives. The Federal Government Hearing Services program is an excellent program for pensioners but its targeting must be improved. Low income unemployed people and elderly self funded retirees should be obvious inclusions for free services. Currently people of working age with hearing loss must find the necessary money themselves, amidst the competing demands of meeting housing, family and other commitments. It is simply unacceptable that such vital medical equipment be treated in the health system as a discretionary luxury item in the family budget.
- Rehabilitation and counselling services for hearing impaired people to address the psychological and identity issues involved in hearing loss and gain information and support. Provision across Australia is sparse and patchy. There is some limited provision for rehabilitation in the Hearing Services Program and some good examples of services are Hearing Solutions in South Australia and the Hearing Loss Advisory Service funded by the Victorian Government through Better Hearing Australia in Melbourne. However, few adults with hearing loss in Australia have access to the rehabilitation process that would enable them to rebuild fulfilling and productive lives with hearing loss.
- Accessibility in a range of premises, transport, media, education and workplace.
- Programs to address the preventable causes of hearing loss.

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<sup>&</sup>lt;sup>33</sup> Howard, D.2006 <u>www.eartroubles.com</u>



## 6. Contact

If you have any questions about the information contained in this submission, please contact

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