Margaret Robertson

SUBMISSION TO SENATE INQUIRY INTO HEARING HEALTH

I make this submission as immediate past Chairperson of the Deafness Forum of Australia and a member for 10 years. Prior to retirement from professional work I was employed for 30 years as a registered psychologist and counselor and developed a particular interest in the psychological implications of hearing loss.

My focus in this submission is on the extremely negative consequences of hearing loss and the current scarcity of health services in Australia to address the needs of deaf people. Isolated and distressing lives and failure to achieve full potential and productivity is often the result.

CONSEQUENCES OF DEAFNESS.

The experience of the 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. Such issues as 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 are all aspects of the losses that need to be faced and grieved, whether the loss be sudden or gradual. Obviously the stage of life at which the hearing loss occurs or develops will determine the impact of specific losses to be managed, but the needs of all age groups are equally urgent.

Adjustment and its Determinants

Some kind of adjustment and accommodation is eventually achieved by most people, but the quality of this adjustment varies enormously. 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**. I would argue that the current scarcity of resources in the Australian community sets a ceiling on the adjustment of all deaf people.**

Some Descriptions of the Experience

Now I want to illustrate with at some quotes from the broad literature that has developed about hearing loss.

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

'*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.* (Stone, 1987, p.117)

Secondly from another writer on the topic:

Be it vigilant or, as the years go by, dulled and weary, the deafened person's passage through the hearing world, oblivious to much that transpires, is characteristically guarded and uncertain, hoping to avoid but necessarily encountering pitfalls, surprises, misunderstandings, error, frustrations, irritation, embarrassment, pain, puzzlement and a simple lack of comprehension. (Orlans, 1987).

And finally the most eloquent of all:

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'.
(Beethoven Heiligenstadt Document, 1802)

Consequences for Self Esteem and Identity

While Beethoven had perhaps more reason than most for distress at losing his hearing, his statement expresses so succinctly for all of us the depression, the frustration and the loneliness. He also gives voice to one of the most problematic consequences and burden of losing one's hearing – the fear of '*letting people know of my condition'.*
Because it does seem 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**'. (Hetu, 1996).

Bluffing or trying to pass as someone with normal hearing is clearly common practice. Unfortunately the price paid for this deception can be high. While their not normal hearing goes perhaps undetected, hearing impaired people are at risk of having their behaviour regarded as very abnormal. (Orlans,1987) 'Unfriendly', 'stupid', 'rude', 'uncooperative', 'snobbish', 'socially unskilled', 'no personality' are all judgments the deaf person is apparently prepared to risk. Apparently they are preferable to 'deaf'.

Hetu in a 1996 paper examined this phenomenon at length and concluded that 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. '*Social incompetence is consistently felt to be a more tolerable negative identity than that of being viewed as a hearing impaired person".*

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. **It is a dismal fact that the fear that revealing a hearing impairment can limit employment or social opportunities can be shown to be accurate**. 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!'

Consequences for Emotional Health

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.

An intensive study in Belfast by Kerr and Cowie in 1997 of 87 hearing impaired people of working age investigated the overall impact of hearing impairment on people's lives, and produced evidence of severe impacts on quality of life and incidence of depression. Contributing factors were reported as communicative deprivation, restrictions put on their lives, hearing people's poor communication, distress in interaction and a profound sense of loss and bereavement. Interestingly, they concluded that these factors, rather than the actual severity of deafness, were more important determinants of the impact of deafness and should be targets for rehabilitation.

Summary of a few more studies :

‘Psychological disturbance was evident in a hearing impaired sample at a rate four times that of the general population’
(A study of 88 people of employment age by Thomas (1984)

‘*A significant relation between deafness and depression was independent of age and socio economic status’*
(A study of 253 elderly people, 60% of whom were HI, by Herbst & Humphrey 1980)

‘Elderly patients with late life psychosis with a paranoid symptom complex were four times as likely as the controls to have a hearing impairment’.
(Almedia et al 1995)

Hearing Impaired elderly report significantly more depressive symptoms, lower self-efficacy and mastery, more feelings of loneliness, and a smaller social network than normally hearing peers. Whereas chronic diseases show significant associations with some outcomes, HI is significantly associated with all psychosocial variables’
(A study of over 3000 people , aged 55 to 85, with a variety of chronic diseases including HI, investigating links with psychosocial variables by Kramer et al 2002)

Consequences for Physical Health

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. Author Kisor, in a personal memoir of deafness (1990),describes the exhausting process of communication for a hearing impaired person, all that listening, concentrating, checking out clues, guessing, etc, contrasting it with the experience of those with normal hearing *‘soaking up auditory information as it washes over them*’.

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

Other health connections are being made. Here is an example. In a Swedish study of 62 audiology patients aged 40 to 60 years, all employed, Hallborg and Carlsson (1991) reported:

Frustration, irritation and perceived inferiority in social interactions were mentioned frequently by the subjects. The psychophysical effects of stress are known to elevate output of stress hormones, leading to increased risk of diseases. Emotional responses ought to be the focus in any hearing rehabilitation program.’

And in current research depression is being shown 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'
(Report on World Conference on Health in the Age, 28 April 2004)
And as we have seen there is a frequent association between hearing impairment and depression and social isolation.

Consequences for Relationships and Family Life

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.** Previously equal relationships can become distorted as the normally 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 hearing impaired people out of activities where they know they would have difficulty hearing.

'D*eafness is essentially interactive. It is an experience which is necessarily shared with others. The closer the relationship, the stronger the impact of hearing difficulties'*

This is a quote from an article by Hetu, Jones and Getty who reported research with couples in 1993. They found common communication breakdowns between couples when one had acquired a hearing loss. These 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. Harvey (2000) describes a couple and what he terms as the 'vicarious loss' of the non hearing impaired partner.
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'

Consequences for 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

Stika(1997) carried out a USA focus group study of 107 hearing impaired people. Findings included:

- 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 re-educate 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 by Anthony Hogan et al 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'*

Conclusion

Given this vast array of possible negative consequences for people with hearing impairment, I would submit that there is an urgent need for the provision of 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 undersupported.

Specifically, what is required is

- Affordable access to audiological services for hearing assessment. 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 Seniors but its targeting must be improved. Low income and unemployed people should be obvious inclusions for free services. Currently people of working age with hearing loss must find the necessary several thousand of dollars 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 counseling 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 Service 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.

- Programs to address the preventable causes of hearing loss.

(Literature References from the original article that was adapted for this submission are available)