A submission to the Inquiry of the Australian Senate into Hearing Health in Australia

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Introduction

Dr Anthony Hogan is a leading Australian Social Epidemiologist and Rehabilitation Counsellor, with more than 20 years' experience working with deaf and hearing impaired people. His work has focused extensively on the psycho-social and health impacts of under-managed hearing loss.

This paper argues that:

1. hearing loss in western society is an inherently stigmatised condition
2. that the affects of such stigmatisation result in under-managed hearing loss and adverse mental and physical health outcomes
3. Australia's device centred approach to hearing loss does not address the health and social impacts of such stigmatisation nor do the devices themselves
4. indeed the paper notes that almost half the people who receive hearing aids do not readily use them
5. a public health approach to hearing loss is required where such an approach would include a significant community education campaign designed to enhance the social participation of people with hearing loss in keeping with the United Nations convention on the rights of persons with disabilities.

People with hearing loss are stigmatised in our society

The experience of living with hearing loss has carried a social stigma across millennia. In ancient Greece, for example, hearing loss (or deafness) represented a curse, an absence of intelligence, an inability to reason, dull wittedness and an inability to participate in community life. In the biblical era there were at least three symbolic meanings for hearing loss. First, hearing loss referred to stubbornness of heart, the refusal to listen, co-operate and obey. One who is deaf is thus disobedient and immoral. Second, people with hearing loss and disabilities generally in biblical times, were poor outcasts, dependent on the charity of others for survival. Third, being dumb (i.e. mute) is regularly linked with hearing loss throughout the bible. Of course, today, being dumb relates to stupidity, so that hearing loss and stupidity are linked as consistent themes across time and space. Through medieval times the inability to understand or express speech meant that an individual was not a person in law. A person unable to speak was not allowed to inherit the family fortune. Being unable to reason (i.e. speak), one was not allowed to receive the sacraments of the Church, which reflected one of the primary elements of full participation in community life at that time. These symbolic uses of the concept of hearing loss are used metaphorically today. In the community, to be deaf or hearing impaired is to be likened to being stubborn (stubborn as a mule), immoral and deserving of punishment, a charity case, needing care, a beggar and stupid. Indeed hearing loss also has several other meanings including being a phoney, an isolate, an incompetent, and simply an association with growing old (St Claire and He, 2009). Westbrook (1991) undertook a study to investigate whether or not Australians from different ethnic backgrounds explained the occurrence of a disability such as hearing loss in similar of differing ways. Distinct to Western culture, sinfulness and loss of karma were seen as significant contributing factors to hearing loss across cultures.

People with hearing loss are well aware of the attitudes the community has towards them and is well justified in fearing stigmatisation. For example, a lip-reading class was asked to list some of the labels used to describe hearing impaired people of which they were aware. Their responses included:

"Deaf, heedless, snobbish, inattentive, stupid, idiot, not with it, dumb, ignorant, useless, retarded, boring, arrogant, stubborn, slow, vague and psycho" (Self-reported labels gathered from a group of twenty hearing-impaired people in a lip-reading class). A similar group at the same lip-reading club, reported the psycho-social consequences of these stereotypes: " I'm a nuisance, I'm hard to include, I don't matter, , I don't fit in, I feel depressed, isolated, I'm difficult, I feel less of a person, I am invisible, I feel left out".

Stigma is associated with a fear of marginalisation (Getty & Hetu:1991:41-45). This fear of marginalisation motivates the individual to be reluctant to acknowledge their hearing loss or to conceal or deny their hearing loss. The fear of marginalisation leads to high levels of stress as the person is ever vigilant to hide their disability through fear of stigmatisation. People will continue to be reluctant to address their hearing health while they continue to be marginalised.

The effects of stigmatisation impact on the health and wellbeing of people with hearing loss

We have recently demonstrated an association between hearing loss and poor health outcomes (Hogan et al. 2009) which we attribute to the stress effects of stigmatised identity. Indeed, under-managed hearing loss has consequences in terms of health related quality of life, employment and psycho-social wellbeing. With regards health impacts the published literature shows people with hearing loss report[1]:

- elevated risk rates for diabetes and high blood pressure for people with hearing loss
- a higher incidence of stroke
- increased rates of heart attack and psychiatric illness among people who rated their hearing as poor

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[1] For fuller details of this literature review and for a discussion of the possible links between loss of hearing and loss of quality of life see Wilson 1997, Hogan et al. (2001), Access Economics (2006) and Hogan et al. (2009b).

- higher users of prescribed medications
- being three times more likely to see their doctor than members of the general population
- people with moderate to severe loss being 15 times more likely to need assistance in activities of daily living and up to seven times more likely to require assistance in the home
- a relationship being demonstrated between self-reported hearing-related social participation difficulties and reduced health-related quality of life
- a threshold effect being demonstrated between increasing communication difficulties (due to under managed hearing) and health, even when using hearing aids.

Psycho-social effects of hearing loss are also evident in the literature.[2] We know that people with hearing loss:

- report increased rates of affective mood disorders and poorer social relations
- persistently experience problems hearing in background noise – even when using hearing aids
    - the inconsistency of problems across social settings is confusing and de-legitimises the need to seek help
- role breakdown leaves clients feeling less confident about their ability to function socially
- there are critical social roles that the client now has trouble fulfilling (e.g. grandparent, scout leader):
    - breakdowns in critical social settings tend to occur when environmental demands exceed their physical abilities to hear; tried and proven strategies are ineffective and key helpers (such as spouses) are not available to assist
    - this scenario of high demand, low control, and poor support is a near textbook definition of psychological stress.
- reluctant to acknowledge hearing difficulties, they avoid critical social activities and fear stigmatisation (Hetu & Getty 1991)
- take up to 15 years to act on their hearing difficulties (Kockhin, 1999, Davis et al. 2007, Hogan, 2009)
- bluff and pass to avoid awkward communication situations and feel marginalised as a result (Orlans), and
- experience anomic symptoms as a resulting from a loss of social identity (Hogan, 2001).

People with hearing loss have also been shown to be:

- less likely to be in paid work[i] [ii] by a minimum of at least two percentage points for adults of working age, with the rate potentially being much high in harder economic times where people with disabilities are more vulnerable to the impacts of economic downturns, and[iii]
- more likely to be on lower income than the population.[iv]

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[2] For fuller details of this literature review see Hogan et al. (2001 and 2009) and Hogan (2001).

Existing models of intervention do not adequately address the psycho-social and health impacts of hearing loss.

The predominant intervention offered people with hearing loss in Australia is a hearing test, followed by the provision of hearing aids where indicated. Given the very wide range of psycho-social effects associated with hearing loss, and the emerging literature data on the health and social effects of hearing loss, a device only model of intervention falls well short of meeting the clients' needs. Moreover, the provision of hearing aids must not be seen as a panacea for hearing loss. In *Lancet* for example, Smeeth et al. (2002) report that 40% of people with hearing aids do not use them regularly. Chisolm et al. (2007) similarly report that 'only 59% of patients are reported to be satisfied with their hearing aids, a level that has remained unchanged over the past 10 years'. Studies cited above indicate that hearing aids mediate the effects of hearing loss, but they do not eliminate them. It is a concern that a group of people who have been demonstrated to be poorer than the rest of the community, can be asked to pay in excess of $10 000 for a pair of hearing aids and services on the open market only to find that they do not meet their needs. The data in the international literature on dissatisfaction with hearing aids indicates that there are significant inefficiencies in the existing model of service delivery that can and must be greatly improved upon for the benefit of Australian society.

There is essentially no support in Australia for interventions that enable people to address the psycho-social impacts of hearing loss. Similarly, most front line staff in hearing services lack the necessary skills to deliver such a service. Resources under the recently introduced Rehab Plus program could be used to this end. However, access to these services should not be through existing channels. Rather, community–based hearing wellbeing centres need to be established. Such centres could provide psycho-social support for people with hearing loss and also serve as a much needed centre for independent advice on hearing services and devices, such as the original Hear Service in Victoria.

A device centred model is an inadequate solution to a social problem

Given that hearing loss is a strongly stigmatised condition and that such stigmatisation results in adverse health effects, a therapy-only model is not going to redress the existing social prejudices. A public health approach to hearing health is required. Such an approach, which would be in keeping with the United Nations convention on the rights of persons with disabilities, would promote the validity of living with hearing loss and legitimate the many necessary changes that are required in society so that people with hearing loss can fully participate in social life. The basic strategies people need to use to cope with hearing loss in social settings are not difficult to learn (e.g. asking people to face you, to speak slowly and clearly, to move away from the light). However, most people with hearing loss feel that it is not legitimate to ask people to make these basic changes for them. A sustained community education campaign is required to validate the communicative needs of people with hearing loss. Such a campaign would result in substantive cost savings to society as a result of higher employment participation rates, and reduced costs for health. It would also greatly reduce the need for and cost of hearing rehabilitation services.

[iv] References available on request.