A FAIRER HEARING

ENHANCING THE SOCIAL INCLUSION OF PEOPLE WITH HEARING LOSS

PROF ANTHONY HOGAN, DR REBECCA PHILLIPS
INSTITUTE OF GOVERNANCE AND POLICY ANALYSIS, THE UNIVERSITY OF CANBERRA
AND MS MICHELE BARRY AND MS SARA DUNCAN
BETTER HEARING AUSTRALIA (VIC) INC.
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ABOUT THE AUTHORS

Anthony Hogan PhD
Anthony Hogan is Professor and Chair of Regional Governance at ANZOG’s Institute of Governance at the University of Canberra. He is also Adjunct Professor in Sociology at The Australian National University in Canberra. Anthony’s main research interest is the social impact of living with hearing loss.

Rebecca Phillips PhD
Rebecca Phillips is a research consultant and a Visiting Fellow at ANZOG’s Institute of Governance at the University of Canberra. Rebecca’s main research interests include the health and wellbeing of people, as well as the accessibility of health services. Her most recent projects have included the evaluation of a program to improve the psychosocial outcomes of farmers with hearing loss, the social inclusion of children with hearing loss, and consumer and clinician perspectives of services available to self-manage chronic conditions.

Michele Barry MBA, MPH
Michele has over 20 years experience in the assistive technology, aged and disability sectors. Michele is the CEO of Better Hearing Australia, an independent not for profit organisation that supports people to manage hearing related conditions. Previous roles have included CEO of LifeTec Qld and Director at Vision Australia. Michele has a particular interest in matching people with the best solution to enable functional equivalence for all.

Sara Duncan
Sara Duncan is the Business Analyst at Better Hearing Australia, an independent not for profit organisation, assisting people to manage hearing related conditions. Sara has over 15 years experience in the health, social service and disability sectors across not for profit, peak and government organisations. Sara is particularly interested in improving health outcomes, through improved public policy.
EXECUTIVE SUMMARY

The fact that almost 1 in 6 Australians has a hearing loss is a big deal. It is a big deal because compared with other Australians, people with hearing loss experience poorer social, economic and health outcomes on almost every social indicator available. The Australian Government has provided hearing devices to eligible Australians with hearing loss for over 80 years. While extensive resources and research support are being invested in the provision of these aids and devices; devices cannot overcome prejudice and discrimination and they cannot provide social support, education or employment. They are just aids to these processes. If people with hearing loss are to enjoy full and effective participation and inclusion in society; substantial changes are required to the way Australia seeks to enable people with hearing loss to take their rightful place in our society.

The narrow framing of existing hearing policy in Australia is readily evident by the fact that most people with hearing loss will not be able to access the National Disability Insurance Scheme (NDIS). This is because their hearing loss is not deemed to sufficiently impact on their life. This document provides a summary of quality research which demonstrates that hearing loss does indeed have a substantial social, economic and health impact which warrants policy attention.

Equality of opportunity for all Australians to enjoy the highest possible standards of living, health, education and social justice is central to our governments’ policy goals. This paper makes the case that if these goals are to be achieved Australia needs to give deafness a fairer hearing!
The fact that almost 1 in 6 Australians has a hearing loss is a big deal.

Not being able to hear well means not being able to communicate or participate in activities of choice.

Devices alone are not enough!
Not being able to hear well means not being able to communicate or participate in activities of choice. For many it is an isolating and debilitating experience. Most importantly the support services that they receive will have a lifelong impact upon how they experience their hearing loss. Listed below are some of the many impacts of hearing loss, with the body of this paper providing further details regarding each of these issues.

- Children with hearing loss may experience a delay in developing language skills, with longer term social and emotional impacts on their wellbeing.

- A person with a hearing loss may often feel stigmatized, leading to a range of behaviors which include denying and hiding their hearing loss and withdrawing from social interaction.

- People with hearing loss are more likely to suffer from increased rates of a range of social, psychological and physical health issues.

- As a group, people who have a hearing loss experience poorer health related quality of life and poorer physical health than the rest of the community.

- People with a hearing loss have poorer educational outcomes, are under-represented in both full and part-time work and tend to leave the workforce earlier.

A concerted change in policy is required to provide all Australians with hearing loss with the opportunity and encouragement to enjoy the highest possible standards of living, health, education and social participation. This group deserves the supports necessary to enable them to fully participate in education, employment and entertainment.
RECOMMENDATIONS

ENHANCING THE LIVED EXPERIENCE OF PEOPLE WITH HEARING LOSS

In order to address the social, health and economic barriers faced by people with a hearing loss:

01

Services provided across Australia for people with a hearing loss should be focused on ensuring that:

a. people with hearing loss achieve economic participation and social inclusion
b. people with hearing loss enjoy choice, wellbeing and the opportunity to live as independently as possible
c. families and carers of people with hearing loss are well supported.

02

Services provided across Australia aimed at addressing hearing loss should take a holistic perspective with the social service model to include, but not be limited to:

a. health promotion campaigns aimed at addressing preventable hearing loss
b. community education about the social participation needs of people seeking access to social and communicative inclusion, addressing but not being limited to people who experience hearing loss and communication difficulties
c. community-based delivery of psycho-social support programs tailored to meet the distinct needs of the respective community groups (i.e. a broad church of service delivery models and modules) including early intervention for children
d. education and employment support services.

03

Publicly funded services should be effective, efficient and regularly evaluated against outcome measures. Any under-utilised program funds should be quickly diverted to more effective service delivery models.

04

The structure and delivery of hearing services should be reviewed so that they are more aligned with the outcomes oriented principles of the National Disability Agreement (as endorsed by the Council of Australian Governments) and the goals stated above.
To enable services to meet the needs of people with a hearing loss more effectively and efficiently, it is proposed that a process be commenced to reorient existing device-centric hearing services to follow international best practice and embed outcome measures to ensure consumers enjoy full and effective social participation in Australian society. To these ends the following outcomes are sought:

a. the Commonwealth to develop and implement, in consultation with members of key consumer groups, a strategic community education campaign on hearing loss in the community. This campaign would address issues of stigma, social participation, the need for personal action and include a GP education component

b. allow people eligible for an Office of Hearing Services voucher to receive a community-based (non-audiological) service that addresses the psycho-social aspects of living with hearing loss before proceeding to device fitting and as a legitimate alternative to device fitting

c. that community-based organisations be funded to provide this psycho-social intervention using appropriately trained staff (such as social and welfare workers, psychologists and rehabilitation counsellors)

d. funding for a program of research on the social impacts of hearing and the development of solutions to address issues identified generally. As well as a specific program targeting Aboriginal and Torres Strait Islander peoples.
THE DEMOGRAPHICS OF PEOPLE WITH HEARING LOSS

One in six Australians has a hearing loss. A demographic profile of this community can be found at www.betterhearing.org.au.

We note in particular that key community groups include children, Indigenous people, people of working age and older Australians.

WHAT DOES THE EVIDENCE TELL US ABOUT THE SOCIAL IMPACT OF HEARING LOSS?

FOR CHILDREN

Children with hearing loss participate in social communication in ways that are different to children without hearing loss. Even with the aid of devices, communication can be quite difficult because of glare and background noise.

Children with hearing loss may experience a delay in developing language skills. Language delays impact on:

- vocabulary development
- use of grammatical structures
- sentence construction
- numeracy skills
- pragmatics (interactive skills)
- emotional development, and
- mental health outcomes.

FOR ADULTS

Hearing loss is associated with a large range of psycho-social impacts. These include:

- increased rates of affective mood disorders and poorer social relations
- higher rates of overall psychiatric disorders
- persistently experiencing problems hearing in background noise – even when using hearing aids

Because the social impact of hearing loss varies according to environment (I can hear sometimes but not others) people can be confused as to whether they
really have a hearing problem that requires attention role breakdown resulting in decreased confidence in their ability to function socially ix:

• trouble fulfilling critical social roles (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.

• greater stress and social anxiety, and
• experiencing psycho-social symptoms resulting from a loss of social identity x.

Partners and carers of people with hearing loss also experience psycho-social impacts including: reduced self-esteem, a loss of intimacy, stress and tiredness due to communication-based conflicts and a reduced social life because their partner does not wish to socialize.

As a group, people who have a hearing loss experience poorer health related quality of life and poorer physical health than the rest of the community. With regards to health impacts the published literature shows people with hearing loss may experience:

• elevated risk rates for diabetes and high blood pressure
• higher incidence of stroke xi
• increased rates of heart attack xii
• higher mortality rates, especially among men xiii
• higher use of prescribed medications xiv
• elevated rates of all causes of morbidity
• reduced functioning in activities of daily living xv, and
• overall poorer physical and mental health related quality of life, particularly among women xvi

This literature has also shown that xix:

• people often take up to 15 years to act on their hearing loss
• people with severe hearing loss are three times more likely to see their doctor than members of the general population
• people with moderate to severe hearing loss are 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 exists between self-reported hearing-related social participation difficulties and reduced health-related quality of life
• a threshold effect exists with increasing communication difficulties (due to hearing loss) and health related quality of life.
• people with hearing loss have three additional health conditions than the general population, with 53% reporting at least one health condition. The most prevalent health conditions being other long term conditions such as arthritis, asthma, heart disease, Alzheimer’s disease, or dementia
• people with hearing loss rated their hearing loss as the most restrictive condition that they experience after chronic pain and restriction in physical activity.

Many people with hearing loss are socially isolated.

1. These findings do control for age effects.
SOCIO-ECONOMIC IMPACTS

In this section we report on the research on socio-economic impacts.

EDUCATION AND EMPLOYMENT INDICATORS

People with hearing loss have poorer educational outcomes. They are over-represented among those who leave school by year 8 or year 9 and are under-represented among those who have completed a year 12 education or a university degree.

In relation to employment, while people with hearing loss are over-represented in intermediate production and transport jobs they are under-represented across a variety of skilled areas including professional jobs in management and commerce; food and hospitality; associate professionals; and advanced, intermediate and elementary clerical, sales and services. Overall, people with hearing loss are less likely to be found in highly-skilled jobs and are over-represented among low income-earners.

The data shows that even though this cohort is socially autonomous and wants to work, they are under-represented in both full and part-time work. Their experience at work is one of stress and isolation. Approximately 40% reported that their hearing had no impact at all on their capacity to communicate at work. Nonetheless, compared to other Australians, the cohort reports that their jobs are less secure and they are more worried about future employment security. In addition, they report that the work they are assigned tends to be less challenging, their skills are under-utilised and they are often left to work alone.

People with hearing loss experience difficulties achieving equity in the workplace, noting that their employers and co-workers repeatedly fail to accommodate reasonable communication needs. Unsurprisingly, people leave the workforce early because of a lack of support and in turn report an increased rate of unemployment between 11.3% and 16.6%.

Having an additional illness or disability increases the likelihood that people with hearing loss will be outside the workforce. People with hearing loss who have a second disability (e.g. mental illness) are 1.5 times more likely to be unemployed than other people with hearing loss.

Access Economics reported that hearing loss costs the Australian community 1.4% of gross national product each year in lost productivity with the bulk of these costs being caused by reduced participation in the workforce. A net impact of being outside the workforce is poverty, evidenced by people with hearing loss reporting greater troubles paying specific bills when compared with the broader population.

SOCIAL INDICATORS

Research indicates that people with hearing loss fair more poorly than other Australians across a wide range of social indicators (including personal autonomy, community participation and social cohesion).

We review each of these indicators in turn.

PERSONAL AUTONOMY

Personal autonomy is concerned with one’s capacity to face challenges and solve problems. People with hearing loss, compared to other Australians, report:

- a reduced capacity to solve problems or change things which are of concern to them
- more frequently experiencing feelings of helplessness
- a reduced capacity to take on challenges into the future, and
- having less control over their lives.

COMMUNITY PARTICIPATION

Compared to other members of the population, people with hearing loss more commonly talk with their neighbours, attend church services and communicate with politicians. By contrast, they are less commonly involved in group events (e.g. fetes,
political activities, community activities) and more complex social interactions such as participating in complex discussions, or social activities with friends.

**SOCIAL COHESION**

Compared to other members of the population, people with hearing loss report on average higher levels of trust and are more likely to find people to be reliable and honest. Nonetheless, they are not naïve to the possibility that people may try and take advantage of them if the opportunity arose. They do however report poorer outcomes on all indicators of social cohesion. Reviewing the literature it can be seen that two primary problems are experienced:

- being more socially isolated, and
- having less personal support.

Stigmatising processes are legitimated by a highly complex interplay between the re-enforcement of dominant stereotypes and values overtime in a variety of settings including the media as well as key institutional and economic interests. The media appears ever-ready to run naïve stories about the miracles of technology while rarely being prepared to look behind the media release to inquire as to what is really happening in this community.

Individuals with hearing loss have to trade off the risks of further stigmatization with any benefits that might arise from behaviourally identifying as having a hearing loss. Both options, it seems come at a high personal cost.

**THE SOCIAL IMPACT OF HEARING LOSS**

Social reactions to hearing loss are highly stigmatizing and have been across millennia. A wide range of highly demeaning labels have been used to describe people who participate in communication in different ways. Across History, deafness has had quite specific social consequences in that people were denied property rights, they could not inherit, they were denied citizenship, and denied access to rites of social passage (e.g., not being allowed to participate in church rituals). Deep within our society’s psychic there is a strong sense that there is something inherently wrong about having a hearing loss.

It comes as no surprise then that people with hearing loss seek to avoid and manage this stigma by:

- denying that they have a hearing loss
- being reluctant/embarrassed to talk about difficulties;
- misperceiving the nature of the problem (accusing people of mumbling/believing that others no longer speak as clearly as they once did)
- bluffing (pretending to understand, smiling, nodding, laughing when others laugh)
- passing (pretending to ignore requests not understood)
- minimizing problems
- withdrawing socially (including devaluing previously valued social settings)
- avoiding non-critical social activities, and
- expecting technology to do more than it can to help.
ENDNOTES

7 Hogan (2001) IBID
8 Hétu & Getty (1991) IBID
11 Hogan (2001) IBID
13 Mitchell (2001) IBID
17 Wilson et al. (1992) IBID
18 Wilson et al. (1992) IBID
19 Wilson et al. (1992) IBID
20 The majority of these data are from the following sources unless specified otherwise: Wilson et al. (1992), or Hogan, A., O'Loughlin, K. & Kendig, H. (2009). The impact of hearing loss on personal health – a threshold effect model. Journal of Ageing and Health. 21: 1098-1111.