CHAPTER 6

ADEQUACY OF HEARING HEALTH RESEARCH PROGRAMS

> We need to have evidence based practice. We only work on evidence based practice.
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> Ms Dimity Dornan, Hear and Say Centre, *Committee Hansard*, 7 December 2009, p. 71.

Introduction

6.1 This chapter examines the adequacy of current hearing health research programs and explores the need to overcome identified research gaps.

Major Hearing Health Research Programs and Organisations

6.2 The Australian Government provides financial support for hearing health research through a number of funding mechanisms, including:

- the Hearing Loss Prevention Program (HLPP), announced in May 2007. This ongoing program ($3.5 million in 2007-08) provides funding for research and prevention activities to help reduce the burden and incidence of avoidable hearing loss in young people, Indigenous Australians, and those in the workplace. As this is a designated 'ongoing program', there will be opportunities to respond to identified gaps and emerging needs after the initial establishment phase of the program. Six research projects have been commissioned through this program. The research programs funded to date address issues for all three target groups;
- research by the National Acoustic Laboratory (NAL) which is funded under the Australian Government Hearing Services Program, Community Service Obligation (CSO) arrangements;
- funding for the National Health and Medical Research Council (NHMRC) grants, which currently includes funding for research into deafness, ear physiology, hearing aids, otitis media and tinnitus;
- the Cooperative Research Centre (CRC) program administered by the Department of Innovation, Industry, Science and Research (DIISR) which in 2007 provided funding of $32.55 million over seven years to the HEARing CRC;[1]
- the Department of Veterans Affairs (DVA) which is undertaking a study of the Neuromonics tinnitus program, which has been available in private

1 Department of Health and Ageing (DOHA), *Submission 54,* pp 57-61.

practices in Australia for several years. Approximately 60 veterans are taking part in the study, with results to be finalised in 2011.[2]

6.3 The committee received many submissions that noted Australia's position as a world leader in hearing health research, and which encouraged Australian governments to maintain adequate funding for hearing health research, particularly for the NAL.[3]

6.4 The NAL focuses on research into three major areas: better ways of assessing hearing loss; hearing rehabilitation once hearing loss has been diagnosed including advancement of hearing aid devices; and prevention, including the effects of noise on people.[4] NAL is recognised internationally for its work. Signal processing software used in hearing aids that has been developed by NAL is used widely throughout the world.[5] In the words of Professor Dillon, Director of NAL: '…any little place or shop around the world that sells hearing aids will know about NAL because they use our methods on a daily basis.'[6]

6.5 NAL is currently undertaking the Longitudinal Outcomes of Children with a Hearing Impairment (LOCHI) study, which is the most comprehensive study of its type in the world. NAL has recruited 475 children with a hearing loss at the time, or not long after, they received their first hearing aids.[7] LOCHI will examine the development of speech, language function and psychosocial skills, and the educational attainment of the children. The study measures the:

- importance of early detection of hearing loss, intervention and special education;
- effects on outcomes of a range of factors including age at time of intervention, cause of hearing loss, type of hearing aid prescription and type of intervention;
- rate of development and relative impact of different factors at different ages.

When all data is available, the study will assist in the understanding of:

- whether normal speech and language development among hearing impaired children who have received early intervention will continue through school years;

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2 Department of Veterans Affairs (DVA), *Submission 135,* p. 3.

3 See for example Dr Jenny Rosen, *Submission 2,* [p. 3]; Self Help for Hard of Hearing People (SHHH), *Submission 72,* [p. 13]; Mr Paul Hickey, *Submission 115,* [pp 4-5].

4 DOHA, *Submission 54,* p. 59; Professor Harvey Dillon, Director, NAL, *Committee Hansard,* 13 October 2009, p. 50.

5 DOHA, *Submission 54,* p. 59.

6 Professor Harvey Dillon, Director, National Acoustic Laboratory (NAL), *Committee Hansard,* 13 October 2009, p. 51.

7 Professor Harvey Dillon, Director, NAL, *Committee Hansard,* 13 October 2009, p. 46.

- the impact of many factors on long-term speech, language, functional, psychosocial; and
- the impact of hearing loss on educational attainment.[8]

6.6 The HEARing CRC is a consortium of research, clinical and industry organisations that facilitates communication between academic, clinical and industry members with the aim to ensure coordinated research. The HEARing CRC focuses on the development of targeted remediation of lost productivity that results from hearing loss in adults and children, and research into technical and behavioural means of preventing hearing loss. The HEARing CRC has four research programs:

- biomolecular, genetic, physiological solutions;
- intelligent sound processing;
- integrated bioengineering; and
- clinical tools and techniques.[9]

6.7 Other key Australian hearing health research organisations include:

- Macquarie University (audiology and cognitive research);
- The Bionic Ear Institute;
- University of Melbourne (audiology and cochlear implant research);
- Cochlear Ltd (cochlear implant development);
- Menzies School of Health Research; and
- The Ear Science Institute.[10]

Research Gaps

6.8 Prior to the 2006 publication of *Listen Hear!* by Access Economics, there had been no definitive research on the economic impact of hearing loss and impairment in Australia. Most studies have focused on clinical, prevalence and social issues connected to hearing loss.[11]

6.9 A study into the epidemiology of hearing loss conducted by the then Centre for Population Studies in Epidemiology within the South Australian (SA) Department of Human Services has been the only epidemiological study of hearing loss in

8 DOHA, *Submission 54,* p. 60.

9 HEARing Cooperative Research Centre (CRC), *Submission 45,* [p. 3]; DOHA, *Submission 54,* p. 60.

10 HEARing CRC, *Submission 45,* [p. 2]; Dr Jenny Rosen, *Submission 2,* [p. 3]; Ear Science Institute, *Submission 66;* The Menzies School of Health Research, *Submission 174.*

11 Access Economics, 2006, *Listen Hear!: the economic impact and cost of hearing loss in Australia*, p. 9.

Australia. As noted by Access Economics, in order to monitor progress in the management and prevention of hearing loss there is a need to maintain an accurate and current epidemiology.[12]

6.10 Submissions received by the committee also outlined the need for further research into the feasibility of a national hearing and tracking database for newborns, the impact of recreational noise and personal media players on hearing health, overcoming occupational noise induced hearing loss, acoustic shock, the incidence of comorbidity of hearing loss and other disabilities, mental health issues associated with hearing impairment, addressing employment issues for people with hearing impairment, caring arrangements, ototoxicity, and Meniere's Disease.

A National Tracking Database for Newborns

6.11 The committee received many submissions expressing frustration at the lack of nationally consistent data about newborns and children diagnosed with hearing impairment.

6.12 In particular, Professor Dillon and NAL have discovered through the LOCHI study that a significant number of children who are diagnosed with hearing impairments are not recorded to have received treatment:

> A gap that we just discovered actually only in the last month or two, [is that] 25 per cent of the children diagnosed [with hearing loss] have not ended up with rehabilitation, so they have fallen through the cracks somewhere along the way.[13]

6.13 The committee heard from Professor Dillon that this research was undertaken only in New South Wales (NSW), however it is likely that the same is occurring in other parts on Australia.[14] Further investigation by NAL into this matter has found 15 of the 25 per cent stated above made it to Australian Hearing, but were not issued with hearing aid devices. The reasons for the 'missing' 10 per cent remain unknown. Professor Dillon noted that many individual states had their own records and databases, however given this 10 per cent gap:

> There is a real need for a national database associated with newborn screening so that we do not have to catch this up on a special-occasion basis, but it just becomes part of the system…The way I envisage it working is…that information would be [regularly] downloaded from the state databases to a national one, and there we could compare the children

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12 Access Economics, 2006, p. 79 (citing 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 and Wilson D H, Walsh P G, Sanchez L, Read P, 1998 *'Hearing Impairment in an Australian Population,* Centre for Population Studies in Epidemiology, South Australian Department of Human Services).

13 Professor Harvey Dillon, Director, NAL, *Committee Hansard,* 13 October 2009, p. 47.

14 Professor Harvey Dillon, Director, NAL, *Committee Hansard,* 11 November 2009, pp 91, 47.

> who have been shown to have a hearing loss with who has been picked up by Australian Hearing and received rehabilitation. Immediately then we would spot the gap in every state and those children could be followed up.[15]

6.14 The discovery by NAL of children who are diagnosed with hearing impairments, but who are not known to have received intervention, is a concern in relation to their development outcomes. As was discussed in chapter four, research has shown the benefits of identifying hearing impairments in children at a young age, provided that diagnosis is followed by early intervention.

6.15 As noted in chapter two, children with hearing loss represent only a small proportion of all people with a hearing loss. However the impact on this group is particularly significant as they require a high level of support in developing communication skills and accessing education.[16] Due to the lack of research that tracks patient outcomes nationally, it can be difficult for parents to determine the most appropriate intervention for their child, and which communication strategies and hearing technologies to adopt.[17]

6.16 Submissions received by the committee referred to new trends in therapy services for the deaf, including a move away from hands-on therapy services and an increasing number of cochlear implants in children. Submissions outline the need to research the educational, cognitive, linguistic, social and emotional development outcomes, and future life situations of children who engage in different forms of treatment for hearing loss, in order to help parents to make informed decisions about treatment and intervention options.[18]

6.17 The Department of Health and Ageing (DOHA) submitted to the committee that:

> A national data set for state and territory neonatal hearing screening and post screening services is in the process of being developed, and will;
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> 1. Allow for the monitoring and evaluation of neonatal hearing screening programs
> 2. Underpin the development of a nationally consistent quality and standards framework
> 3. Permit for national and international benchmarking and collaboration

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15 Professor Harvey Dillon, Director, NAL, *Committee Hansard,* 11 November 2009, pp 47, 92.

16 DOHA, *Submission 54,* p. 21; Access Economics, 2006, pp 16-17.

17 Australia New Zealand Parents of Deaf Children (ANZPOD), *Submission 24,* p. 11; Parents of Hearing Impaired South Australia (PHISA), *Submission 25,* [p. 10]; Government of South Australia, *Submission 145,* p. 19; and Professor M Hyde, Professor D Power, *Submission 160,* p. 3.

18 The Cora Barclay Centre, *Submission 64,* p. 4; Professor M Hyde, Professor D Power, *Submission 160,* pp 5-6.

4. Enable research into risk factors and health conditions associated with permanent childhood hearing impairment.[19]

A national register will be established as part of the national approach to neonatal hearing screening and will be a central point for the collection and management of all data. The data parameters of a national register are yet to be finalised and consultation with key stakeholders will be undertaken to determine the most appropriate national register for neonatal hearing screening data. Consideration will also be given to the ethics of allowing academic and other researchers accessing data held on a national register for appropriate research projects.[20]

Recreational noise and personal music players.

6.18 Access Economics reported that 37 per cent of all hearing loss in Australia is preventable and is caused by exposure to excessive recreational or occupational noise.[21]

6.19 Many submissions received by the committee expressed concern with the lack of definitive research that exists regarding the impact of excessive recreational noise, particularly personal music players, but also including shooting, motor sport and the use of power tools. [22] Concern regarding exposure to excessive noise from personal music players was particularly in relation to use by young people.[23]

6.20 As was noted in chapter two, despite research evidence that exposure to noise through personal music players can be loud enough to pose a danger for hearing loss, it has not been well-established whether, or how much, this recreational exposure is contributing to significant, long-term hearing loss in later life.[24]

6.21 Some research into the effects of recreational noise is currently being undertaken. NAL has been funded under the HLPP to undertake a research project to establish the prevalence of hearing loss in adolescents, and the relationship to recreational noise.[25] This report is due to be released in December 2012. A complementary study by NAL will further provide a comprehensive picture of the noise exposure of young people, and an assessment of the contribution that different activities and environments pose on the hearing of young people over a lifetime. Edith

19 DOHA, *Submission 54*, p. 41.

20 DOHA, *Submission 54*, p. 42.

21 Access Economics, 2006, p. 18 (citing Wilson et al 1998, p. 34).

22 University of Melbourne, Audiology and Speech Sciences, *Submission 9,* p. 2.

23 DOHA, *Submission 54,* p. 19.

24 DOHA, *Submission 54,* p. 19.

25 DOHA, *Submission 54,* p. 57.

Cowan University is also undertaking a similar research project into the effect of personal music players at high volumes among young people.[26]

6.22 Submissions received by the committee suggest that current research into the impacts of recreational noise should be extended into longitudinal population studies that establish the long-term effects of recreational noise exposure, including from personal music players. [27]

Occupational noise induced hearing loss (ONIHL)

6.23 Safe Work Australia estimate that a third of workers in Australia are exposed to noise levels that could lead to noise-induced hearing loss.[28] This hearing loss, which is entirely preventable, makes a substantial contribution toward the high cost of hearing loss to Australia, as discussed in chapter three.

6.24 Submissions received by the committee note that legislation already exists in Australia to limit noise exposure, and to protect employees from exposure to excessive noise in the workplace. However, submissions have argued that there are significant obstacles to the effective implementation and acceptance of occupational noise management which contribute to the failure of efforts to reduce personal noise exposure, and that understanding these barriers is a key research challenge.[29]

6.25 Safe Work Australia is undertaking research into ONIHL, including:

- analysis of the National Hazard Exposure Worker Surveillance (NHEWHS) Survey 2008, which gathered national data on the exposure of workers in Australia to various hazards, including loud noise. It also gathered data on the provision of control measures in Australian workplaces, including controls for noise exposure.[30] This information will enable identification of workers at risk of ONIHL, with the aim of reducing the incidence of ONIHL through better targeted occupational health and safety policy, enforcement and information/education campaigns; and
- the *Getting Heard* project, as mentioned in chapter two. This project will determine the personal and institutional factors that influence the control of hazardous noise exposure and the prevention of ONIHL. Outcomes from this

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26 DOHA, *Submission 54,* p. 57.

27 See for example University of Melbourne, Audiology and Speech Sciences, *Submission 9,* p. 2; Audiology Australia, *Submission 74,* p. 24; and Access Economics, 2006, p. 79.

28 Dr Fleur Champion de Crespigny, Assistant Director, Research and Education, Safe Work Australia, *Committee Hansard*, 19 March 2010, p. 2.

29 DOHA, *Submission 54,* p. 58; University of Melbourne, Audiology and Speech Sciences, *Submission 9,* p. 1; Dr Fleur Champion de Crespigny, Assistant Director, Research and Education, Safe Work Australia, *Committee Hansard*, 19 March 2010, p. 2.

30 Dr Fleur Champion de Crespigny, Assistant Director, Research and Education, Safe Work Australia, *Committee Hansard*, 19 March 2010, p. 2.

project will provide the Office of Hearing Services (OHS) and stakeholders with a greater understanding of why ONIHL still occurs among workers in Australia. The findings will also assist stakeholders in the design, implementation and evaluation of strategic initiatives to control hazardous occupational noise.[31]

6.26 Submissions received by the committee indicate that further research into the opportunity, ability, willingness and intent of workplaces to prevent hearing loss, the design of workplace equipment, and more appropriate forms of hearing protection, such as pharmacological protection, could have a large impact in improving workplace practices to prevent ONIHL.[32]

Under-use of hearing aid devices

6.27 As was discussed in chapter five, evidence suggests that between 20 and 40 per cent of all hearing aids provided with public funding may be under-used, or not used at all. The committee also received submissions from health practitioners and researchers that indicate a low take-up rate of hearing aid devices. This includes the suggestion that less than 20 per cent of adults who could benefit from hearing devices pursue those services, and less than 10 per cent of people who could benefit from cochlear implants seek this form of treatment.[33]

6.28 Submissions to the inquiry note that the low usage rates of hearing aids represents a waste of public funding, and that research into the reasons for under use of hearing aids is required, including cosmetic and technical problems.[34]

Health outcomes and mental well-being of the hearing impaired

6.29 As noted in chapter three, hearing loss has been linked to a range of increased risks for other health conditions including diabetes, stroke, elevated blood pressure and heart attack.[35]

6.30 DOHA reports a growing body of Australian and international research regarding the prevalence of mental illness among the hearing impaired. DOHA note, however, that research findings are inconsistent and even conflicting, which has resulted in '…the mental health industry in Australia being ill-equipped to adequately meet the need of people with a hearing difficulty'.[36]

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31 Safe Work Australia, *Submission 5,* [pp 1-2].

32 Access Economic, 2006, p. 79; University of Melbourne, *Submission 9,* p. 2; and New South Wales (NSW) Health, *Submission 167,* p. 19.

33 Access Economics, 2006, pp 74, 80; University of Melbourne, *Submission 9,* p. 6.

34 Neil and Susan Clutterbuck, *Submission 36,* [p. 2].

35 DOHA, *Submission 54,* p. 22.

36 DOHA, *Submission 54,* p. 23.

6.31 Submissions further identify the need to clarify potential links between hearing impairment, social isolation and mental health issues in order to develop methods for early intervention and treatment.[37] Access economics notes that long-term research is necessary in this area.[38]

6.32 DOHA has provided evidence to the committee that there is no research on the relationship between mental health and hearing impairment currently funded by the NHMRC, nor funded in previous years. Since 2005, the Australian Research Council has provided funding to support four child-specific research projects examining the relationship between hearing loss and mental health issues such as development of social skills, social participation and wellbeing and happiness.[39]

The effects of ototoxicity

6.33 Ototoxic substances are chemical substances that may damage the hair cells of the cochlear or the auditory pathway, and which can also increase the risk of preventable hearing loss.[40]

6.34 Ototoxic substances may be present in medicines, including antibiotics and chemotherapy treatments, or inhaled through the fumes of fuels, metals, fertilisers, herbicides or pharmaceuticals.[41] The nature of ototoxic substances is that they are often present in the workplace, which makes the issue of awareness and safety around these substances a workplace issue.

6.35 Evidence received by the committee suggests that little is known about the complete effect of ototoxic chemicals on long-term hearing loss, or how many people are exposed to these substances in the workplace. The findings from such research may help reduce the incidence of preventable hearing loss, and identify a need for different audiological tests to properly assess impacts of ototoxic exposure.[42]

Meniere's Disease

6.36 Meniere's disease affects around 40,000 people in Australia who consequently experience hearing impairment including fluctuating hearing loss, tinnitus, spinning and vertigo, and other symptoms.[43]

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37 Farmsafe Australia, *Submission 33,* p. 1.

38 Access Economics, 2006, pp 80-81.

39 DOHA, *Submission 54,* [p. 1].

40 DOHA, *Submission 54,* p. 19.

41 NSW Health, *Submission 167,* p. 5; Access Economics, 2006, p. 80.

42 Ms Marion Burgess, *Submission 172,* p. 4.

43 Meniere's Australia, *Submission 156,* pp 2, 4.

6.37 Meniere's Australia noted that few other submissions received in this inquiry mention Meniere's disease. Meniere's Australia has advised the committee that there is not research available that determines the cause of the disease, and that little funding is available from the Australian Government to advance this. Further, Meniere's disease is often misdiagnosed or undiagnosed. Meniere's Australia submit that more extensive research into the prevalence of the disease, rates of diagnosis, treatment and personal management options, and the impact on the employment and lifestyles of those with the disease is necessary.[44]

Committee comment

6.38 The committee would like to note that it has heard from many sources during the course of this inquiry that Australian research into hearing health is highly regarded internationally. Whilst there are many organisations in Australia conducting world class research in this field, the committee would particularly like to acknowledge the leadership and vision of National Acoustic Laboratories under the direction of Professor Harvey Dillon.

6.39 Having acknowledged that Australia is at the forefront of hearing health research, the committee did learn about gaps in the collective knowledge and understanding that will benefit from further attention. The committee understands that funding is finite, and has directed its recommendations toward two areas. Firstly, toward research that will have greatest benefit for the quality of life of people with hearing loss. Secondly, the committee's recommendations are directed toward research that is likely to benefit Australian productivity.

6.40 In particular the committee is concerned by the potential for 'missing' children who are registered to have been diagnosed with a hearing impairment but are not recorded as having received intervention. Given the unambiguous evidence before the committee about the many benefits of a greater understanding about the clinical and developmental pathways of children diagnosed with hearing loss, development of a national data base should be a high priority for research and development.

6.41 The committee heard a widespread note of concern from many sectors of the community, including concerned individuals, research bodies and government agencies, about the possible effects of personal music players on hearing health. The committee believes that the high visibility of these devices in the community, particularly among young people, has driven this general concern. The committee understands that the research on this issue is not conclusive, and that a long term study will be of great benefit to future safety practices.

6.42 The committee notes that there is a knowledge gap around detailed understanding of the extent of hearing loss caused by ONIHL. To some extent this gap may be attributable to the nature of hearing loss, whereby it is often difficult to

44 Meniere's Australia, *Submission 156,* p. 4.

attribute a hearing loss to one workplace or event. What seems certain to the committee, however, is that despite good knowledge about safe workplace practices, many workers and employers do not comply with hearing safety regulations, especially in smaller workplaces. The committee has included workplace safety awareness raising in its recommendations at chapter seven. A deeper understanding of the reasons for non-compliance and other risk behaviours will contribute to national policy and workplace practices.

6.43 A greater understanding of the nature of ototoxins, particularly in the workplace, may also contribute to reducing preventable hearing loss.

6.44 The committee noted in chapter four the association between hearing health and some negative health outcomes, including mental health outcomes. This is an area that needs greater understanding if practitioners and policy makers are to respond effectively to improve the quality of life for people with a hearing loss. The committee believes there would be great benefit from further research into the link between hearing loss and mental and physical health outcomes.

6.45 The issue of publicly funded hearing aids sitting unused in the top drawer was discussed in chapter five. Improved understanding of the reasons for low take-up and use of hearing aids could have benefits for both people with hearing impairment (who may be more inclined to use hearing aids), and public funding currently going toward between 60,000 and 80,000 unused hearing aids each year could be targeted more effectively.

6.46 The committee heard that Meniere's disease may affect around 40,000 Australians. The disease is little understood, and is consequently often misdiagnosed or undiagnosed. The committee believes that improved understanding of this disease could benefit a large number of Australians.

Recommendations

Recommendation 14

6.47 The committee recommends that the national data set and register for neonatal hearing screening, currently under development by the Neonatal Hearing Screening Working Group on behalf of the Australian Health Minister's Advisory Council, be expanded to include a national database which can:

- **(a) track children through neonatal hearing screening, diagnosis and intervention;**
- **(b) record and report cognitive, linguistic, social and emotional development outcomes of children diagnosed at birth with a hearing loss; and**
- **(c) be expanded in future years to track all children diagnosed with a hearing impairment later in life.**

Recommendation 15

6.48 The committee recommends that the Australian Government fund the National Acoustic Laboratory to undertake longitudinal research into the long-term impacts of recreational noise, particularly exposure to personal music players.

Recommendation 16

6.49 The committee recommends that Australian Governments continue to prioritise and fund research into occupational noise exposure. The focus of research should be informed by the results of the '*Getting heard: effective prevention of hazardous occupational noise*' project, currently being undertaken by Safe Work Australia, and include investigation into the effectiveness of current legislation in limiting occupational noise exposure. Research should continue to develop understanding about the design of workplace equipment, hearing protection, and the long-term effects of acoustic shock and acoustic trauma.

Recommendation 17

6.50 The committee recommends that Australian Governments prioritise and fund research into the reasons for the under use of hearing aids, and develop practicable strategies for hearing health practitioners to help overcome the under use in the community.

Recommendation 18

6.51 The committee recommends that the Department of Health and Ageing work closely with Safe Work Australia to investigate the relationships between ototoxic substances and hearing impairment, and the possible implications for workplace safety practices.

Recommendation 19

6.52 The committee recommends that the Department of Health and Ageing works with Meniere's Australia to identify opportunities for research into the prevalence of the Meniere's disease in Australia, rates of diagnosis, options for treatment and personal management, and the socio-economic impact of the disease, including on the employment and lifestyles of those affected.