

## CHAPTER 4

# THE IMPLICATIONS OF HEARING IMPAIRMENT FOR INDIVIDUALS AND THE COMMUNITY

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 on his increasing deafness, Heiligenstadt Statement, 6 October 1802.

...[hearing loss] annoys me as I don't enjoy things as much. Music is dull, going out is too much noise, eating and...socialising in cafes is difficult, I miss the birds and the sound of the sea.

Ms Erica Smith, *Submission 79*, [p. 1].

### Introduction

4.1 The committee heard about many implications of hearing impairment during the course of this inquiry. Evidence about its effect on the lives of individual people made a strong impression. Dozens of people shared their often personal and emotional experiences, and the committee was deeply moved by their passion and their courage.

4.2 What was less obvious, though in some ways just as powerful, was the impact of hearing loss on the broader Australian community. Hearing loss can lead people to isolate themselves and deny the rest of society their talents and creative ideas. The lost productivity and revenue caused by early retirement or under-employment is a tangible loss to all Australians, as was discussed above in chapter three.

4.3 This chapter examines the personal, social, economic and other costs of hearing impairment for individuals and the community in Australia.

### The impact of hearing loss on individuals

#### *Emotional and physical wellbeing*

4.4 Evidence was presented to the committee that hearing loss can have a profound impact on a person's emotional wellbeing. The particular impact differs according to whether hearing loss occurs early or later in life, and its severity.<sup>1</sup> The

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<sup>1</sup> Department of Health and Ageing (DOHA), *Submission 54*, pp 20-21.

common factor when considering the impact of hearing loss on individuals appears to be its impact on people's capacity to communicate.

4.5 The committee received evidence about the psychological and other health implications of hearing loss.<sup>2</sup> The Department of Health and Ageing (DOHA) noted that the effects of hearing loss can include isolation, depression, anxiety, paranoia, loss of intimacy and anger.<sup>3</sup> Whilst provision of hearing assistance devices and rehabilitation support can mitigate negative experiences<sup>4</sup>, the committee is in no doubt that, as the University of Melbourne Audiology and Speech Sciences put it:

...once a hearing loss reaches the severe level (a point where people are unlikely to be able to use the telephone successfully), the effects on vocational, social and educational activities are often truly devastating.<sup>5</sup>

4.6 Most evidence received by the committee was practical and constructive in nature. A large quantity of evidence was also received which testifies to the impact of hearing loss on individuals. The following statements are typical of the range of very personal, emotional experiences shared with the committee by hearing impaired Australians:

I have been profoundly deaf since the age of seven. I am now seventy-one. During that time I have operated on the periphery of what goes on every day, and I often feel confused and vulnerable. Due to my hearing impairment, I cannot make accurate judgments about verbal events which affect me constantly. In attempting to interact with people, I frequently experience significant levels of stress, through not knowing if my judgment or responses to situations are accurate, and if these judgments or responses are going to result in adverse outcomes.<sup>6</sup>

It [hearing impairment] feels as though we're punished for something that is out of our control...I certainly never asked to be hearing impaired.<sup>7</sup>

The cost of hearing Impairment is great, but not in the dollars, it's with the individual. Can anyone put a price on the importance of good hearing? Can you put a price on hearing your daughters, mother, fathers, sons voices? Can you put a price on the feeling and complete loss?<sup>8</sup>

The experience of the loss of one's hearing is invariably a negative one.<sup>9</sup>

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2 See also Dr Aaron Groves, Director of Mental Health, Queensland Health, Select Committee on Regional and Remote Indigenous Communities, *Committee Hansard*, 15 April 2010, p. 70.

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

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

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

6 Mr Peter Lindley, *Submission 106*, p. 5.

7 Ms Hilda Sutcliffe, *Submission 118*, [p. 1].

8 Ms Sandra Nelson, *Submission 151*, [p. 2]

9 Ms Margaret Robertson, *Submission 1*, p. 1.

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I just stay home now and keep my garden. I don't go out [because] I can't hear.<sup>10</sup>

4.7 One of the more confronting accounts provided to the committee was included as a case study in Hearing Impaired and Deaf Kindred Organisation Network (HIDKON)'s submission to the inquiry:

I am 35 years old and live in rural SA. Farming is a tough slog at the moment. I can't hear well due to the years I have been around farm machinery. It has damaged my hearing. I have significant tinnitus which impacts on my communication and state of mind. I [can't] *concentrate* to do the [Business Activity Statement] and my hearing loss means that I have difficulty when [I] attend lectures to learn how. My GP sent me to an ENT, I had to drive 3 [hours] to Adelaide all for him...to say there was nothing he could do. This left me on the shelf...I tried to do the right thing and I have investigated hearing aids and after paying for another hearing test...I found out they would cost a couple of thousand dollars – at a minimum. I've gone down hill in the past year. I'm now on antidepressants and anti-anxiety medication. I feel like I'm giving up. I don't go to meetings any longer, don't attend church and avoid social situations [because] I can't hear. Communication with my family is very difficult and I know it is causing relationship breakdown. Sometimes it would be easier to end it all...I learnt a few years back at a field day about noise and hearing loss and now wear ear muffs all the time to protect them. But it's too late.<sup>11</sup>

4.8 Several hearing impaired submitters commented on the difficulty they have accessing public announcements,<sup>12</sup> particularly where there are no visual clues to reinforce spoken announcements:

I cannot hear train announcements as when the person is speaking the sound distorts and it sounds to me like Donald Duck. As a consequence I have missed trains, gotten lost, and couldn't use a phone to call a cab to get home.<sup>13</sup>

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...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-

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10 Quoted in Hearing Impaired and Deaf Kindred Organisation Network (HIDKON), *Submission 41*, p. 12.

11 Quoted in HIDKON, *Submission 41*, p. 12.

12 See for example Ms Shona Fennell, *Submission 108*, [p. 1].

13 Mrs Shirley Edwards, *Submission 81*, p. 1.

threatening, and that the delay will not be so long as to cause me to miss a critical appointment.<sup>14</sup>

4.9 The committee also received evidence that hearing impairment has an effect on people around the person who is hearing impaired. The finding of one study was quoted by Phoenix Consulting in their submission:

Hearing loss affects both the individual who has it and those with whom he or she interacts. If the listener is hard of hearing and does not understand what is being said, the person speaking will also experience a communication problem. In the same way, speakers, as well as listeners who are hard of hearing, share responsibility for preventing or reducing communication problems related to hearing loss...(listeners) cannot prevent or resolve communication problems by themselves; they often need the co-operation of those with whom they communicate.<sup>15</sup>

4.10 Connect Hearing remarked on the way people without hearing impairment perceive people with a hearing impairment in everyday life, noting that individuals with hearing impairment can be variously considered 'stupid' (because they answer questions incorrectly or respond inappropriately), 'senile' (among elderly due to lack of response or engagement), or 'aloof' (perceived as arrogant when they don't respond).<sup>16</sup> Or, in the words of Michael Uniacke: '...for most people, blind people arouse concern, but deaf people arouse impatience'.<sup>17</sup>

4.11 Whilst the most common impacts of hearing loss on adult health are social and emotional, hearing loss in adults is also associated with an increased risk for a variety of physical health conditions including diabetes, stroke, heart attack, and elevated blood pressure.<sup>18</sup>

4.12 Margaret Robertson noted in her submission a Swedish study which reported findings from research into the association between hearing loss and increased risk of other diseases:

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.<sup>19</sup>

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14 Jill, 42, quoted in Deafness Forum of Australia, *Submission 34*, pp 24-25.

15 Quoted in Phoenix Consulting, *Submission 112*, p. 21.

16 Connect Hearing, *Submission 23*, p. 2.

17 Mr Michael Uniacke, *Submission 168*, p. 3.

18 DOHA, *Submission 54*, p. 22; Access Economics, 2006, p. 23.

19 Mrs Margaret Robinson, *Submission 1*, p. 4.

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## ***Employment***

4.13 Access Economics has shown that people with a hearing loss are less likely to be employed than other Australians.<sup>20</sup> Furthermore, people with a hearing impairment in the workforce are 25 per cent less likely to be earning higher incomes.<sup>21</sup> This under-employment results in lost productivity, as noted already in chapter three. Lost productivity costs will grow in the future. Australian Hearing stated: 'The impact of hearing loss on workforce participation will become greater as the population ages, and the pension entitlement age increases'.<sup>22</sup>

4.14 The broader economic implications of this were explored in chapter three of this report, however the psychological and emotional burden of lower levels of employment are part of the impact of hearing health on individuals.

4.15 One submitter remarked on this aspect of the impact of hearing loss that 'Having a hearing loss has meant that I can't work in my trained and experienced field, therefore I have a lower paid job'.<sup>23</sup> Another submitter commented that they also were no longer working at their former level:

I cannot any longer take full part in meetings, undertake lecturing or teaching or run community consultation, all work I used to do...I am still in paid work but am only able to be so because of the patience and consideration of my colleagues, and because I work in a quiet environment.<sup>24</sup>

4.16 The committee heard from one hearing impaired person that being willing to work and study to improve their chances in life is not always enough:

It is hard to find jobs too when [you] have a hearing impairment...I can't work in anything that requires the use of a phone, or face to face customer interaction, and I'm even prevented from studying to broaden my career aspects, due to the lack of interpreters available, so I miss out greatly on getting anywhere in life. I have dropped out of 3 TAFE courses over the years due to not being able to get enough interpreters. As a result, I have no way of funding earmoulds or hearing aids when the need arises.<sup>25</sup>

4.17 Deafness Forum Australia commented on some of the barriers that might be faced by employers wanting to engage hearing impaired staff:

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20 Access Economics, *Listen Hear! The economic impact and cost of hearing loss in Australia*, February 2006, pp 52-53.

21 Access Economics, 2006, p. 52.

22 Australian Hearing, *Submission 38*, p. 8.

23 Ms Erica Smith, *Submission 71*, [p. 1].

24 Dr Andrea Lindsay, *Submission 155*, p. 1.

25 Ms Hilda Sutcliffe, *Submission 118*, [p. 1].

...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 [do] 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.<sup>26</sup>

4.18 The issue of early retirement or disengagement due to hearing loss was raised by many people, and is central to Access Economics' 2006 economic analysis of hearing loss in Australia.<sup>27</sup> The following quotes from Deafness Forum Australia's submission to this inquiry illustrate the human face of early retirement:

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'.<sup>28</sup>

I had to leave my job as I could no longer cope with struggling to hear what was being said in meetings.<sup>29</sup>

4.19 It is recognised that employment provides people with the ability to earn an income to support themselves and, importantly, employment provides a sense of contribution, achievement and community. Submissions received by the committee indicate that hearing impairment can have a considerable impact on a person's working life, and is a key factor in the socio-economic impact of hearing loss.<sup>30</sup>

4.20 Access Economics outlines research which:

...suggests that people with hearing loss are on the margins of the workplace and struggle to maintain their employment. Key problems include equally participating in meetings, coping with background noise and discrimination, keeping up to date with informal conversations, negotiating reasonable communication accommodations and being able to participate in spontaneous but critical workplace conversations.<sup>31</sup>

4.21 National Disability Services suggested that with the help of appropriate technological assistance and the support that disability employment services for

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26 Deafness Forum Australia, *Submission 34*, pp 21-22.

27 Access Economics, 2006.

28 Professor Jennie Brand Miller, New South Wales (NSW), quoted in Deafness Forum Australia, *Submission 34*, p. 22.

29 Margaret, aged 62, Melbourne, quoted in Deafness Forum Australia, *Submission 34*, p. 22.

30 New South Wales (NSW) Health, *Submission 167*, p. 17; Access Economics, 2006, p. 81; National Disability Services, *Submission 46*, pp 1, 3.

31 Access Economics, 2006, p. 82 (citing Hogan A, Giles E, Stewart M, 2002, 'It's a whole new ball game: patient perceived employment benefits related to cochlear implants', *Cochlear Implants International* 3(1): 56-69).

people who are hearing impaired, challenges in the workplaces can be overcome.<sup>32</sup> However, further research is necessary to clearly identify the current employment participation and economic productivity of people who are hearing impaired, the extent of their difficulties within the workplace and, subsequently, the development of innovative and effective ways to overcome these challenges and ensure that the economic productivity of those who are hearing impaired is improved.<sup>33</sup>

### ***Imprisonment***

4.22 The committee heard some evidence which suggests that people with a hearing impairment experience higher rates of imprisonment than other Australians.<sup>34</sup> The causal relationship between hearing loss and criminal activity is that hearing loss can impact on an individual's education, and importantly on their language and behaviour development. These factors then become part of a complex pattern of behaviours in individuals, sometimes including social dislocation and high levels of unemployment, which may contribute to higher levels of engagement with the criminal justice system.<sup>35</sup>

4.23 The particular criminal justice system issues affecting Indigenous people with a hearing impairment are discussed in detail at chapter eight.

### ***Children and education***

4.24 It is crucial that children who have been diagnosed with hearing loss in the early stages of life receive appropriate support and intervention if their language and communication skills are to develop at a comparable rate to children who do not have hearing impairment.<sup>36</sup> It has been shown that children who have had their hearing impairment diagnosed in their first six months develop language skills at 80 per cent of the rate of non-hearing impaired children, compared to 60 per cent for children diagnosed after 6 months.<sup>37</sup> Early results of the Longitudinal Outcomes of Children with a Hearing Impairment (LOCHI) study also show the importance of early intervention in language and communication skills development later in life.<sup>38</sup>

4.25 Professor Richard Dowell remarked on the nature of language acquisition for children who are born deaf:

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32 National Disability Services, *Submission 46*, p. 3.

33 NSW Health, *Submission 167*, p. 19; Access Economics, 2006, pp 46, 82.

34 See for example Better Hearing Australia, *Submission 7*, p. 6; Hearing Link Tasmania, *Submission 144*, [p. 3]; Australian Hearing, *Submission 38*, p. 9; Ms Ann Jacobs, *Committee Hansard*, 9 December 2009, p. 54.

35 Australian Hearing, *Submission 38*, p. 9.

36 DOHA, *Submission 54*, p. 21.

37 DOHA, *Submission 54*, p. 21.

38 DOHA, *Submission 54*, p. 21.

For children born deaf they may never learn to speak intelligibly and often do not develop language skills to a level beyond early primary school...This is the real educational problem for hearing impaired children – their language skills lag continually behind their hearing peers. This gap grows over time such that very few are in a position to gain an adequate secondary education.<sup>39</sup>

4.26 A number of parents of hearing impaired children told the committee that they had worked hard to ensure their children acquired and developed language and communication skills at a comparable rate with other children.<sup>40</sup>

4.27 The committee notes in chapter five that 95 per cent of children born with hearing loss are born to parents who have no experience of deafness, and who do not have a hearing loss themselves.

4.28 The committee received many submissions from educational experts and parents on the range of pedagogical approaches for teaching deaf children in Australia. Hear The Mums stated that the approach a family takes will depend on their decision about the communication options they want for their child:

Parents initially need to decide the mode of communication they believe is the most appropriate for their family and their child. The choices that are generally made are Auditory-Verbal, Auditory-Oral, Auslan, Total Communication or Bilingual – sign/spoken language. The mode of communication chosen will then often determine the early intervention program that the family will enrol in as most organisations specialise in providing a specific type of intervention.<sup>41</sup>

4.29 The committee heard evidence that as technology is currently available to allow the vast majority of children with severe hearing impairment the ability to hear, it should be the first choice for hearing impaired children. While the success of technologies such as cochlear implants is undoubted, other witnesses argued that there should be an absolute choice for families.

4.30 Mr Christopher Rehn, Sydney Cochlear Implant Centre, commented that while he supported funding for universal access to cochlear implants, the decision for a child to have implants, requires families to fully understand the procedures and outcomes. Mr Rehn went on to state:

We really do believe that in partnering up with the family that the family make an informed decision and that informed decision is about the choices for the child's life, irrespective of what that looks like.<sup>42</sup>

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39 University of Melbourne Audiology and Speech Sciences, *Submission 9*, pp 2-3.

40 See for example Mrs Mary Ryan, *Submission 133*, [p. 1].

41 Hear The Mums, *Submission 71*, [p. 2].

42 Mr Christopher Rehn, *Committee Hansard*, 13 October 2009, p. 10.



4.31 Ms Leonie Jackson also argued that there was a need for choice and that all options should be considered by families as 'there is no one size fits all for hearing impaired children'. Ms Jackson stated:

It is my very strong belief that there is not one approach that will suit everyone. As a country, we need to stop promoting that one approach is better than another. We need to promote the fact that cochlear implants are not necessarily better than hearing aids; nor is it the other way around, in fact. All deaf children are individuals, so we need to think about what the best fit for that child is. It may be that neither a cochlear implant nor hearing aids are the best fit for that child; it may be better for them to learn signing so that they are able to communicate.<sup>43</sup>

4.32 Mr Alex Jones provided the committee with this comment on the need to focus on the individual child:

So it is about the approach and fitting best with each individual. You cannot have one size fitting all. You cannot just close your eyes and hope for the best; you absolutely cannot. You need to look at each individual child and what their needs are, where they are living, how their parents can support.<sup>44</sup>

4.33 Ms Jackson commented that perhaps hearing impaired children should use both speech and sign language. However, it was noted that services are not always available in schools and that some governments were not supporting the use of Auslan in education. For example, Ms Kate Nelson, Deaf Society of NSW, stated that the NSW education department 'is quite actively dismissive of Auslan and they are focusing on mainstreaming deaf children'. In addition, because of the advances in technology, many believe that Auslan is no longer needed. Ms Nelson went on to argue that this will 'never happen' and that children should be able to access the school curriculum via Auslan as technology will not be the solution for all children.<sup>45</sup>

4.34 Ms Nelson noted that if specialist staff in schools do not have the skills then language development, whether it be in English or Auslan, will be further delayed. Ms Nelson commented:

As a deaf child, obviously your access to English is limited or possibly nonexistent. Sign language is a more obvious language. It is a visual language and it is the way you would be able to learn language. By having a proficient level of sign language, Auslan, you are then able to learn English. Later on in life, students have the choice of using either or both of these languages. These children are falling through the gaps. That is probably the best way of saying it.<sup>46</sup>

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43 Ms Leonie Jackson, *Committee Hansard*, 13 October 2009, p. 61.

44 Mr Alex Jones, *Committee Hansard*, 13 October 2009, p. 62.

45 Ms Kate Nelson, Deaf Australia New South Wales (NSW), *Committee Hansard*, 11 November 2009, p. 31. 11

46 Ms Kate Nelson, Deaf Australia (NSW), *Committee Hansard*, 11 November 2009, p. 32.

4.35 The Royal Institute for Deaf and Blind Children (RIDBC) drew to the committee's attention changes in the training for teachers of deaf and hearing impaired children. Whilst teachers need to know more about working with deaf children than ever before, the RIDBC stated that the qualification requirements for teachers have become less intensive and more generalised. Among other changes, the number of hours of dedicated coursework required by trainee teachers of children with hearing loss has declined from 325 in 1989 to 144 now.<sup>47</sup> This does not compare favourably with international practice, as RIDBC commented:

Notably in that same period of time, the average contact hours dedicated to education of the deaf in programs in North America has risen. The benchmark program at Washington University, for example, requires 660 contact hours and the program at York University in Canada requires 432 contact hours in deafness and hearing impairment related coursework.<sup>48</sup>

4.36 The committee received evidence that children who are hearing impaired receive in-classroom support to participate in mainstream schooling, however there was concern expressed that the availability of teacher's aides to assist these children is not sufficient, and that children should be afforded more support.<sup>49</sup>

4.37 The social experiences of children with hearing loss in a hearing world can be confusing and isolating, as several witnesses testified:

...it is heart breaking to see my [profoundly deaf] daughter being excluded from conversations because it is so difficult [for her] to understand through noisy situations, and situations where groups gather.<sup>50</sup>

I was born with a hearing loss and fitted [with hearing aids] at an early age, however going to a mainstream primary and secondary school meant there was a lack of support to cope academically and socially. There was no education given to other hearing students to understand and accept how to deal with peers who have a hearing loss. Being the only one throughout my schooling days meant I was constantly bullied and depressed.<sup>51</sup>

4.38 The impact of hearing loss on individual children was often raised by witnesses and submitters. A frequent comment heard by the committee was that people who suffered from undiagnosed hearing loss at school felt stupid or dumb. The following description is typical:

[My hearing impaired son] would come home and tell me that he was stupid...it was very emotional to have a 12-year-old kid tell you that they are dumb, that they are stupid and that they should not be alive. That was

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47 Royal Institute for Deaf and Blind Children (RIDBC), *Submission 67*, p. 10.

48 RIDBC, *Submission 67*, p. 10.

49 See for example, Ms Roslee Fyfe, *Submission 121*, [p. 1], Ms Yvonne Batterham, *Submission 129*, p. 5.

50 Mrs Mary Ryan, *Submission 133*, [p. 3].

51 Ms Susanna Carter, *Submission 102*, [p. 1].

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my experience but I have found out that it is also the experience in a lot of other communities with children who have that. They come back and say that they are dumb and they are stupid...He did not want to go to school. He thought the teachers hated him. It was simply because they would yell at him when he did not understand what they said, but they did not realise that the more they yelled at him the less he understood. He was in a vicious cycle that made him become depressed.<sup>52</sup>

### **Costs**

4.39 The committee notes that the broader issue of economic costs to the Australian economy are discussed at chapter three of this report. Whilst the focus in this section is on the financial costs of hearing impairment to individual people, some duplication was unavoidable.

4.40 Many submitters and witnesses raised with the committee the cost to individuals of hearing impairment. Of particular concern was the lack of funding and insurance options available to non-Office of Hearing Services (OHS) clients. Many of the issues connected with eligibility for OHS services are dealt with in chapter five of this report.

4.41 The cost of hearing aids is between \$3,000 and \$10,000 per pair.<sup>53</sup> Many submitters remarked on the financial hardship caused by having to meet these costs every few years. For example:

When I was unemployed and a student, I had to buy new hearing aids for \$8,000, and I had to get a personal loan to pay for it, and then I had to go on Centrelink payments as well, because I had trouble paying my rent.<sup>54</sup>

4.42 The impact of these costs is particularly felt by young people, who are often low income earners, as is neatly illustrated by this remark from a young Canberra woman: 'My friends are saving up for an overseas trip. I am saving up for my next hearing aids'.<sup>55</sup>

4.43 Some people commented on the perpetual strain of worrying about the cost of replacing damaged hearing aids. In Ms Hilda Sutcliffe's words: 'I live in fear of the day my hearing aids die and I can't afford to have them replaced'.<sup>56</sup>

4.44 Maureen from Victoria stated that the cost of buying new hearing aids means she can only afford one aid, though she really needs two to hear well:

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52 Ms Sandra Nelson, *Committee Hansard*, 16 February 2010, p. 74.

53 Australian Hearing, *Submission 38*, pp 13-14.

54 Ms Kate Locke, *Submission 82*, [p. 1].

55 Kirsten, quoted in Deafness Forum of Australia, *Submission 34*, p. 27.

56 Ms Hilda Sutcliffe, *Submission 118*, [p. 1].

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.<sup>57</sup>

4.45 Evidence was provided in connection to the high cost of maintaining and replacing cochlear implant speech processors. This issue is discussed in detail below.

### ***Other costs of living for people with a hearing impairment***

4.46 Additional costs of living for people with a hearing impairment are not limited to purchasing aids or processors. The following comment captures a sense of the many other costs that non-hearing impaired Australians do not have to factor into their lives:

I have 5 children all of whom have been afforded the same educational and social opportunities...My deaf 21 year old son, however, must always factor extra 'disability' costs into his life – he must always have funds available for regular audiological and ENT assessment, hearing aid maintenance and replacement, hearing aid batteries and essential safety devices. It will always cost him more than his siblings to work 'normally'.<sup>58</sup>

4.47 The cost of maintaining hearing aids, including batteries, can also mount up. These costs are subsidised for OHS clients, who pay a small annual maintenance fee.<sup>59</sup> For others, the costs of maintenance can be significant:

...batteries for the Cochlear Implant can be an expensive item...Currently I use 3 batteries every 6 days and a packet of 4 batteries can be up to \$9 [\$400 per year].<sup>60</sup>

4.48 Numerous submissions commented on the costs of hearing assistive devices to individuals. The sorts of devices that people with a hearing impairment may need day to day include specialised alarm systems, visual smoke alarms, teletype phones, captioning decoders for televisions, visual doorbells, special alarm clocks, and FM systems.<sup>61</sup>

### ***Private Health Insurance and hearing devices***

4.49 People with a hearing impairment provided evidence to the committee that some cover for hearing aids, including speech processors, is available under private

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57 Maureen, quoted in Deafness Forum of Australia, *Submission 34*, p. 29.

58 Quoted in the Australian and New Zealand Parents of Deaf Children (ANZPOD), *Submission 24*, pp 5-6.

59 Australian Hearing, *Submission 38*, p. 12.

60 Ms Nikki Haseldine, *Submission 165*, [p.1].

61 DOHA, *Submission 54*, p. 50.

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health insurance. Cover for hearing devices is available under some ancillary (or 'extras') packages, and the level of cover varies according to the health insurance provider and the level of cover taken out by the individual. The committee also notes that private health insurance extras packages include some level of cover on a range of health items in addition to hearing devices, including such things as dental, optical and health management costs.

4.50 Numerous submissions commented that they perceived the level of benefit available for hearing devices to be very low when compared to the costs. Mr Isaac Marcus elaborated on this in his submission:

...[my] current level of health cover does not provide for hearing aids. My private health insurer advises that the next level of cover which provides for hearing aids costs an additional \$40 per fortnight. The coverage extends to \$1,000 per hearing aid, with a three-year waiting period for making a claim and three-year intervals. While the next level of cover also results in some level of increases for other extras such as major dental, optical and physiotherapy, the benefit for hearing aids does not justify the increase in premium payments. An additional \$40 per week over three years amounts to \$3,120 for possibly claiming \$2,000.<sup>62</sup>

4.51 Another submission remarked that the benefits payable for hearing devices under private health insurance do not justify the cost of premiums:

...we have a drought-stricken farm and [hearing aids are] just another cost we simply have to shoulder. Private health insurance for hearing aids makes it very hard to claim on extra benefits, and so little is paid back we didn't even bother trying.<sup>63</sup>

4.52 DOHA advised the committee that private health insurers are under no obligation to provide cover for hearing aids. Private health insurers may offer some coverage for hearing aids, however the amount of cover is a decision for the insurer.<sup>64</sup>

4.53 There are some circumstances where the private health insurer has an obligation to provide coverage for cochlear implant speech processors, such as when the processor was provided as part of a hospital treatment which was covered by the private health insurance policy. However in other circumstances any coverage of processors will depend on a person's insurer and the level of cover they have taken out.<sup>65</sup>

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62 Mr Isaac Marcus, *Submission 162*, [p. 1].

63 Ms Janice Evans, *Submission 132*, [p. 1].

64 DOHA, answer to question on notice 19 March 2010 (received 6 May 2010), Question 21.

65 DOHA, answer to question on notice 19 March 2010 (received 6 May 2010), Question 21.

## **The impact of hearing loss on communities**

4.54 It was noted above that hearing impairment affects a person's ability to communicate, and the impact of this for individuals can affect their mental and physical wellbeing. The impact on the broader Australian community is also great, as measured by reduced contribution and increased reliance on social welfare support.<sup>66</sup>

4.55 As has been mentioned above, the economic impact of hearing loss on the broader community has been estimated by Access Economics at nearly \$12 billion per year. This cost was reckoned in terms of lost earnings due to early retirement and workplace separation, cost of carers, foregone taxation revenue, health system costs, education support and aids, and increased reliance on social welfare.<sup>67</sup> The 2003 Disability Census suggests that 81 per cent of people with a hearing loss receive welfare benefits.<sup>68</sup>

4.56 Evidence before the committee is that one effect of people with hearing loss withdrawing from socialising and employment is that the community as a whole could be missing out on their contributions: 'Systematic exclusion of people who cannot hear from Australian society means that we all miss out on the potential contributions of these talented individuals...'<sup>69</sup>

4.57 The level of awareness about hearing loss among both people with a hearing impairment themselves and all Australians is low. As Better Hearing Australia commented in their submission:

Despite being the most widespread disability in the community, hearing loss is also the most misunderstood by the many Australians who have a hearing loss. Far too many hearing impaired Australians simply do not know or take the trouble to discover the support services that are available to help them. Rehabilitation services and assistive listening devices can greatly improve quality of life and assist in managing hearing loss. Families, friends and colleagues are also often unaware of the implications and damaging effect of hearing loss.<sup>70</sup>

4.58 Australian and New Zealand Parents of Deaf Children (ANZPOD) noted the impact hearing impairment can have on family members:

Hearing impacts on the whole family not just the individual with the loss. There is a higher level of marriage breakdown where parents are dealing with the emotional and financial implications of raising a child with a disability. Similarly siblings of children with a hearing loss often resent the

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

67 Access Economics, 2006.

68 Cited in DOHA, *Submission 54*, p. 23; see also Access Economics, 2006, p. 66.

69 Access Innovation Media, *Submission 44*, p. 5.

70 Better Hearing Australia, *Submission 7*, p. 3.

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extra time and attention provided to their sibling which can lead to behavioural issues.<sup>71</sup>

4.59 Several submitters provided the committee with a copy of the prose piece 'Welcome to Holland' by US writer Emily Perl Kingsley. The piece was written about the author's experience with her son Jason, who was born with Down Syndrome, yet many submitters felt that it could just as easily apply to families of a baby diagnosed with a hearing loss. 'Welcome to Holland' is reproduced in full below.

### **Welcome to Holland**

**By Emily Perl Kingsley**

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very very significant loss. But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

Provided by North Shore Deaf Children's Association, *Submission 39*.

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71 ANZPOD, *Submission 24*, p. 7.

4.60 Many submissions referred to hearing impairment as an 'invisible' disability in that, unlike the vision impaired or the physically disabled, hearing impairment is not obvious to the casual observer. However Deaf Children Australia argued that the 'invisibility' of people with a hearing impairment in the Australian community may result in part from lack of effort by the hearing community to engage:

It would appear that exclusion of people with a hearing loss is implicitly accepted as part of Australian community life. For example: Federal state and local Governments continue to produce information on DVDs without captions, Parliaments meet without ongoing provision for interpreters and most mainstream community events are neither Auslan interpreted or captioned. Other examples include public transport systems failing to address the fact that people standing on the train platform may have a hearing loss and therefore not hear public announcements and cinemas not allowing the screening of captions. All of these are simple examples of the widespread community exclusion of people with a hearing loss. The exclusion of children, young people and adults with a hearing loss appears to be widely accepted and endemic.<sup>72</sup>

### **Committee comment**

4.61 The committee understands that with hearing impairment projected to grow along with Australia's ageing population, it is crucial to make changes now that will improve the way people with a hearing impairment are supported before the system has to manage the increased volume of demand for services and support.

4.62 The committee was moved by the individual experiences which hearing impaired Australians shared during this inquiry. Their sense of disempowerment and isolation came through clearly from the evidence.

4.63 The committee was concerned at the psychological and other health impacts of hearing loss for Australians, and accepts that the ability to communicate with others is central to a person's health and wellbeing.

4.64 The committee heard about the different approaches to communication and education available for children with severe hearing impairment, and believes that it is important that parents be informed about what those choices are, and will be equally supported regardless of the choice they may make for their child.

4.65 The committee is concerned at evidence about a decline in training standards for teachers of children with hearing loss, and agrees with the RIDBC that a more sophisticated understanding of hearing loss education should be reflected in specialist teacher preparation programs. The committee believes that there is a need for agreed Australian national qualification standards for teachers of children with hearing impairment, and these should be benchmarked against international best practice.

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72 Deaf Children Australia, *Submission 176*, [p. 13].



4.66 The committee is concerned by evidence which suggests that children with hearing impairment in mainstream classrooms may not be receiving adequate levels of in-class support. It would be valuable for states and territories to review support arrangements, to ensure children in mainstream classrooms are given every chance of success.

4.67 The committee notes the tremendous effort required by families seeking to support their children successfully through their education and on to fulfilling lives.

4.68 The committee notes that hearing loss may lead to higher engagement with the criminal justice system. Recommendations have been made in chapter eight around this issue.

4.69 Hearing impairment results in a cost burden for some members of our society, often at very vulnerable points in their life. Private health insurance cover is not enough to completely offset the high cost of hearing devices, which need replacing regularly. The committee has made recommendations in chapter five which aim to expand access to Australian Government Hearing Services Program support.

4.70 People with a hearing impairment leave the workforce earlier, earn less money, and are more likely to be unemployed than people without hearing impairment. The committee notes that the largest economic cost of hearing impairment is due to lost productivity. The committee believes that the Australian Government is well placed to lead development of a long term policy that seeks to better support people with a hearing impairment in the workplace, to the benefit of all Australians.

## **Recommendations**

### **Recommendation 2**

**4.71 The committee recommends that the Department of Education, Employment and Workplace Relations engage with state and territory jurisdictions, and with employment and hearing loss peak bodies, to develop a 10 year strategy to better support, engage and retain hearing impaired Australians in the workforce. The strategy should be made publicly available, and detail annual performance targets and the level of resources committed to achieving them.**

### **Recommendation 3**

**4.72 The committee recommends that the Department of Education, Employment and Workplace Relations engages with state and territory education systems, higher education providers of training for teachers of children with hearing impairment, and major stakeholders (including the Royal Institute for Deaf and Blind Children and parent representative bodies), to develop and implement an agreed national qualification standard for teachers of children with hearing impairment. This standard is to be benchmarked against international best practice.**

