

The 2012

Libby Harricks

Memorial Oration



Libby Harricks Memorial Oration number 14

Honouring the Deafness Forum's first president & profoundly deaf achiever

Elisabeth Ann Harricks AM 1945 – 1998



deafness forum of australia

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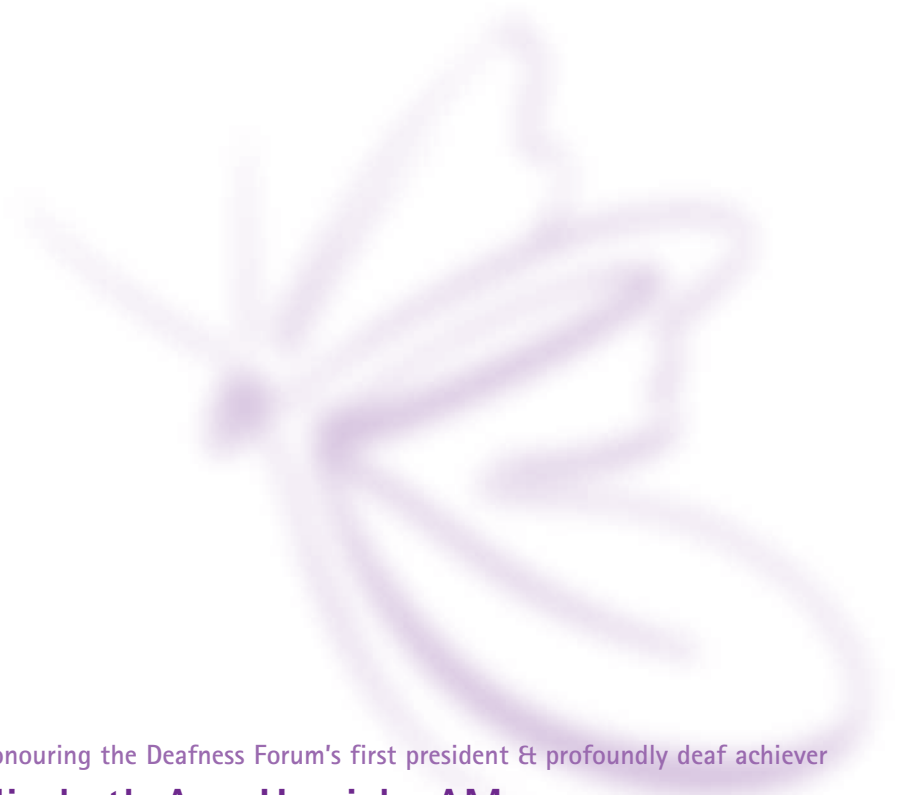
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Introduction to the 14th Libby Harricks Memorial Oration

Dr Jenny Rosen AM, Chairman, Libby Harricks Memorial Oration Committee



Libby Harricks grew up with apparently normal hearing. As a young wife and mother she developed a profound hearing loss, and quickly educated herself with skills to manage her own hearing difficulties. She soon became a committed advocate for hearing impaired people, a founding member and longterm President of SHHH Australia Inc (Self Help for Hard of Hearing People) and amongst many other challenges, in 1993 was elected inaugural President of Deafness Forum of Australia (DFA), the national peak body in deafness and related issues. In these voluntary roles, she worked ceaselessly to raise awareness of the need for equal inclusion in life activities for hearing impaired people, and travelled widely throughout Australia to lobby for this on their behalf. Libby also served for a number of years as consumer representative on the Board of Australian Hearing and was the official representative for hearing impaired people on the Sydney 2000 Olympics Access Committee. In recognition of her very significant contributions, in 1990 Libby was made a Member of the Order of Australia.

Libby died in 1998. Subsequently, Deafness Forum established the Libby Harricks Memorial Oration Series to honor her achievements and to continue her work towards gaining appropriate recognition, awareness, and access, for hearing impaired people. In order to reach further than each Oration audience and indeed to make these important contributions available on an on-going basis, the Orations are published by Deafness Forum of Australia in a Monograph series.

The inaugural Oration entitled '*Hearing Access Now!*' was presented by Emeritus Professor Di Yerbury in Sydney in 1999. In 2000, at the International Federation of Hard of Hearing Conference in Sydney, Professor Bill Gibson's topic was '*Recent Advances in the Understanding of Meniere's Disease and Tinnitus*' and in Canberra in 2001 Senator Margaret Reid spoke on '*The Politics of Deafness*.' At the XXVI International Congress of Audiology in Melbourne in 2002 Professor Paul Mitchell presented the results of a major demographic study, '*The Prevalence, Risk Factors and Impacts of*



Hearing Impairments in an Older Australian Community: The Blue Mountains Study. In 2003 Donna Sorkin addressed progress in disability law and hearing loss from an international perspective. This was at Macquarie University, Sydney.

In Brisbane at the 3rd National Deafness Sector Summit in 2004, Dr Peter Carter spoke about *'A Sorry Business: Lack of Progress in Aboriginal Hearing Health.'* In 2005 in the Blue Mountains NSW, Alex Jones made the first Auslan presentation, with the powerful message of his *'Deafness and Disability Transformed: An Empowering Personal Context.'* At the 4th National Deafness Sector Summit in Perth in 2006 Professor Harvey Dillon's topic was *'Hearing Loss: The Silent Epidemic'* and in 2007 Rick Osborn reached a rural audience at the 9th Rural Health Conference in Albury NSW with *'Hearing and Communication – A Primary Concern in Aged Care.'* At the 5th National Deafness Summit in Canberra in 2008, Professor Robert Cowan updated us on *'Access, Equity and Hearing Loss in Australia in 2008'* and in 2009 Professor Graeme Clark spoke on *'The Bionic Ear: From an Idea to Reality'* at a Continuing Educational Conference for General Practitioners in Sydney. In 2010, also in Sydney, Professor Greg Leigh addressed the 6th National Deafness Summit with *'Early Identification of Hearing Loss in Australia; Well Begun is not All Done'* and at the 11th National Rural Health Conference in Perth in 2011, Dr Robert Patuzzi spoke on *'Molecules, Managers or Mentors: How Can We Minimize Noise Damage in the Worksite?'*

Over the years, the Oration Series has developed a well-deserved reputation for continuing Libby's commitment to raising awareness of issues relating to hearing impairment, and for furthering the aims of Deafness Forum. This is undoubtedly due to the great contributions of our outstanding Orators who have presented on such a wide range of relevant topics. We are most appreciative that it has been possible to provide the opportunity for audiences across Australia to hear these Orators, as well as to enable continuing availability via the Oration Monograph series. I would like to acknowledge here the support of the Libby Harricks Memorial Oration Committee, and that of the Deafness Forum national secretariat. I am very pleased to acknowledge our Oration sponsor for 2012 which is, once again, Cochlear Ltd. Without the generous

support of all of these people, neither presentation of the Oration nor preparation of the companion Monograph series would be possible.

This year, we are privileged to welcome as our 14th Orator, Dr Anthony Hogan. Anthony began his career providing community-based social services for deaf and hearing impaired people. During this time, he frequently worked closely with Libby. Dr Hogan is now an academic and researcher at The Australian National University. He has an international reputation for advocating for inclusive community-based client-driven services for people with hearing loss rather than the more common medical and/or device-driven models, and has published extensively on this work.

We are indeed fortunate that Anthony has been able to accept the invitation to present this 14th Oration. In it, he shares with us his latest research results. Monograph copies of Dr Hogan's Oration are available from the Deafness Forum office in Canberra. Indeed, copies of all Monographs in the series are available in hard copy from the Deafness Forum office, or can be accessed on the publications section of the Deafness Forum website (www.deafnessforum.org.au).

Would you please welcome Dr Anthony Hogan.

A REPORT CARD ON THE SOCIAL WELLBEING OF IDENTIFYING AS LIVING WITH HEARING LOSS IN AUSTRALIA

Dr Anthony Hogan



Acknowledgements

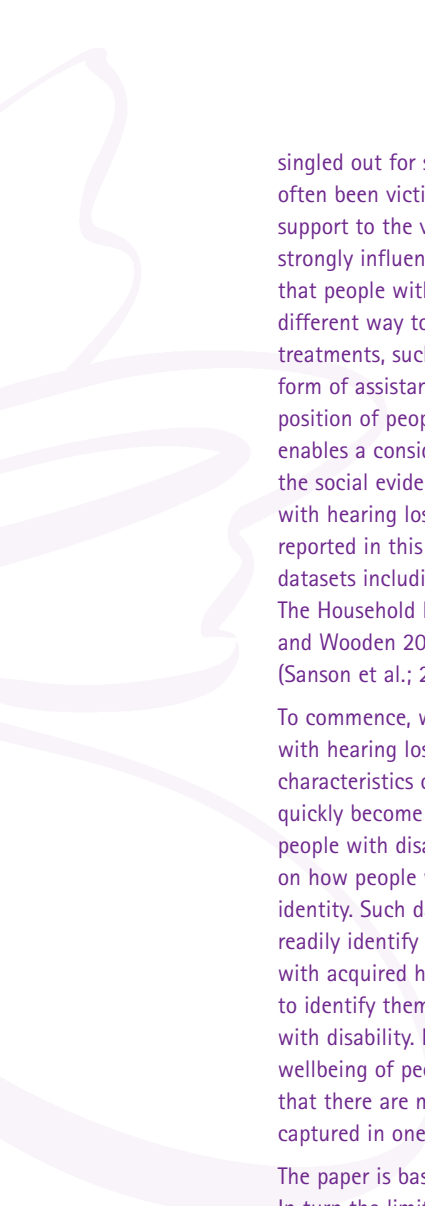
This material presented in this paper draws on research papers produced in collaboration with my research colleagues. In particular I wish to acknowledge the work of Jenny Welsh who worked with me to produce a social profile of people identifying as having a hearing loss. This material will appear later this year as a chapter in my book 'A fairer hearing'. In particular I also wish to acknowledge the work of Vas Yieng and Damien Howard who worked with me to produce refereed journal articles on the social impacts of ear infection. I would like to thank Simon Pfeiffer for his work with me on industrial deafness. Finally I would like to thank Megan Shipley Lyndall Strazdins, Alison Purcell and Elise Baker for their work with me on the social impacts of hearing problems among children.

The opportunity is taken to thank the Deafness Forum for its kind invitation to me to present this distinguished Memorial Oration. I had the privilege of knowing and working with Libby Harricks, both in her capacity as President the Australian Deafness Council and as Chair of the Deafness Forum. The Memorial Oration is a fitting tribute to Libby, whose vision and values continue to influence the work we do and the goals we strive for among Deaf people and those who identify as having a hearing loss.

"Government statistics, independent research projects and personal experience show that on nearly every indicator of participation in mainstream life disabled people come out extremely badly" (Finkelstein 1993: 11)

Introduction

This paper provides a social profile of people living with hearing loss. A social profile is one of the most basic tools that can be used in social research. In considering social phenomenon C. Wright Mills (1970) was concerned with the question as to whether differences in experience were due to individual misfortunes or whether such outcomes stemmed from systemic factors in our society. Elsewhere I have argued that people with disability generally and people with hearing loss in particular, have been



singled out for specific forms of social management over time and have often been victims of stigmatisation. The data I present today lends support to the view that the social position of people with hearing loss is strongly influenced by factors outside of individual control. To the extent that people with hearing loss are collectively treated in a systematically different way to other citizens, it would follow that individualizing treatments, such as the provision of technical devices as the primary form of assistance, would be limited in their ability to equalize the social position of people within this cohort. The development of a social profile enables a consideration of these questions by systematically examining the social evidence that is available on the social wellbeing of people with hearing loss to that of people in the broader community. The data reported in this paper have been derived from several large national datasets including the Survey of Disability, Ageing and Carers (ABS 2003), The Household Income, Labour Dynamics Survey of Australia (Watson and Wooden 2001) and the Longitudinal Survey of Australian Children (Sanson et al.; 2002; Soloff et al.; 2005).

To commence, we will report on the wellbeing of young children with hearing loss. In turn the paper provides the basic demographic characteristics of people with hearing loss in Australia. However, as will quickly become apparent, national data collection systems construct people with disability in specific ways, based as they are on assumptions on how people with disability understand their social position and social identity. Such data collection processes are quite useful where people readily identify themselves as a person with disability. However, people with acquired hearing loss are invariably reluctant (Hetu & Getty 1992) to identify themselves as having either a hearing loss or as being a person with disability. In considering datasets which provide insight into the wellbeing of people with hearing loss one must remain open to the fact that there are multiple groupings of our cohort, not all of whom will be captured in one dataset.

The paper is based on data found in Australia's larger national data sets. In turn the limitations of these data sets will be discussed before the picture provided by such research is supplemented with additional data.



The wellbeing of children with hearing problems

Hogan et al. (2011) studied the wellbeing of children reporting hearing problems. Children from Indigenous backgrounds were found to be over-represented among children with hearing problems. Households with children with hearing loss comprised statistically significantly higher proportions of people reporting lower SEIFA scores on education and occupation (66.7% versus 33.3%). Households with children with hearing problems were substantively over-represented among respondents with below average education and occupation. The study found that children with hearing loss showed elevated prevalence across most dimensions of emotional and behavioural difficulties, and on indicators of communication disorders, language and cognitive development, and motor skills. Notably they found that reduced receptive language skills and increased difficulties understanding others were predictive of increased psychosocial difficulties in children with hearing problems.

The wellbeing of children with ear infections

Yieng and Hogan (2012a & b) and Hogan et al. (2012) studied the wellbeing of children reporting ear infections. Children from Indigenous backgrounds were found to be over-represented among children with ear infections and related problems. Yieng and Hogan (2012a) found that repeated exposure to ear infections, particularly among children in their later years, was associated with hearing problems. Parent of 4-5 year olds reporting ear infection reported below average socioeconomic wellbeing with regards their education and employment outcomes. Hogan et al. (2012) found that children with ear infection showed elevated prevalence across most dimensions of emotional and behavioural difficulties, and on indicators of communication disorders, and fine motor skills. Once again they found that reduced receptive language skills and increased difficulties understanding others were predictive of increased psychosocial difficulties in these children. Yieng and Hogan (2012b) reported that at the age of 4/5 years, ear infection was strongly and significantly associated with the child's use of hospital outpatient services (OR=2.08; $p=0.000$), use of prescribed medication (OR=2.31; $p=0.000$), and the use of speech therapy (OR=1.79; $p=0.000$). At the age of 10/11 years, ear infection was found to be statistically significantly associated with the child's use of speech therapy (OR=3.24; $p=0.000$) and early education services (OR=3.08; $p=0.010$).

Adults – Basic demographics

Using data from the Survey of Disability, Ageing and Carers (SDACs) we find that 12% of the population identified themselves as having a hearing loss. Within the Household Labour Dynamics of Australia (HILDA) (Watson and Wooden 2002) survey dataset, only 4.2% of people identified themselves as having a hearing loss. Both figures are markedly lower than the population data produced by David Wilson and friends (1992) which found that 22% of people aged over 15 years had a hearing impairment. Data collection methods in both studies impact on the number of people reporting hearing loss. SDACs asks people to report if they have a condition which results in restrictions, such as communication difficulties. Within HILDA, people are first asked if they have a disabling condition before being asked to specify which one. As such, and as evidenced below, even if people identify as having a hearing loss, they may not identify as being disabled or restricted by it and are subsequently not captured by these datasets.

Within SDACs men (60%) are more likely to report having a hearing loss than women (40%). HILDA reports similar proportions of hearing loss by gender. Hearing loss is commonly associated with older age (see for example Wilson et al. 1992). Indeed, approximately 80% of people reporting hearing loss in SDACs are aged 50 years and over with 37% aged 50 to 69 years and 45% aged over 70 years. Notably though, some two-thirds of people report non-age related causes for their hearing loss including congenital hearing loss (10%) disease processes of middle (13%) or inner ear (2%) or noise exposure (36%).

Sociologists and psychologists are particularly interested in the interpersonal impacts of hearing loss. As such we are more interested in the degree of difficulty people report having with communication, due to hearing loss, than we are with the more precise audiological measurement of hearing impairment. Figure 1 depicts the extent of communication difficulty reported by people with hearing loss in SDACS. Note that 72% of respondents who report have a hearing loss report that they have little or no difficulty communicating, although having a hearing loss. There are several explanations for this outcome, not least of which for some, this report may well be true. However, in the early 1990s Raymond Hetu and Louise Getty (1992) identified several critical psycho-social dynamics associated with acquired hearing loss.

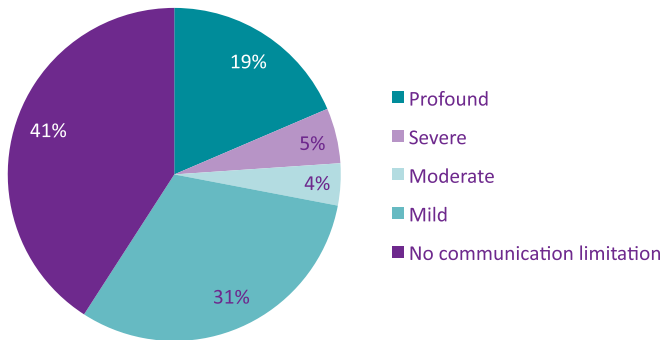


Figure 1: Level of communication difficulty
 Source: ABS Survey of Disability Ageing and Carers 2003

Specifically they reported that people misperceive the effects of hearing loss and/or that they are reluctant to acknowledge the effects of their hearing loss. Further discussion of these psycho-dynamics can be found in my new book – A fairer hearing (Hogan 2012). But for now we simply wish to highlight one of many tensions in the story which surrounds people with acquired hearing loss. This tension is highlighted for example with 41% of SDACs respondents with hearing loss reporting, for example, that hearing loss did not make communication difficult for them. Given that promptings from partners is a significant reason that people seek help for hearing problems underscores the insight from Hetu and Getty (1992) that a comprehensive understanding of the social and psychological dynamics of hearing loss is central to working effectively in this field.

One third of respondents in the SDACs survey reported using hearing aids to assist with hearing while a further 5% reported using some other form of assistive listening device. Results from HILDA were somewhat similar with 22% reported using electronic communication aids. Figure 2 provides data on the extent to which respondents report hearing aids being beneficial to hearing. A large majority (85%) of SDACs respondents report that the aids are of benefit to them. This contrasts significantly with data reported in Lancet (Smeeth et al. 2002) where more than 40% of respondents report being dissatisfied with the hearing aids they have received.

It is important that this analysis take into account both the level of device usage reported in the HILDA data (which is much higher than that found in other studies where the usage rate is around 16% (see for example Wilson et al. 1992; Hogan et al. 2001)) and the extent of satisfaction users have with the devices. Importantly, the data suggest that people identifying with hearing loss in public surveys, such as SDACs and HILDA, in fact have a greater degree of hearing loss than the average person with hearing loss in the community. We therefore must approach these results with some degree of caution and treat the findings as useful thematic insights rather than as definitive statistical outcomes.

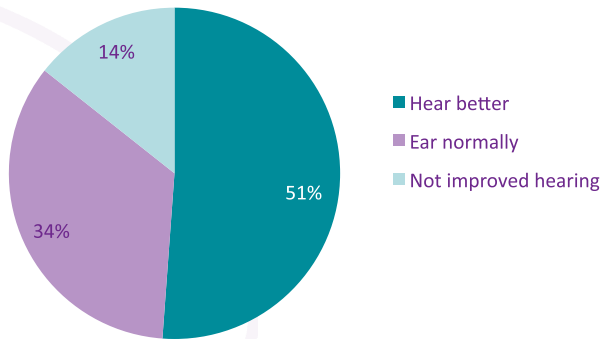


Figure 2: Impact of hearing devices on ability to hear.
Source: ABS Survey of Disability Ageing and Carers 2003

Education and employment outcomes

The education of people with hearing loss has been one of several policy strategies focused on this cohort. In 2006, the Australian community spent approximately \$140 million (Access Economics 2006) on educational services for deaf and hearing impaired children. The data suggests that these efforts have been particularly successful for people with total hearing loss, but less so for people with partial hearing loss. Notable differences evident in education and training outcomes are apparent for people with partial hearing loss. In educational terms, people with partial hearing loss were significantly under represented among



those who had completed year 12 (Adjusted Residual (AR)¹ – 7.5) or a university degree (AR – 5.1) while being significantly over represented among those who left school by year 8 (AR 9.7) or year 9 (AR 3.4) ($X^2 (24) = 293.4; P < .001$). People with partial hearing loss were significantly over represented in the areas of engineering (AR 9.3) and architecture (AR 4.2) while being under represented in management and commerce (AR – 5.8) and food and hospitality services (AR – 3.0) ($X^2 (24) = 169.5; P < .001$)

People with hearing loss were substantially under represented in full time work (ARs 4.8 – 5.5). People with hearing loss were also under represented in part time work (AR – 6.2) and over represented among those not in the labour force (AR 9.8). The under representation of these people with hearing loss in the labour force is in turn reflected in their significant under representation across a variety of skilled areas of employment (professionals (AR-4.4), associate professionals (AR-4.5), advanced clerical and services (AR-4.2), intermediate clerical, sales and services (AR – 5.5), elementary clerical, sales and services (AR-4.0)). The only area where they were over represented was in intermediate production and transport (AR4.0) ($X^2 (20) = 231.5; P < .001$).

Population weighted comparative weekly cash incomes were compared for people with hearing loss versus the population for people of work age (over 20 years to less than 65 years of age) using SDACs data. Statistically significant differences ($F (2) = 11754.8; p < .001$) in weekly cash income were observed. On average, the reported cash weekly incomes were:

- people without hearing loss averaged earnings in the income range of \$450-\$574
- people with partial hearing loss averaged earnings in the income range of \$320-\$449
- people with total hearing loss averaged earnings in the income range of \$225-\$319.

1 An adjusted residual of greater than +/ – 2 is considered, in statistical terms, to mark a significant difference in outcomes. Larger differences in these statistics provide an insight into the size of the differences being considered.

Social capital

The HILDA dataset provides information on peoples' experiences of wellbeing in the workplace, including a number of indicators from Karasek's Whitehall study (Karasek et al. 1998) on job stressors. Within this framework, job stress is defined as experiencing high workplace demands, low workplace control and not having access to sufficient support.² Table 2 provides data reporting outcomes for people with hearing loss versus the population on these indicators. On the positive side, compared to the population, people with hearing loss reported that they are being fairly paid and enjoy greater autonomy in the workplace. However, these benefits are offset by these workers experiencing a large array of significant workplace stressors including a more stressful work environment, less secure employment and being engaged in less challenging work. Taking these factors into account one may look more critically at the outcome of workplace autonomy reported in this table. It is feasible for example that rather than having a lot of freedom in doing their work, people with hearing loss are in fact isolated in their work and left to their own devices because of communication difficulties.

2 For further details see <http://safeworkaustralia.gov.au/AboutSafeWorkAustralia/WhatWeDo/Publications/Pages/RR200803NHEWSSurveyResults.aspx>

TABLE 1: LABOUR FORCE OUTCOMES FOR PEOPLE WITH TOTAL AND PARTIAL HEARING LOSS VERSUS THE POPULATION.

LABOUR FORCE STATUS	NO HEAR LOSS (%)	PARTIAL HEAR LOSS (%)	TOTAL HEAR LOSS (%)
N/A	2.3	4.5	16.2
Employed Full time	52.5	44.8	29.7
Employed part time	20.7	13.1	18.9
Unemployed looking for F/T work	2.3	2.7	0
Unemployed looking for P/T work	1.0	1.3	2.7
Not in labour force	21.3	33.6	32.4

Source: ABS Survey of Disability, Ageing and Carers X2 (10) = 179.4; P < .001

TABLE 2: WORKPLACE STRESSORS

WORKPLACE EXPERIENCE	POPULATION	PEOPLE WITH HEARING LOSS	STATISTICAL VALUE
My job is more stressful than I had ever imagined	3.0	3.13	F (2)= 18.0; p< .001
I fear the amount of stress in my job will make me ill	2.29	2.39	F (2)= 37.1; p< .001
I get paid fairly for the things I do in my job	4.68	4.70	F (2)= 8.6; p< .001
I have a secure future in my job	5.02	4.34	F (2)= 62.3; p< .001
The company I work for will still be in business in 5 years from now	5.86	5.33	F (2)= 40.3; p< .001
I worry about the future of my job	2.75	3.01	F (2)= 21.8; p< .001
My job is difficult and complex	3.76	3.58	ns
My job often requires me to learn new skills	4.44	4.15	F (2)= 7.4; p< .001
I use many of my skills and abilities in my current job	5.25	4.96	F (2)= 16.0; p< .001
I have a lot of freedom to decide how I do my work	4.71	4.91	F (2)= 10.8; p< .001
I have a lot of say about what happens on my job	4.71	4.91	F (2)= 10.7; p< .001
I have a lot of freedom to decide when I do my work	3.64	3.98	F (2)= 3.7; p< .025

TABLE 3: SATISFACTION WITH LIFE FROM HILDA

SATISFIED WITH	POPULATION	PEOPLE WITH HEARING LOSS	STATISTICAL VALUE
The home in which you live	7.97	8.35	F (2, 12405)= 12.1; p< .001
Education you received	7.35	6.59	F (2, 12405)= 199.1; p< .004
Employment opportunities	6.94	4.04	F (2, 12405)= 1048.9; p< .001
Future job prospects	7.70	6.97	F (2, 12405)= 289.1; p< .004
Financial situation	6.56	6.35	F (2, 12405)= 83.2; p< .001
How safe you feel	8.25	8.01	F (2, 12405)= 67.2; p< .001
Feeling part of the community	6.84	6.71	F (2, 12405)= 5.7; p< .004
Health	7.89	6.16	F (2, 12405)= 1624.8; p< .001
Neighbourhood in which you live	8.01	7.92	F (2, 12405)= 14.1; p< .001
Amount of free time you have	6.5	7.8	F (2, 12405)= 103.2 p< .001
With your life	8.05	7.86	F (2, 12405)= 102.1; p< .001
With friends and friendships	8.1	7.5	F (2, 12405)= 132.7 p< .001
With your love life	7.46	6.54	F (2, 12405)= 201.6; p< .001
Spare time activities	6.94	6.69	F (2, 12405)= 72.9; p< .001



The HILDA dataset provides information on peoples' social capital, taking into account their satisfaction with life, personal autonomy, community participation and social trust. As can be seen in Table 3, people with hearing loss report higher levels of life satisfaction pertaining to the home in which they live and the amount of free time they have. They also report high levels of dissatisfaction across a wide range of issues including dissatisfaction with:

- the education they received as well as their employment opportunities and prospects
- financial wellbeing
- community connectedness, and
- social relations.

Analysis of HILDA data on personal autonomy provides further insight into the wellbeing of people with hearing loss (see Table 4). These data show that as compared with the general population, people with hearing loss report having less control, reduced capacity to solve problems or change things which are of concern to them and have more frequent feelings of helplessness. Moreover, this cohort reports a reduced capacity to take on challenges into the future.

Table 5 provides a comparative insight into the extent of community participation enjoyed by people with hearing loss. Compared to 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 (e.g. participating in complex discussions, social activities with friends).

TABLE 4: PERSONAL AUTONOMY

AUTONOMY	POPULATION	PEOPLE WITH HEARING LOSS	STATISTICAL VALUE
Little control	2.66	3.29	F (2, 12405)= 185.6; p< .001
No way to solve problems	2.46	3.19	F (2, 12405)= 303.7; p< .001
Cannot change important things in life	2.47	3.29	F (2, 12405)= 277.9; p< .001
Feel helpless	2.47	3.03	F (2, 12405)= 218.5; p< .001
Future depends on me	5.65	5.33	F (2, 12405)= 66.3; p< .001
Can do just about anything	5.47	4.78	F (2, 12405)= 221.5; p< .001

TABLE 5: COMPARING COMMUNITY PARTICIPATION BY HEARING LOSS

COMMUNITY PARTICIPATION	POPULATION	PEOPLE WITH HEARING LOSS	STATISTICAL VALUE
Contact with friends/relatives not living with me	4.75	4.39	F (2, 12405)= 41.1; p< .001
See members of extended family	3.78	3.78	ns
Chat with your neighbours	3.49	3.71	F (2, 12405)= 20.3; p< .001
Attend events (fetes, shows, festivals)	3.23	2.91	F (2, 12405)= 56.1; p< .001
Involved in activities for a union, political party ...	1.65	1.48	F (2, 12405)= 9.14; p< .001
Make time to attend services/worship	2.13	2.26	F (2, 12405)= 3.7; p< .024
Talk about current affairs with family/friends	3.69	3.59	F (2, 12405)= 9.13; p< .001
Make time to keep in touch with friends	4.34	4.05	F (2, 12405)= 43.5 p< .001
Volunteer spare time to work with community groups	2.24	2.06	F (2, 12405)= 4.2; p< .015
Get in touch with local politicians	1.46	1.67	F (2, 12405)= 45.7; p< .001

TABLE 6: COMPARING SOCIAL COHESION BY HEARING LOSS

SOCIAL COHESION	POPULATION	PEOPLE WITH HEARING LOSS	STATISTICAL VALUE
People don't come to visit me as often as I would like	3.47	3.72	F (2, 12405)= 30.9; p< .001
I often need help from other people but can't get it	2.30	2.69	F (2, 12405)= 96.6; p< .001
I seem to have a lot of friends	4.60	4.24	F (2, 12405)= 50.4; p< .001
I don't have anyone I can confide in	2.34	2.84	F (2, 12405)= 51.5; p< .001
I have no one to lean on in times of trouble	2.22	2.70	F (2, 12405)= 69.1; p< .001
There is always someone who can cheer me up when I'm down	5.37	4.96	F (2, 12405)= 3.7; p< .024
I often feel lonely	2.59	3.02	F (2, 12405)=125.1; p< .001
I enjoy the time I spend with the people who are important to me	6.28	6.04	F (2, 12405)= 19.2 p< .001
When something's on my mind, just talking with the people I know can make me feel better	5.68	5.52	F (2, 12405)= 15.2; p< .015
When I need someone to help me out, I can usually find someone	5.70	5.51	F (2, 12405)= 43.6; p< .001



Table 6 provides a comparative insight into the experience of social cohesion enjoyed by people with hearing loss. Compared with the general population people living with hearing loss reported poorer outcomes on all indicators of social cohesion. These differences can be summarised under two themes; people with hearing loss are more socially isolated and have less personal support.

Table 7 provides a comparative insight into the experience of social trust enjoyed by people with hearing loss. Compared with the general population people living with hearing loss report on average, higher levels of trust that the population, finding people to be reliable and honest to deal with. Nonetheless they are not naïve to the possibility that people may try and take advantage of them if the opportunity arose.

TABLE 7: COMPARING SOCIAL TRUST BY HEARING LOSS

SOCIAL TRUST	POPULATION	PEOPLE WITH HEARING LOSS	STATISTICAL VALUE
Most people would try to take advantage of you if they got the chance	1.55	1.75	F (2, 12405)= 49.3; p< .001
Most people you meet keep their word	4.71	4.78	F (2, 12405)= 17.1; p< .001
Most people you meet succeed by stepping on other people	2.96	3.05	F (2, 12405)= 25.6; p< .001
Most people you meet make agreements honestly	4.98	5.15	F (2, 12405)= 9.3; p< .001
Most of the time people try to be helpful	5.24	5.34	ns
People mostly look out for themselves	4.50	4.59	F (2, 12405)= 3.3; p< .04
Generally speaking, most people can be trusted	4.87	5.02	F (2, 12405)=8.96; p< .001

TABLE 8: THE NUMBER AND PER CENT OF PEOPLE WITH HEARING LOSS THAT ALSO REPORT OTHER HEALTH CONDITIONS

	HEARING LOSS	
	N	%
Sight problems	79	15.0
Speech problems	15	2.9
Blackouts, fits or loss of consciousness	17	3.2
Difficulty learning or understanding things	28	5.3
Limited use of arms or fingers	60	11.4
Difficulty gripping things	66	12.6
Limited use of feet or legs	125	23.8
A nervous or emotional condition	51	9.7
Any condition that restricts physical activity or physical work	169	32.2
Any disfigurement or deformity	16	3.0
Any mental illness which requires help or supervision	13	2.5
Shortness of breath or difficulty breathing	102	19.4
Chronic or reoccurring pain	111	21.1
Long term effects as a result of head injury, stroke or other brain damage	30	5.7
A long term condition or ailment which is still restrictive even though it is being treated or medication being taken for it	124	23.6
Any other long term condition such as arthritis, asthma, heart disease, Alzheimer's disease, dementia etc.	196	37.3

Note: these numbers do not equal 277 because each category is not mutually exclusive.



Other health conditions

An analysis of health condition data revealed that of those with a hearing condition, 277 (or 53%) reported another health condition. The most prevalent health conditions were other long term conditions such as arthritis, asthma, heart disease, Alzheimer's disease, dementia etc. This indicated that those with hearing loss were not as healthy as the rest of the sample. The average number of conditions reported for those with hearing loss was 3.

Severity of health condition

It is important to note that these questions do not distinguish between health conditions, so while a respondent may indicate that their health condition limits their capacity to work, if they report more than one condition we are unable to distinguish which condition limits them. 56% of those with a hearing condition (N = 294) reported that their condition limits the type or amount of work; 39.2% (N = 206) reported that their condition has no impact. Only 25 respondents (4.8%) reported that they can't work. Almost 90% of those with hearing loss reported that they had no difficulties communicating in their own language, 57 (10.9%) reported that they did have problems communicating. 85 respondents (16.2%) reported that their health condition requires help or supervision. Of those 85 respondents, 15 people (or 2.9%) reported that they need help communicating. Of these, only 5 respondents reported that they always needed help communicating.

To date, general medical practitioners have not given a great deal of attention to hearing as a health issue. In adults, it is commonly discounted as being simply a factor of age or as a condition co-morbid with heart disease (see for example Wu et al. 2010). The HILDA data do not report specific cardio-vascular diseases in any detail, so we turned instead to reports of main health condition recorded in SDACs. As noted in Figure 4 below, cardiovascular diseases only accounted for 14% of all main health conditions. Similarly we noted earlier the many reported causes of hearing loss including exposure to excessive noise, congenital disorders and disease processes of the ear.

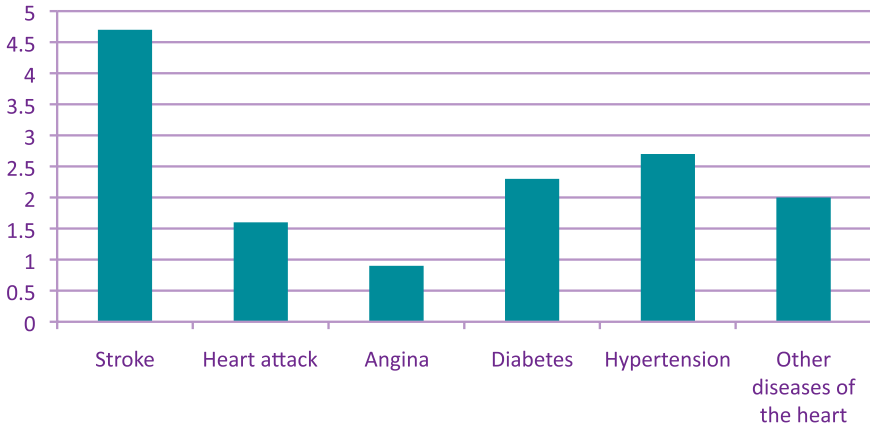


Figure 4: People with hearing loss whose main health condition is cardio-vascular in nature

Table 9 provides comparative data for health related quality of life (HRQoL) outcomes for people with hearing loss versus the population and those with other health conditions. The measure used in the internationally recognised SF 36 measure of HRQoL. While people with hearing loss rate their overall wellbeing more highly than the general population, they report poorer health related quality of life outcomes on every other indicator in the scale including poorer physical and social functioning, more body pain and reduced vitality.

TABLE 9: SF-36 HEALTH

	NO HEALTH CONDITION	A HEALTH CONDITION OTHER THAN HEARING LOSS	HEARING LOSS
Self rated health	1.53	2.29	2.22a
Physical functioning	81.63	56.96	53.41b
Role physical	80.92	43.41	40.85a
Body pain	73.20	48.26	50.20a
General health	66.99	44.92	45.45a
Vitality	58.03	43.13	45.19b
Social functioning	79.87	60.36	59.92a
Role emotional	79.56	58.32	57.05a
Mental health	69.29	59.75	61.10b
Physical activity	2.75	2.11	2.16 a

Notes: a those with a hearing loss are statistically different ($p < .000$) from those with no health conditions but not different to those with a health condition other than hearing loss. b: those with hearing loss are statistically different ($p < .000$) from both those with no health conditions and a health condition other than health loss.

We note that the jury is still out (see Hogan et al. 2009) as to whether health factors contribute to acquired hearing loss or whether hearing loss contributes to poor health. We observe however that the many causative factors associated with hearing loss noted above occur before the age of fifty while the poorer health outcomes occur after the age of fifty. Further research is required so that a better understanding of the relationship between hearing and health can be understood. The evidence though creates a compelling case for general practitioners to give greater attention to the role hearing loss plays in patient health outcomes.

Earlier I reported that people with hearing loss had poorer employment outcomes compared with the general population. It is important to note however that I have also found (Hogan et al. 2009) that people with hearing loss who have no other health conditions in fact report higher workforce participation rates than the general population. So the factors that prevent people with hearing loss from being in work have something to do with other conditions, in addition to being deaf or hearing impaired.

TABLE 10: PERCENTAGE OF THOSE WHO EXPERIENCE EMPLOYMENT RESTRICTIONS DUE TO LONG TERM HEALTH CONDITION BY HEARING LOSS (YES/NO)

LONG-TERM HEALTH CONDITION	PEOPLE WITH HEALTH CONDITION OTHER THAN HEARING LOSS	PEOPLE WITH HEARING LOSS	CHI-SQUARE STATISTICS
Restricts employment	49.1	52.2	X2= .84
Permanently unable to work	3.1	4.8%	X2= 3.75
Restricts type of job can do	60.6	57.5	X2= 4.43
Restricts number of hours that can be worked	44.6	45.0	X2=.01
Makes it more difficult to change jobs / get a better job / find a suitable job	23.9	25.0	X2=.07
Need additional time off work	17.4	12.5	X2=1.82
Need ongoing assistance / supervision at work	4.5	8.3	X2=3.28
Need special equipment / arrangements	7.9	7.5	X2=.02
Other needs	7.1	9.2	X2=.67



With few exceptions, the impact of hearing loss on employment is not particularly different to that of any other condition. People report that their condition restricts their job choice and reduces their opportunity to change jobs, such as pursuing better opportunities, working conditions or pay. Notably though people with hearing loss report needing less time off work due to their condition than people with other conditions but report requiring a greater degree of assistance in the workplace. We noted earlier that people with hearing loss tend to work with less supervision than other staff and yet the data in this table suggests that they need more supervision. This quandary requires further investigation to better understand the problem which is occurring. However, one can envisage that where communication is an issue, supervisors may need to take more time in providing instruction to staff, before they can commence work on a particular assignment.

What cohort of people with hearing loss does SDACs appear to report on?

The profile of people with hearing loss from SDACs is one of older people who more readily use hearing devices and whose life chances (education, employment and income outcomes) have been restricted. These data support several possible groupings of people with hearing loss including those with (i) early onset hearing loss such that educational outcomes could be affected and (ii) those with more advanced losses such that there is a higher rate of device usage among them. Niskar et al. (1998) report that the prevalence of early onset hearing loss lies between 5% and 15% of children, a rate of hearing loss consistent with that reported in SDACs. To the extent that the onset of hearing loss results in unavoidable communication breakdown and/or the need to use hearing devices, the capacity to avoid identifying as a person with hearing loss is reduced. As such, either by design or by outcome, hearing loss in such circumstances may more readily form part of a person's social identity and be managed as such.

People in the community with hearing loss

To address some of the limitations in the data which have been used to describe the cohort 'people living with hearing loss', I undertook a cross-sectional population study utilizing aspects of the engagement process suggested by Hetu and Getty (1992) to screen participants with regards to identifying as having a hearing loss and experiencing day-to-day interactional difficulties. The study involved 401 people aged over 55 years with the data being weighted to the Australian population with regards to gender, age and domicile. Equal numbers of men and women were recruited for the study.

Table 11 shows that those identifying as having hearing loss are well represented among the younger groups of ageing Australia.

Notably, as Table 12 shows, the vast majority of people (57%) aged over 55 years identify as having a mild hearing loss. This outcome has quite specific implications for the kinds of services that should be offered this cohort as the provision of social and communication support may be more useful, and certainly more acceptable, than the provision of hearing aids.

Table 13 shows that the majority (59%) of people identifying as having hearing loss aged over 55 years have post-school qualifications.

Table 14 shows that the majority (68%) of people identifying as having hearing loss aged over 55 years are not in the work force, with most having retired.



TABLE 11: AGE OF PEOPLE IDENTIFYING IN THE COMMUNITY WITH HEARING LOSS

AGE	%
55 – 64 years	49
65 – 74 years	40
75 years and over	20
TOTAL	100

TABLE 12: DEGREE OF SELF REPORTED HEARING LOSS

DEGREE OF HEARING LOSS (SELF-REPORTED)	%
Mild	57
Moderate	28
Severe	15
TOTAL	100

TABLE 13: EDUCATION OUTCOMES

EDUCATION	%
No formal schooling	0
Primary school only	0
Some secondary school	18
Completed secondary school	22
Trade/technical qualification	25
University trained	34
Other	1
TOTAL	100

TABLE 14: EMPLOYMENT OUTCOMES	
OCCUPATION	%
Manager/administrator	5
Professional (e.g. doctor, architect)	3
Para professional (e.g. nurse, police)	5
Trade	2
Clerical	6
Sales/service	2
Machine operator	1
Labourer/stores person	1
Unemployed	2
Home duties	6
Student	0
Retired (Self-funded)	17
Pensioner (full or part)	43
Other	6
TOTAL	100

Table 14 shows that the majority (64%) of people identifying as having hearing loss are in a formal relationship of some kind, indicating that social policy impacting on 'carers' is highly relevant to this sector. Table 15 reports marital status.

Table 16 shows that household income of people identifying as having hearing loss aged 55 years and over is well distributed, keeping in mind that the annual average weekly earnings is about \$60,000.



TABLE 15: MARITAL STATUS OUTCOMES

MARITAL STATUS	%
Never married	6
Married	59
De facto	5
Widowed	10
Divorced	17
Separated	3
Other	0
TOTAL	100

TABLE 16: HOUSEHOLD INCOME (BEFORE TAX)

HOUSEHOLD INCOME	%
\$1-\$4,199	1
\$4,200-\$8,299	1
\$8,300-\$15,599	4
\$15,600-\$25,999	19
\$26,000-\$36,399	13
\$36,400-\$51,999	13
\$52,000-\$77,999	12
\$78,000-\$103,999	10
\$104,000-\$129,999	3
\$130,000-\$149,999	2
\$150,000 +	3
Other	1
Prefer not to say	18
TOTAL	100

TABLE 17: EVERYDAY COMMUNICATION DIFFICULTIES AS USED IN THE MONTREAL RECRUITMENT PROCESS

ISSUE	MILD (%)	MODERATE (%)	SEVERE (%)
Reports difficulty hearing in noisy places	86	91	97
Pretends to understand to avoid asking for repeats	58	83	84
People complain I don't hear the telephone/doorbell ring	29	32	40
People complain I have the TV up too loud	40	57	77
There are times I feel left out of a group	88	73	55
I tend to notice my hearing problems more these days	66	80	52
Often come into conversation on wrong topic	13	30	35

All differences statistically significant <.001

TABLE 18: ACTIONS TAKEN TO MANAGE HEARING LOSS

ISSUE	MILD (%)	MODERATE (%)	SEVERE (%)
Sought information	16	27	12
Had a hearing test	83	82	65
Purchased a hearing aid	27	58	81

All differences statistically significant <.001

TABLE 19: MOTIVATION FOR TAKING ACTION TO MANAGE HEARING LOSS

ISSUE	MILD (%)	MODERATE (%)	SEVERE (%)
Encouraged by significant other	16	30	26
Response to advertising	22	13	5
Referred by health care professional	20	15	33
Experienced specific hearing problems	12	44	67
Personal concerns (no significant difference)	54	58	51

Differences statistically significant <.05



Table 17 shows that the most common communication problems experienced by people identifying with hearing loss are hearing in background noise and social exclusions. Such outcomes suggest that enhancing the accessibility of communicative spaces is a social priority for people with hearing loss. Social inclusion remains a key issue.

Table 18 reports the actions taken by people identifying with hearing loss to manage their hearing loss. As one would expect, the majority of people with hearing loss are people with mild loss and they do not seek out devices and vice versa.

Table 19 shows that the most common factors underpinning why people identifying with hearing loss sought help. The most common reason being 'personal concerns'.

Miners with hearing loss

In 2003 I conducted a study of hearing outcomes among coal miners in Australia, surveying the wellbeing of 100 consecutive coal miners when they had their annual health check. Two out of three of these coal miners had a hearing loss.³ Almost half the miners with hearing loss were aged less than 50 years. Approximately half the miners (47%) had post-school qualifications with the vast majority (72%) reporting incomes above average weekly earnings. Common occupations were trades people, general miners and plant operators. More than half of the miners with hearing loss (54%) reported that it was hard or very hard to hear in background noise, 42% in noisy group settings, and 36% at home or in groups. Just under half the group (47%–49%) reported that hearing loss reduced their confidence to some degree, reduced the satisfaction they took from participating in social activities and reduced their ability to concentrate. More than one third (37%) reported that hearing loss reduced their self-esteem to some degree, 43% reported feelings of self-consciousness and 36% reported that hearing loss impacted to some degree on how they got on with others. Overall, hearing loss accounted for 21% of peoples' health related quality of life, with the impact of hearing loss on their self-image being the most influential driver ($F(4) = 3.3; p < .02$). Notably only 5% people in this cohort had ever been offered help, such as in the form of a hearing aid. Of the two who did try a hearing aid, one no longer uses it and the other reported being dissatisfied with its performance.

3 I gratefully acknowledge the work of my co-researcher on this project Simon Pfeifer.



Concluding remarks

So what do we make of this report card on the wellbeing of people identifying with hearing loss in Australia? Without doubt, those of you who know me well can probably guess what I think about these issues. But at the end of the day, it is your view, and your readiness to act on your views, that in fact is the view that counts. What we make of these data and any policy changes we might wish to pursue, must be determined by those whose lives are affected by such decisions. It is for this reason time and again, I have been prepared to share the outputs from my research while at the same time stepping back, waiting and watching for how you react to these insights and where you want to take things into the future. This has been very frustrating process for me in many respects, because as a collective we have not readily taken up the policy issues in a coherent and persistent manner. As a collective, I think we have put too much trust in professionals and policy makers to do the right things by us, while at the same time, other disability groups and professional interests have progressed their cause and secured policy change by playing the political game. So I will firstly summarise some of the key points made in this paper before suggesting next steps.

The social outcomes for children with hearing loss and ear infections, particularly children with unilateral and mild to moderate 'unavoidable' losses are a critical concern. Left unchecked, up to a third of these children will end up in our mental health system as adults. Moreover we see in the data that such young people in time under achieve at school. The data supports the view that these people are more likely to be unemployed and under-employed with those employed working in a narrow range of job opportunities. Moreover, as a group people identifying with hearing loss earn less. Work is a place of significant stress and as a group, people are quite dissatisfied with these outcomes.

People identifying as having a hearing loss enjoy the homes in which they live and are engaged in their neighbourhoods and church groups; they enjoy higher levels of social trust. But perhaps this trust in the social arena is misplaced? At the same time our cohort report having lower social capital evidenced in less community connectedness and less engagement in broader community activities. Members of this cohort do not get to

participate in social activities requiring complex social interaction and as such are marginalised from important community decision making processes. Our people feel less safe, less healthy, enjoy poorer relationships, are more socially isolated, have less support and report greater dissatisfaction with their love lives. Identifying with hearing loss is highly stigmatized and the effects of this marginalisation impact on the capacity of us as a group to engage with change and change processes. Stigmatization is possibly the social barrier which prevents people from taking early and effective action to manage their hearing loss. The second biggest barrier to social participation is background noise or what we might term the acoustic inaccessibility of the social space. In the 1980s our society did ramps; we now need acoustic tiling etc in public places. Both social awareness and the real accommodation of different patterns of communication are essential if social participation is to be achieved. The majority of people identifying with hearing loss have milder levels of hearing loss, but the bulk of the resources go to other groups of people identifying with hearing loss, both on a per capita basis, but also on a group basis. We need to move away from a medically based model of service provision for people with hearing loss. We need to stop saying that people are not motivated to help themselves and shift our language to a social model of disability which is concerned with disabling barriers and enabling environments (Swain et al. 1993). And to do this we need a large and powerful advocacy body which can represent us.

The Deafness Forum has been around for 20 years or so now and it hasn't really grown in size during that time. Personally I have managed community neighbour centres that have had bigger operational budgets than the Forum. If we want to improve the social position of people identifying with hearing loss in Australia, one of the first tasks that we must do is politically support the capacity of the Forum to grow so that it can more effectively engage in the political space at a level commensurate with the size and need of our constituency. It's time for us as a collective to be less trusting of the political process and assert our rights within it.

Paul Jacobs might rightly criticise this paper for not focusing on the positive. I would though turn this suggestion around by saying we need a report card on where we are up to, because without it we do not have a mirror to hold up to government and to the world which says how we are doing. Yes we are good and together we can be better!



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About the Deafness Forum

Introduction

Deafness Forum is the peak body for deafness in Australia. Established in early 1993 at the instigation of the Federal government, the Deafness Forum now represents all interests and viewpoints of the Deaf and hearing impaired communities of Australia (including those people who have a chronic disorder of the ear and those who are DeafBlind).

Structure

Deafness Forum is divided into four classes.

Consumer means an adult who is Deaf or has a hearing impairment or has a chronic ear disorder; or a parent of such a person.

- **Deaf** refers to people who see themselves as members of the Auslan using Deaf community by virtue of its language (Auslan) and culture.
- **Hearing Impairment** refers to a hearing loss. People with a hearing impairment (or who are hard of hearing) may communicate orally (sometimes described as 'oral deaf') or may use a sign language or other communication methods.
- **Chronic Ear Disorder** refers to such disorders of the ear as tinnitus, Meniere's Disease, Acoustic Neuroma, hyperacusis and recruitment. People with some such ear disorders may also have a hearing impairment.

All Consumers are entitled to describe themselves using whatever terminologies they prefer, and are asked to do so at the time of joining and each time they renew membership.

Consumer Association means an incorporated Association of, or for, consumers (as defined above).

Service Providers also include various other occupations that provide services to consumers who are Deaf, have a hearing impairment or have a chronic disorder of the ear.

Service Provider Association means an incorporated organisation, which has (as its principal purpose) the provision of services that promote the wellbeing of consumers (as defined above).



Objectives

The Deafness Forum exists to improve the quality of life for Australians who are Deaf, have a hearing impairment or have a chronic disorder of the ear by:

- advocating for government policy change and development
- making input into policy and legislation
- generating public awareness
- providing a forum for information sharing and
- creating better understanding between all areas of deafness.

Community Involvement

The Deafness Forum is consumer driven and represents the interests and concerns of the entire deafness sector, including:

- the Deaf community
- people who have a hearing impairment
- people who have a chronic ear disorder
- the DeafBlind community
- parents who have Deaf or hearing impaired children in their families

Libby's Story



Libby's story is one of courage and triumph over adversity by utilising the knowledge of her own severe hearing loss to help others.

Libby started to lose her hearing following a bad dose of flu in the English winter soon after her marriage in 1969. Having returned to Australia in 1970 she began to find difficulty in understanding conversation and instructions, particularly on the telephone which was very important in her profession of pharmacy.

In spite of advice to the contrary, Libby tried hearing aids and found they helped. Had she heeded the negative advice, Libby believed she might never have embarked on the road to self-help, which so enriched her own life and that of many others. She thought her two boys quickly learnt to sleep through the night and her friends remarked they had loud voices, which was the boys' mechanism for coping with a deaf mother!

The more the doctors said nothing could be done to help, the more Libby looked towards self help and so she learnt to lip read, a tool she relied on heavily in her quest to help others.

Libby's will to win led her, with the help of others, to get involved with the setting up of a support group, which became SHHH – Self Help for Hard of Hearing people. The American founder, Rocky Stone, was invited to Australia in 1982 and did a lecture tour entitled "The Hurt That Does Not Show" which cemented the bonds between the US and Australian groups and helped the local SHHH develop.

Libby, with others, then began SHHH News, a quarterly publication, and with Bill Taylor set up the first Hearing Information and Resource Centre at "Hillview", Turrumurra with support from Hornsby/Kuringai Hospital. This centre provided reliable information on, and demonstrated, assistive listening devices for hearing impaired people. Through this interest, Libby became an enthusiastic user of technology and with her handbag full of electronic aids was enabled to join in a full social life with family and public.



Libby became President of SHHH in 1986 and began to develop her role as an advocate for hearing impaired people generally.

She became involved in ACCESS 2000, under the Australian Deafness Council, and a member of the Disability Council of NSW. Her horizons broadened further as Vice President of the Australian Deafness Council and then as the first, and two terms, President of the newly formed national peak body in deafness, the Deafness Forum of Australia. In this latter role Libby made a huge contribution to bring together all the different organisations into a central body, and actively lobbied on behalf of Deaf and hearing impaired at the highest level – the archetype of a successful achiever despite her profound hearing loss.

For her work on behalf of hearing impaired people Libby was made a Member of the Order of Australia in 1990. Later she was appointed by the Government to the Board of Australian Hearing Services and was asked to represent the needs of hearing impaired on the Olympic Access Committee.

Unfortunately, Libby faced another hurdle when she was diagnosed with breast cancer in 1995. Following surgery, she continued her family and volunteer work with undiminished vigour.

She would wickedly show off her wig at public functions after her chemotherapy, and talked openly of her "mean disease". She died peacefully on 1 August 1998 and was honoured by hundreds who attended her Thanksgiving Service on 6 August.

In her own words, Libby related her outlook:

"I look back over these years since I became hearing impaired and realise that any efforts that I have made have been returned to me threefold. I have found talents I never knew I had, I have gained so much from the many people I have met and worked with to improve life for people with disabilities and through self help I have turned the potential negative of a profound hearing loss into a positive sense of purpose and direction in my life".

The Libby Harricks Memorial Oration

The Libby Harricks Memorial Oration program is supported by the Libby Harricks Memorial Fund of the Deafness Forum of Australia. Donations to this fund are tax deductible.

Donations should be made payable to Deafness Forum. Additional donation forms and general information regarding deafness can be obtained from:

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"I look back over these years since I became hearing impaired and realise that any efforts that I have made have been returned to me threefold. I have found talents I never knew I had, I have gained so much from the many people I have met and worked with to improve life for people with disabilities and through self help I have turned the potential negative of a profound hearing loss into a positive sense of purpose and direction in my life"