

The 2003

Libby Harricks

Memorial Oration



Libby Harricks Memorial Oration number 5

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

Elisabeth Ann Harricks AM 1945 – 1998

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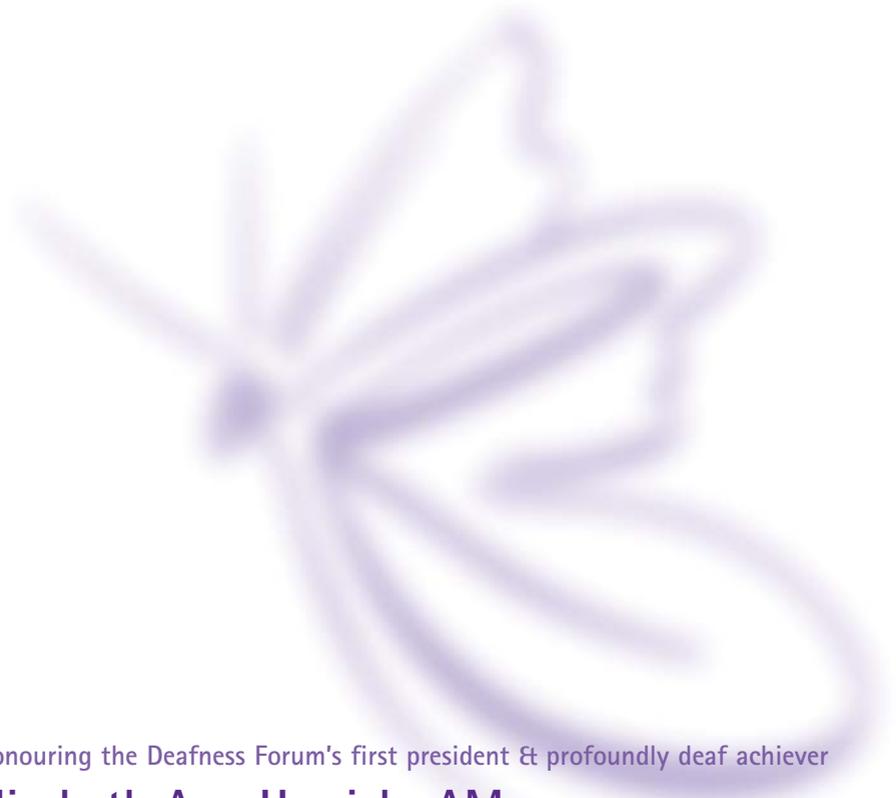
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Introduction to the 5th Libby Harricks Memorial Oration

By Ms Margaret Robertson



Dr Victor Bear Chairman, Mr David Harricks and other members of the Libby Harricks Memorial Oration organising committee; Mr Graeme Innes Deputy Disability Discrimination Commissioner; Professor Di Yerbury Vice Chancellor of Macquarie University; Ms Donna Lee Sorkin today's Orator; other distinguished contributors to the symposium to follow; my colleagues on the Deafness Forum Board of Directors; ladies and gentlemen, it is my very great pleasure to welcome you to the fifth Libby Harricks Memorial Oration.

My first task is to acknowledge the many generous contributions and sponsorships that have made it possible to bring the Oration to you today.

We thank Macquarie University for its assistance in providing the excellent facilities we are enjoying on this occasion.

The Real time transcription facilities, that make hearing access a reality for many of us today, are being provided by the Australian Caption Centre. We thank the Caption Centre for this; a wonderful instance of the many ways in which it supports the work of the Deafness Forum.

The Australian Communication Exchange is another very good friend to the Forum, and we thank ACE for its generous sponsorship of this event.

The Libby Harricks Memorial Orations (and the associated access seminar today) would not happen without the hard work of the Oration Organising Committee. Thank you to all the members of this committee. We value very highly your expenditure of time and effort that brings to us once again a distinguished speaker on this important occasion. Thank you too to our staff at our national secretariat office in Canberra who administer the arrangements for the oration with such great efficiency.



The fifth Libby Harricks Memorial Oration is to be delivered by Ms Donna Lee Sorkin and I am delighted to welcome her here today.

Donna Lee Sorkin is based in Virginia USA. She was Executive Director of Self Help for Hard of Hearing People (USA) in Bethesda from 1993 to 1999 and she served as executive director of the Alexander Graham Bell Association for the Deaf and Hard of Hearing from 1999 to 2001. She was appointed by President Clinton to the US Access Board in 1994 and was re-appointed to a second term in 1998. This Board advises the US Congress on revision of the 1990 Americans with Disabilities Act.

She served a term on the National Institute on Deafness (National Institutes of Health) Advisory Board and has advised numerous US businesses on accessibility for people with disabilities. Currently Donna is Vice President, Consumer Affairs at Cochlear Americas. In that capacity she leads a range of activities at Cochlear aimed at the broad life needs of the cochlear implant community including appropriate educational options for children, early intervention, accessibility for people with hearing loss, and insurance reimbursement. Donna holds a Masters Degree in city planning from Harvard University and a B. A. from Mount Holyoke College, where she graduated with honours in economics. She has been an enthusiastic cochlear implant user since 1992.

Today, Donna addresses us on the topic: 'Disability Law and People with Hearing Loss: We've come a long way (but we're not there yet.)'

Ladies and gentlemen, please welcome Donna Lee Sorkin.



Disability Law and People with Hearing Loss: We've come a long way (but we're not there yet)

Delivered by Donna Lee Sorkin on the 14th of April 2003.



Abstract

The Americans with Disabilities Act was landmark legislation that broadly affirmed the premise that people with disabilities should be judged on the basis of their abilities, not their disabilities. Since its passage in 1990, more than forty nations have enacted disability laws that sought to bar discrimination and exclusion on the basis of disability.

Many of the early laws left much to be desired in terms of fully addressing the needs of deaf and hard of hearing people. Today, the legislative scope has been broadened to require greater use of technology, consideration of acoustics in classrooms, appropriate services for children, provision of captioning and interpreters in a variety of venues, telecommunications access, workplace accommodations, and more.

Still, passage of laws is one thing, ensuring that the laws and the necessary regulations to carry them out are properly implemented is another matter entirely. Full implementation of disability laws requires broad changes in the way society views its responsibilities in addressing the different needs of people with disabilities. This year's Libby Harricks Memorial Oration will examine the progress in disability legislation as well as the societal implications of an expanded definition of what constitutes appropriate accessibility.

Introduction

I am honored to have been asked to deliver this oration, which is a tribute to Libby Harricks, a woman who was known and loved by all of us at Self Help for Hard of Hearing People in America. Libby was an effective advocate for her own needs as a person with hearing loss, which is what the SHHH organization teaches its members. She also advocated for other people and for laws and policies to broaden access for people who are deaf and hard of hearing. It seems particularly appropriate, given Libby's keen interest in advocacy and awareness, for this year's oration to examine the progress that we've made with regard to society's perspectives about disability, and specifically about hearing loss.

Developing an Identity

Sometimes people get mired in terminology and spend considerable time and energy gaining agreement about what to call themselves or how to refer to their organization or their movement. That's a phenomenon that occurs quite a lot in all sorts of environments. Although at first blush this may seem insignificant, the fact is that changes in terminology—particularly in this field—have been reflective of meaningful changes in perspectives over the past decade or more. Even the word we now commonly use —*disability*— is a relatively new term. Significantly, it is a term that was devised by people with disabilities, rather than by a government agency or by professionals in the field. In America, we have tended to move away from using language like "handicapped" or "impaired" to more neutral descriptors of the disability. For example, we describe a person as being deaf or hard of hearing; or being blind or having low vision. For a person who has a physical disability that affects all four limbs, we would use an accurate description of the person's disability, i.e., he or she is a quadriplegic. In the past, we likely would have avoided being quite so graphic in our portrayal but now such terms are considered neutral and acceptable descriptors by people with the disability.



This change of terminology reflects larger changes. There is a new model for disability in America, a paradigm that has been evolving for some years now. This is also the case in other countries around the world, including Australia. The new thinking is that there is no pity or shame in having a disability. Rather, it is the stereotyping and fears about disability, and ultimately the discrimination that occurs because of a lack of access to services that is the real problem. We have moved away from taking pains to hide the fact that someone cannot hear or see. We encourage people to be open about their disabilities and instead focus on *what they need to fully participate*.



This has played out in remarkable ways. Franklin Delano Roosevelt was the 32nd president of the United States. Many people consider him to have been one of America's finest leaders as he introduced totally new concepts relating to the responsibilities of the Federal government for individual citizens, instituting the first social measures to ensure that people had a means of support when they were unemployed or elderly. FDR, as he was popularly referred to, served four terms as president despite a strong tradition (now a law) that American presidents serve no more than two terms. He was enormously popular with the common man and led the United States at a particularly turbulent time in history—during the Great Depression of the 1930s and prior to and during World War II—from 1933 until his death in 1945.

He contracted polio as a young man—before being elected governor of New York State—and he never walked again after his illness. Although it was widely known that he had difficulty moving about because of the paralysis, the fact that he used a wheelchair and could not walk was little known by Americans. He was never photographed in his wheelchair and on those occasions when he appeared in public, he wore painful leg braces and was assisted by others. This was not publicly acknowledged until well after his death because of the stigma associated with being confined to a wheelchair. Most of his advisors felt, probably correctly, that he could never have been elected president of the United States if the electorate knew he used a wheelchair.



Several years ago, a national memorial honoring FDR was completed in Washington, DC. The initial design gave no hint that Franklin Roosevelt used a wheelchair. In fact, the larger than life statue of President Roosevelt at the memorial site shows him seated, with a cape draped over his legs, in such a way that his wheelchair is entirely hidden. Disability groups in America were incensed that a memorial of this magnitude on the national mall in Washington, DC purposely concealed the fact that Roosevelt used a wheelchair. They felt it was a continuation of past practices in which society hid people with disabilities, or in this case, intentionally veiled the fact that a powerful and charismatic person was not able-bodied.

A Community of Interest

Increasingly, around the world, there is a perspective that people with disabilities comprise a community. The term *disability community* is frequently used, as much to call attention to this group as an important political force as to coalesce around a shared philosophy. This commonality of interests and mutual support has been a critical factor in the passage of legislation and approval of regulations—regardless of whether the action benefited the entire community or a particular group.

During the negotiations that led up to passage of the Americans with Disabilities Act, there was an effort by some national legislators to exclude people with AIDS from the proposed employment protections of the law. Advocates recognized early on that might happen and vowed to stick together for the greater good, no matter what. They did not divide themselves or sacrifice their ideals on the AIDS issue, nor have they since. The "one for all and all for one" perspective has remained a guiding principle in the way disability advocates operate. Certainly from time to time, we disagree among ourselves. Deaf and hard of hearing people in particular are not always of the same mind regarding the best way to communicate, or our preferences for how we wish to be accommodated. Regardless, we respect each other's choices and put our differences aside when it comes to advocating for accessibility. In the decade or so that I have been involved in deafness, I've been pleased to see our differences narrow and our spirit of collaboration enlarge.



The Americans with Disabilities Act (ADA)

The Americans with Disabilities Act, passed by the United States Congress in 1990, was landmark legislation that broadly affirmed the premise that people with disabilities should be judged on the basis of their abilities, not their disabilities. The ADA was instrumental around the world in encouraging the development of disability laws that were grounded in a civil rights framework. The ADA prohibits discrimination on the basis of disability in the private and public sectors. With the ADA, American advocates built upon the 1964 Civil Rights Act, which prohibited discrimination on the basis of race, color, national origin, and later on, gender. The ADA is based on the well-established principle of civil rights in America and even used a similar enforcement structure. But there was one key element that was incorporated into the ADA that was not in civil rights law—the principle of *reasonable accommodation*, a principle that requires employers or other entities such as local governments or private institutions to make specific kinds of accommodations that allow people with disabilities access to the workplace or to services.

There were other laws that protected people with disabilities from discrimination prior to the ADA but the protections they afforded were limited. These earlier laws generally focused on prohibiting discrimination by the United States government; they did not place any requirements on private businesses or local governments. The ADA addressed access in all of the key elements of life—the private workplace, state and local government, public transportation facilities, public entities like movie theaters and hotels, and telecommunications.

The definition of disability was construed broadly under the ADA to include anyone who has a physical or mental impairment that substantially affects one or more major life activities. Those life activities are broadly defined to include walking, hearing, seeing, speaking, learning, breathing or taking care of oneself. In recent years, there have been several Supreme Court cases in which the definition of an individual with a disability was narrowed. In one case, individuals were denied jobs as airline pilots because they were nearsighted. With eyeglasses, their vision was corrected to 20/20. The individuals claimed that they should have been protected by the ADA because without their glasses their vision was a significant limitation. The court ruled in favor of the airline. Those individuals were deemed to have too much sight with corrective glasses to fall within the definition of an individual with a disability to be protected under the ADA. The Supreme Court's decision to narrow the definition of disability in this way concerned many advocates. The outcome suggested that an individual may not be protected under the ADA if the individual uses an assistive device to improve his or her functional activities. For example, when the ADA was being considered, it was clear that people who are deaf or hard of hearing would have the protection of this law. But if some of these individuals use a cochlear implant or a hearing aid, devices which can provide many them with the functional equivalent of a mild hearing loss, would they then lose the protection of the ADA?

Before we explore these philosophical issues further, I'd like to discuss some specific protections provided by the ADA and subsequent legislation for people with hearing loss and how these have changed over time. It is important to view such provisions in a dynamic way as society's perspectives change and technological innovations make it possible to address individuals' needs in new, innovative ways.



The ADA was intended to provide people with protection from discrimination in all aspects of their lives. In that respect, it was different from any law that came before. There are four parts to the ADA that address access to: employment; state and local government services (which include educational institutions) and to transportation; public accommodations, which means anywhere the public goes—stores, theaters, places of entertainment, museums, parks, professional offices, hotels and motels, health care facilities; and telecommunications relay services. The goal for all of these parts was to ensure that people with hearing loss could use, benefit from and enjoy, the same services and opportunities as everyone else.

A key component of ADA law is the requirement that both government facilities and private institutions provide deaf and hard of hearing people with auxiliary aids and services to ensure effective communication. These include assistive listening devices, captioning, qualified interpreters, amplified telephones, text telephones (or TTYs), closed captioning capability for television, and visual alerting devices.

Legislators left to specific Federal agencies the responsibility for developing the guidelines needed to implement the law. It is these guidelines that are updated periodically to reflect advances in technology, issues that were not addressed originally, or changes in societal perspectives about meeting people's needs. Hence, we have made modifications in the ADA guidelines without having to pass new ADA legislation. In some instances, when an accessibility issue falls outside of issues that were part of the ADA, language in new legislation has incorporated the new needs. This was the case with requiring telecommunications products and services to be accessible by people with disabilities and also with television captioning—both of which were topics that were not identified, nor addressed in the ADA.

The ADA Accessibility Guidelines (sometimes called ADAAG) provide specific details on how the ADA accommodates people who are deaf and hard of hearing. When the ADA was first passed in 1990

by the Congress of the United States, our legislative body, it was left to two administrative agencies—the Access Board and the Department of Justice to implement the law. The Department of Justice is responsible for adopting rules and enforcing compliance while the Access Board develops specifications for structural accessibility.

The Access Board is an independent Federal agency devoted to accessibility for people with disabilities. The Access Board is governed by a board of public members who are appointed by the President of the United States and Federal members who represent specific Federal agencies. It is significant that, traditionally, a high proportion of the board members and the board staff are people with disabilities. I was appointed by President Clinton to the Board in 1994 and was re-appointed in 1998 for a second term. Having people with disabilities as staff and also on the governing board provides a built-in mechanism for ensuring that the board is responsive to the needs of the population it serves. The board frequently appoints advisory committees comprised of people from business, universities and advocacy organizations to provide input during the rules development process and also to ensure that diverse perspectives are addressed as it develops rules. The process is not perfect and it often results in controversial decisions. Nonetheless, the Board does succeed in developing guidelines that incorporate compromise, which is a necessary component of all such processes. My own time on the board was extraordinarily rewarding, both for the contributions that I could make to accessibility but also for the unique opportunity to develop solutions that balanced a variety of interests.

It is instructive to review some specific accommodations for people who are deaf and hard of hearing and how those accommodations have been addressed under the ADA and other laws over time to reflect people's needs, societal perspectives, and technological changes. Four specific access issues will be reviewed here: assistive listening systems, television captioning, captioning in movie theaters, and access to wireless telephones.



Assistive Listening Systems (ALS)

In the original ADA Guidelines, permanently installed assistive listening systems, which bring the sound source directly into the listener's ear, were required in assembly areas where "audible communication is integral to the use of a space" such as movie theaters, concert and lecture halls. The guidelines further noted that the systems were required where there were fixed seats and where the system would serve those individual seats located within a 50 foot viewing distance of the stage allowing a person "to distinguish performers' facial expressions". The guidelines required that receivers be provided to serve at least 4% of the total number of seats in the facility.

Initially, hard of hearing people were elated that listening technology would be readily available in those environments where they most needed hearing assistance. Many individuals with hearing loss—those who use hearing aids and cochlear implants as well as people with lesser hearing losses who do not use amplification—note that assistive devices dramatically improve their speech understanding in large areas. One study¹ found that speech understanding scores for a group of adults with hearing loss increased an average of 25% using an assistive listening device. Other studies have also confirmed that speech understanding with an assistive listening devices is improved over listening with a public address system. Such systems have long been used in educational environments for young children with hearing loss but their mandated availability in public places was an important advance for people with hearing loss.

There were a number of practical problems that surfaced once the systems became widely available at various facilities because of the ADA requirements. First and foremost was the fact that although public facilities were required to provide listening devices, there were no requirements (or even discussion) regarding the way in which the systems should perform in the ADA Guidelines. In fact, there are wide variations in the quality of the signal received by users of assistive listening systems. These variations result from

a range of variables including the microphone location and characteristics, internal "noise" in the systems, and the way the devices interact with peripherals such as headphones or connecting cables. Additionally, simple operational procedures such as checks to determine if the batteries are charged or even ensuring that an employee turned the system on, were not always followed by facility operators. Consequently, the listening systems provided were of variable quality.

There are large deviations in the types of receivers offered. Many receivers being offered are designed to be used over the ears and work best for those who are not wearing personal amplification. Many hearing aid wearers found these to be uncomfortable and even unusable. There is a lack of standardization in the size of the jacks (used to connect with peripherals); hence, individuals utilizing their own neckloops or cables cannot use the devices without having the proper sized connectors. In many instances, receivers have no jacks at all making the systems unusable by people who need to "plug in" and connect to their personal hearing technology, such as cochlear implant users. Additionally, some systems did not provide sufficient volume boost for listeners with significant hearing loss. Discouraged by poor results or their inability to use the systems at all, patrons stopped trying and many facilities found that few people were asking for the systems. With few users, training and maintenance practices—never what they should have been—deteriorated further in many locations.

From the perspective of many facility operators, the systems that they were required to provide were a complete waste of time and money. Very large facilities pointed out that the number of receivers mandated was far in excess of what might ever be needed—even in locations where the systems were working well and being utilized. The original guidelines adopted in 1991 required that receivers be available for 4% of the seats in a facility. For a small movie theater with 100 seats, this is not an unreasonable number. Indeed in some areas of the country where patrons regularly use devices, there are times when the theaters run short and cannot give receivers to all that ask for them. (Broadway theaters offering live drama in New York City are one such example; there, reportedly, patrons with mild hearing losses enjoy the boost that allows them to hear every word—even when they

1. Bankoski, S.M. and Ross, M. FM Systems effect on speech discrimination in an auditorium. *Hearing Instruments*, 35(7), 8-12, 49. 1984.

are sitting in the worst seats in the house!) However, for a sports stadium with 10,000 seats, the 4% requirement translates into 400 receivers—a number that is so far beyond what might ever be used, that it was rightly determined to be an absurd requirement.

ADA Guideline Revisions to ALS

The Access Board initiated a process to review and revise the ADA Guidelines in 1994. That lengthy process, which included considerably more opportunity for detailed public comment and study than did the original published guidelines in 1991 (only one year after passage of the original legislation), included a number of changes intended to address and correct the problems noted above. The guidelines should be finalized by late 2003. Among the noteworthy expected changes are the inclusion of objective measures for how assistive listening systems in public places must operate as well as greater specificity as to how the receivers should be configured to best meet the diversity of needs. The proposed language for the new guidelines includes the following specifications, none of which were in the original ADA Guidelines.

Assistive Listening Systems²

Receiver Jacks. Receivers required for use with an assistive listening system shall include a 1/8 inch (3.5 mm) standard mono jack.

Sound Pressure Level. Assistive listening systems shall be capable of providing a sound pressure level of 110 dB minimum and 118 dB maximum with a dynamic range on the volume control of 50 dB.

Signal-to-Noise Ratio. The signal-to-noise ratio for internally generated noise in assistive listening systems shall be 18 dB minimum.

Another change in the revised guidelines was made in response to comments from large facilities that were required to stock hundreds of receivers in order to meet the 4% requirement. Instead of having one required percentage for all theaters (or "assembly areas") as was the case in the original guidelines, the proposed ADA Guidelines use a sliding scale that begins at 4% for spaces with 500 seats or less and declines to a 1% requirement for large facilities over 2,000 seats. Advocates are comfortable with this proposed modification and, in fact, they urged that the change be made so as not to force facilities that are diligent about accessibility to incur unnecessary expense or the inconvenience of storing equipment that will never be used.

Television Captioning

The evolution of captioning as a means of ensuring communication access has involved multiple laws, compromise, patience and especially persistence by coalitions of advocates, university researchers, nonprofit institutions, and private interests over a period of more than 30 years. Although we have not yet resolved all of the relevant issues in the United States, access via captioning has improved dramatically in the past 10 years that activities on this topic have been heightened. The lives of people with hearing

2. US Access Board, Draft Final Americans with Disabilities Act and Architectural Barriers Act Accessibility Guidelines, 2002.

loss and others who benefit from captioning, such as people for whom English is a second language, has improved immeasurably now that they have full access to television programming—a source of information and entertainment that has become an integral part of our society.

The first television program to be captioned in the U.S., *The French Chief*, was shown in 1972 and produced by America's Public Broadcasting Service, or PBS. PBS is a nonprofit television network that has led the way in accessibility for many forms of media—including television, abbreviated forms of captioning for children, videos and DVDs, and the Internet. Initially, PBS produced a limited number of TV programs with open captions. In 1975, the station applied to the Federal government to reserve a segment of the broadcast signal for closed captions, which would allow individuals who wanted to see the captioning to access it without requiring that all viewers see the captions. This paved the way for other television stations to voluntarily caption a limited number of programs and also for a retail chain to begin manufacturing and selling caption decoders—essentially a box that sits on top of the television. While the limited, voluntary approach certainly was not a satisfactory solution, it served to introduce the concept of television captioning and test the waters for further advances.

The next critical first step in the process of advancing television captioning was to ensure that the technology required to receive the captions was widely available, convenient and inexpensive. Advocates urged for passage of Federal legislation requiring that all television sets manufactured after a certain date include internal decoder circuitry. By mandating the decoder "chip" on a large scale, advocates argued that the cost to produce the hardware would be spread out over the millions of televisions sold annually. Advocates hoped that once everyone in America began purchasing televisions with built-in decoders, there would be an incentive for television networks to caption more of their programs. Their goal was for captioning to become a mainstream feature of American life. After the law was passed, the television manufacturing industry found that the cost per television was negligible (less than \$1) and not even enough to be reflected in the prices of new television sets.

At the time the Television Decoder Act of 1990 was being considered, manufacturers initially protested that they did not know, technically, how to satisfy the requirements of the law. Armed with technology experts of their own, advocates argued that it could be done and gave the industry a three-year running start—until July 1, 1993. After that time, any television set sold in the United States, regardless of where it was fabricated, was required to have internal decoder circuitry. The deadline was met and the widespread availability of captioning technology did help to increase the demand for captioning as well as the amount of captioned television programming.

Despite the substantial expansion in captioned programming, there were still significant gaps. Advocates were particularly discouraged that local networks in some communities failed to caption local news programming, or provided captioning episodically. Additionally, cable network programming was nearly nonexistent. Five years after the Decoder Circuitry Act became law, only 5 to 10 percent of all cable programming was closed captioned. The voluntary approach was not enough to ensure that people with hearing loss had substantially equivalent access to television programming.

Advocates organized themselves and collectively urged Congress, our national legislative body, to require TV networks to caption. The Telecommunications Act of 1996 included requirements for the provision of captioning of nearly all television programming. The Federal Communications Commission (FCC) was charged with developing a workable schedule for phasing in the requirements over time. United States law requires agencies such as the FCC to receive comments from the public when they develop new rules. After receiving lengthy comments from consumers, television networks, cable providers, and other interested parties, the FCC developed a set of rules and a schedule for television captioning, which balanced the interests of all of the parties. The schedule gave the industry eight years (beginning January 1, 1998) to provide 100% captioning of all new, non-exempt programming. A different schedule was created for re-runs and other older programming first shown on television before 1998—75% of that





programming would have to be captioned by 2008. Consumers were disappointed about the long timeframes allowed to come into compliance but they were willing to compromise on the schedule knowing that eventually, virtually all TV programming would be captioned.

In early 2003, the majority of new primetime programming on major networks was captioned. The biggest gaps are local news programming, and some daytime programming, particularly in smaller markets. Nonetheless, it is definitely the case that the United States is now further along with television captioning than any of us dreamed would be possible just a short time ago—because captioning was required by the law and our enforcement agency has made it clear that it expects compliance.

Captioning in Movie Theaters

The most popular home videos are now closed captioned allowing deaf and hard of hearing people to enjoy accessible films—as long as they watch them at home. Although there is no law requiring home videos to be captioned, producers have determined that it is in their financial interest to make their videos accessible to a greater proportion of the viewing public through captioning. Movies shown in theaters are generally not captioned, with the exception being the relatively few movie theaters that occasionally show open captioned films or those few theaters equipped with the Rear Window closed captioning technology³. Although the Americans with Disabilities Act requires that public places make their programs and services accessible to people with disabilities with “auxiliary aids,” the report language specifically stated that the Act encourages, but does not require open captioning.

At the time the ADA was passed in 1990, representatives of the movie theater industry exerted considerable pressure on federal legislators not to require open captioning of films in movie

3. Rear Window is a closed captioning technology developed by the WGBH Media Access Group in Boston, Massachusetts. In theaters that are equipped with this system, captions are displayed on a light-emitting diode (LED) text display mounted in the rear of a theater. Patrons wishing to see the captions, attach a transparent acrylic panel to their seat. The captions are invisible to other patrons in the theater. For more information, go to www.wgbh.org.

theaters. It was felt at that there would be a negative public response to open captions as being distracting. Although such perspectives have never been confirmed by a public opinion survey, the explicit reference to open captioning in the report accompanying the Act as well as the absence of specific language mandating open captioning in the ADA itself has allowed this lack of access to continue. In addition, the ADA states that accommodations must be provided unless the facility can demonstrate that “taking those steps would fundamentally alter the nature of the goods, services... being offered or would result in an undue burden.” Movie theaters have argued that providing open captions would “fundamentally alter” the nature of movies, and so it is not required under that Act.

Little access is currently offered to films for people with significant hearing loss who do not benefit from assistive listening systems (which are required). Consumers note that on the July 4th holiday weekend in 2002, out of a total of more than 36,000 movie screens in the United States (many theater facilities have up to six or eight screens), there were never more than 24 screens all across the country voluntarily showing captioned prints on Thursday, Friday or Saturday evening.⁴

For some years now, advocates for deaf and hard of hearing people have urged movie theater owners to improve communication access to films. They argue that although the ADA exempted theaters from showing open captioned films, legislators did encourage special captioned showings. A coalition of consumer organizations, the Coalition for Movie Captioning, urges that the number of open captioned showings be dramatically increased. However, given the fact that there is no legal mechanism to support their argument, these efforts to increase captioning voluntarily have done little beyond raising industry awareness of consumer concerns.

4. Cheryl Heppner, Coalition for Movie Captioning: Status of Captioned Movies in Theaters, *Hearing Loss: The Journal of Self Help for Hard of Hearing People*, March/April 2003.



In a class action lawsuit, filed in late 2002 in Washington, DC District Court, consumers argued that although the ADA may not require open captioning of films, given that closed captioning technology is now available—technology that was not in existence at the time the ADA was passed in 1990—theaters should utilize such technology to meet the requirement that effective communication be provided for individuals with disabilities who need it. An effort by industry to dismiss the case failed. In allowing the case to go forward, the judge found that closed captioning would neither be an undue (financial) burden nor would it change the nature of the offerings.⁵ The plaintiffs in the case, three deaf individuals, point to the commercial availability of the Rear Window closed captioning system as being a viable way to provide communication access at movie theaters without changing goods for other customers attending the movie showing.

Though private interests may not particularly like this message, it is clear that, at least in America *voluntary* approaches for achieving access for people with disabilities have generally not been successful. In the case of captioning, we have achieved important successes in making television programming widely accessible because of two laws: one that supported the provision of the captioning circuitry in television sets and a second that required television networks to caption their programming. The financial cost of these laws to society has been minimal while the benefits to people with hearing loss and others have been dramatic. Without a legal mechanism to support them, advocates' long-standing efforts to achieve captioning in movie theaters have been largely ineffective. The (2003) pending lawsuit to consider the closed captioning technology now commercially available as an ADA accommodation is being watched closely by consumers and industry interests.

5. US District Court for the District of Columbia. Memorandum Opinion in Kevin Ball, et al. Plaintiffs v. AMC Entertainment, Inc. et al. Defendants, Civil Action No. 00-867, February 24, 2003.

Digital Wireless Telephones and Hearing Technology

Soon after the first digital wireless telephones were introduced into the United States in 1994, consumer organizations realized that this new technology could cause interference when placed in close proximity to hearing aids and cochlear implants. Organizations representing people with hearing loss called for an immediate halt to the rollout in the U.S. until changes could be made in the hand-sets or to the emerging wireless networks. Advocates knew that these new telecommunications, with their diversity of features and potential for improved service at lower cost, were the wave of the future and they did not want to be excluded from using them.

The identified interference problems were not unique to the United States. Digital phone technology was available in Europe, parts of Asia, and Australia well before it was offered in America. The reported experiences of hearing aid wearers in those regions where digital wireless phones were already being used was not promising. American consumers had heard anecdotal accounts about interference problems—including what we called bystander interference that occurred when a hearing aid user was in close proximity to someone using a wireless phone—but they never dreamed that Federal regulatory agencies would allow this new technology into the United States without first testing its compatibility with hearing aids. They were wrong.

The problem was that although the United States had an existing law that mandated the compatibility of wireline telephones with hearing aids, the law contained an exemption for wireless technology. Fortunately, the law—the Hearing Aid Compatibility Act of 1988—did allow the FCC to review that exemption, and eliminate it under certain circumstances.

Led by Self Help for Hard of Hearing People, a national organization of people with hearing loss in the United States, consumers organized a broad-based coalition that included the major organizations representing adults and parents of children who were deaf and hard of hearing, hearing health care professionals (i.e., audiologists and physicians), university researchers, and hearing aid manufacturers. The coalition filed a petition with the FCC, which asked the agency to lift the exemption to ensure full wireless access for all Americans.



Coalition members also met with Federal officials to request assistance, but quickly learned that the Federal government was unwilling to stop the rollout of wireless devices. At the time, the FCC was auctioning licenses for wireless services, which was bringing hundreds of millions of dollars to the government. In addition, the wireless industry complained that it had invested billions of dollars into the rapid deployment of digital wireless technologies, and wanted to move ahead with that deployment. Instead, consumer groups were encouraged to work collaboratively with the wireless industry to develop a consensus on how to resolve the problems.

The cooperative efforts continued for several years with no legal mechanism in place to require specific compliance efforts by industry. The discussions, meetings, and rounds of summits were extraordinarily time-consuming, sometimes contentious, and generally ineffective. Initially, wireless companies denied the existence of a compatibility problem with their phones. They also claimed that analog wireless services provided a viable alternative to digital technologies for consumers with hearing disabilities. But from experiences in other countries, American consumers knew that analog technologies were on their way out and digital technologies were the future.

Consumers were frustrated by what they perceived as the wireless industry's lack of understanding of the underlying premise of disability rights in America—that is, that people with disabilities should be able to enjoy the same opportunities in life as everyone else and that government and private interests have the responsibility to ensure that their products and services are accessible to people with disabilities, if it is reasonably possible to do so. Viewed from their perspective, the wireless industry had never been asked to deal with issues like this before and they were confused by the demands for changes that were being placed on them by consumer groups.

Although the voluntary activities did serve to educate telecommunications companies about the needs of people with hearing loss, the solutions offered by wireless manufacturers and providers of services (such as neckloops that allowed inductive

coupling with hearing aids equipped with telecoils) were considered by consumers to be inconvenient, short-term at best, and totally unworkable for many people.

One important positive change that resulted from the discussions was the redesign of hearing aids and cochlear implants to include shielding that serves to protect wearers from all forms of electromagnetic interference—from wireless phones and other technologies. Although the shielding in hearing technology reduced the amount of interference for some individuals, particularly when using certain wireless technologies like CDMA, it became increasingly clear that shielding in hearing devices would not in itself provide a solution to the interference problem without companion changes in the wireless phones.⁶

While these discussions were underway, new legislation was passed that included a provision that directly applied to the wireless dilemma. The Telecommunications Act of 1996 included a provision (Section 255) that required manufacturers to design, develop and fabricate telecommunications equipment in a manner that allows people with disabilities to access and use them, if readily achievable to do so. Consumers were hopeful that this new legislation would provide the legal basis—even without lifting the wireless hearing aid compatibility exemption in the other law—that was needed to effectively address the digital wireless problem.

Although Section 255 of the Telecommunications Act has been in place for six years, there has still been relatively little progress made in addressing the two major wireless compatibility concerns: interference between the phone and the hearing technology and providing internal telecoil linkage for hearing aid and cochlear implant users. Several manufacturers did develop accessible phones—particularly in the CDMA format—demonstrating that it is possible to provide services for people with hearing aids and cochlear implants. Nonetheless, the majority of digital

6. Primarily, there are three types of wireless technologies—CDMA (code division multiple access), GSM (global system for mobile communications), and TDMA (time division multiple access). Of these three, CDMA appears to provide the least amount of interference to hearing aid and cochlear implant users while GSM appears to create the most. Many nations are moving towards adopting GSM as the dominant form of wireless technology, raising major accessibility issues for people with hearing loss.



manufacturers have not altered their equipment to the degree that a majority of hearing technology wearers can use wireless phones without experiencing an unacceptable amount of interference.

One of the reasons for this is that Section 255 provides a “readily achievable” safety valve, which has allowed companies to argue that they need not provide compatibility because doing so would “impose significant difficulty or expense.” In addition, compliance with Section 255 has been off to a slow start and the FCC’s enforcement of the law has not been as strong as it needs to be. The government never really put pressure on the industry to provide access to these phones. Further, Section 255 does not allow consumers to bring cases under the law in Federal court; rather, consumers must file complaints with the FCC. While consumers may file complaints informally, a process that is fairly easy, the FCC has done little to resolve the informal complaints that have been brought so far. The more formal FCC complaint process is more promising but it is costly and time consuming, and without the ability to collect attorneys’ fees, it is hard for consumers to find lawyers to represent them. For all of these reasons, the law has not had the impact that many advocates and others had hoped for in terms of encouraging significant changes in telephone design.

In 1999, consumers in Australia tried to resolve the hearing aid compatibility issue in a different way. When your analog network was replaced completely with GSM, consumers filed a complaint under the Australian Disability Discrimination Act with the Australian Human Rights and Equal Opportunity Commission (HREOC). The complaint alleged that hearing aid users had purchased GSM mobile phone services without having been told by service providers that these services were not likely to be compatible with their hearing aids. In response to the complaint, the HREOC directed the consumers and industry to negotiate a means by which individual consumers who had purchased non-compatible GSM phones, could obtain accessible wireless services on a case-by-case basis. Fortunately, around the time that the complaint was filed, CDMA was introduced in Australia. Soon afterward, it was discovered that a certain type of CDMA phone – a “clamshell” phone – would work satisfactorily with the hearing aids of most hard of hearing people in Australia. The negotiations between the industry and consumers resulted in allowing consumers to choose

between switching to CDMA services or obtaining external accessories that would eliminate interference with their hearing aids at low or no cost. While this provided a temporary solution, the final HREOC report on the discrimination case actually points to the accessibility policy in the U.S. as ultimately providing a long-term, global solution to the problem of wireless incompatibility.

Back here in America, in the late 1990s, consumers got tired of waiting for the industry to resolve the compatibility problem. They asked the FCC to re-open a 1995 petition to remove the exemption for wireless under the Hearing Aid Compatibility Act; this law does not use the “readily achievable” language of Section 255 that seemed to be allowing companies to avoid making their products accessible. With analog phones due to be phased out in America within 5 years, consumers are anxious for the government to take a stronger stance. A decision is expected within the coming year.

Lessons Learned

Looking back at what we have accomplished as well as all our efforts that did not result in the outcomes that we had hoped for, there are some key lessons to be learned from the work of disability advocates over the past decade or more. First, consumer advocacy works and it is the only thing that does work. Consumer advocacy requires a focused program of activities, often over a sustained period of time. I can think of no issue in this field—including the topics that I’ve discussed here—that were resolved quickly and easily. It helps to have leaders who are passionate and articulate about the issues so that they can effectively “marshal the troops” and also effectively communicate the needs to private and governmental interests. Effective consumer advocacy always involves coalitions of people with overlapping interests. In America, we routinely join together not only with other organizations representing people with the same disability, we also reach out to others in the disability community to support our efforts.

Secondly, private companies can generally be predicted to oppose change and any action or requirement that will cost them money or slow them down. Expect this and don’t be discouraged by the negative response that you likely will receive when you ask for a major accessibility concession. At the same time, the private sector must be educated and convinced of the need. They must be



involved in any effort to achieve access. Consumers will be more effective if they learn the language of business and aim to work cooperatively with private companies. Although we always emphasize that consumers with disabilities are paying customers and making services accessible to them will generate revenue, this argument has generally not been sufficient to convince private companies to undertake major accessibility changes. Hence, we have generally gone back to the civil rights arguments that are the basis of the ADA and our disability laws. Those arguments emphasize that people with disabilities have a right to be able to access the same opportunities in life as everyone else and businesses have a responsibility to ensure that their products and services are accessible, unless it is truly burdensome to do so.

Remember that businesses are comprised of people, and people sometimes make decisions on a personal level. Everyone knows someone with a disability—whether that is a parent, a sibling, a friend or a co-worker. When people with disabilities tell their own stories, the issues become more compelling.

One last aspect of the private sector discussion should be highlighted here. We have found that voluntary approaches to access generally do not provide the desired results. In each of the examples I gave, it took legislation for business to implement the changes needed for deaf and hard of hearing people to have equivalent access to services.

Thirdly, recognize that while advocates should aim to operate in an effective and efficient manner, it does take time for people to grasp the concepts of disability rights and all such efforts seem to take longer than we think they will. Further, agencies have more to take care of than your issue and although it seems to you like it is the most important topic of the day, not everyone will necessarily agree. Stay focused on your objective, be polite, and stay positive about the eventual outcome. Set schedules and keep calling and writing. As a citizen, remember that you have every right to ask the government to address your concerns. Knowing that it may take time must not frustrate your efforts.

Fourth, if you have the opportunity to effect a major change that provides important accessibility options, even if you have to make concessions in completion time, jump on that opportunity.

The television captioning rules are a good example of this. Those of us involved in the television captioning discussions did not expect to have nearly 100% of television programming captioned. When the opportunity to gain this major concession presented itself, albeit at a time that was much longer into the future than any of us anticipated, we all agreed that it was worth the wait. Sometimes, we work for change that will most benefit those who come behind us. Knowing that our children will benefit more than we have from our efforts is a powerful incentive to keep advocating for change.

Finally, accept the fact that you probably won't get it exactly right the first time. It is impossible to anticipate everything. Further, technology advances and provides greater opportunities. Wherever possible, build reviews at a future time into the process, reviews that will allow you to go back and assess what is working, what is not, and to make needed changes in the system.

The accomplishments that I discussed here were possible because of the new model we have adopted for disability—a model in which people are open about their disabilities and about their needs, rather than attempting to hide them. We have not totally eliminated the embarrassment that many feel about having a disability. And certainly hearing loss, because of its very nature as “the invisible disability” is frequently the disability that people are likely to want to hide. To the extent that all of us who are deaf and hard of hearing are open about what we need to be fully included, we will positively change our own lives.

I would like to conclude with one final note on the topic of this new model of disability. Several years after the dedication of the memorial to President Franklin Delano Roosevelt in Washington, DC—which I talked about at the beginning of this lecture—disability advocates successfully argued that an additional statue be added to the memorial. This statue shows FDR in his wheelchair. Although his disability was never revealed to the public during his lifetime, disability advocates believe that if he were alive today, Roosevelt would have wanted the world to know that a powerful and charismatic leader of the United States of America was a person with a disability.

Major U.S. Laws Impacting Accessibility for People with Hearing Loss

Americans with Disabilities Act (1990)

Title I was intended to ensure that people with disabilities have the same opportunities to employment as people without disabilities and that employers (with 15 employees or more) be required to provide reasonable accommodations to the person with a disability to allow them to perform their job. The law does not ensure jobs but rather prohibits discrimination in employment for people who are qualified to carry out the "essential" functions for a specific job.

Title II requires that state and local government agencies, including transportation programs, make their programs accessible to people with disabilities. Effective communication for deaf and hard of hearing people must be ensured and auxiliary aids must be provided. Such aids include but are not limited to assistive listening systems, qualified interpreters, captioning, provision of TTYs and amplified telephones, text displays, and transcriptions of audio programs.

Title III requires that public places (operated by private entities) including private businesses, professional offices, and nonprofit organizations provide communications access. The list of affected entities is extensive and includes, for example, hotels, restaurants, movie theaters, stadiums, concert halls, retail stores of all types, transportation terminals, museums, libraries, senior centers, sports facilities, and swimming pools. Required accommodations include all of the aids listed above under Title II as well as television decoders and visual alerting devices (in hotel rooms). The ADA Accessibility Guidelines, first developed by the Access Board in 1991, provided specific requirements for certain accommodations to be provided in new construction and renovation of existing structures (i.e., assistive listening devices in theaters and other facilities, visual alerting devices in hotel rooms, TTY and accessible pay phones in public places).

Title IV required that all telephone companies provide relay services throughout the United States after July 26, 1993. Such services must be provided 24 hours per day/7 days per week. Individuals may not be charged for such services and there are no restrictions on the length or nature of the calls.

Hearing Aid Compatibility Act (1988)

Required that all telephones manufactured after August 16, 1989, be compatible for use with the telecoil in hearing aids. The definition of compatible was changed and expanded in later years to include a requirement for volume control.

Individuals with Disabilities Education Act (1975, amended 1990 and 1997)

Requires that children with disabilities be provided with a free and appropriate public education that includes special education and related services to meet the "unique" needs of children. Safeguards were built into the act to allow parents to pursue remedies if their local schools do not meet their child's needs. States and local governments are required to provide education for children through grade 12 in the United States and the law applies to public (not private) educational institutions.

Television Decoder Circuitry Act (1990)

Required all television sets with screens 13 inches or larger, manufactured or imported into the United States after July 1, 1993, to be capable of displaying closed captioned television transmissions.

Rehabilitation Act of 1973 (1973, amended 1978)

Requires that programs receiving Federal funds can be used by people with disabilities, thus the Federal government cannot operate in a discriminatory manner. Any grant, loan or contract to an entity or program—public or private—requires that entity to follow the regulations of the act.



Telecommunications Act of 1996 (1996)

Required television programming including broadcast, cable and satellite to follow a specific schedule (over a period of eight years and beginning in 1998) for providing captioning. Although there are specific exemptions (i.e., programming shown between 2 am and 6 am local time, programming in languages other than English and Spanish), by the year 2006 all new non-exempt programming must be captioned.

Required telecommunication products and services to be accessible to and usable by people with disabilities, if readily achievable to do so. A major focus of concern for deaf and hard of hearing people after passage of this act was digital wireless telephone services, which often interfere with hearing technology and are not compatible with text telephones (TTYs).

Acknowledgments

I am grateful to Karen Peltz-Strauss for her thoughtful review of, and contributions to, the content of this lecture. An attorney by training, Karen has spent the last twenty years advocating for telecommunications access for people who are deaf and hard of hearing. Her work directly impacted our greatest successes in America and it has been a privilege to learn from her over the years. Thanks and recognition are also due to the members and staff of the U.S. Access Board, with whom I served as a board member from 1994 to 2002, for all I learned from them about advocacy, compromise, and staying the course. I would also like to thank my son Colin Barry, who lent his keen journalist's eye to this effort.





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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".



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

The representational base of the Deafness Forum is divided into five Sections:

- a) Hearing Impaired Section – persons with a hearing loss who communicate predominantly orally,
- b) Deaf Section – i.e. the Deaf Community – those persons who consider themselves to be members of that community by virtue of its language (sign language known as Auslan) and culture,
- c) Ear Disorders Section – persons with a chronic ear disorder (such as Tinnitus, Meniere's Disease or Acoustic Neuroma) and
- d) Parents section – parents or legal guardians of persons who are Deaf or hearing impaired,
- e) Service Providers section – service providers to the Deaf and/or hearing impaired communities.

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

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. Please see enclosed donation form for full details.

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

Deafness Forum of Australia

218 Northbourne Avenue

Braddon ACT 2612

Tel: 02 6262 7808

TTY: 02 6262 7809

Fax: 02 6262 7810

E-mail: info@deafnessforum.org.au

Web: www.deafnessforum.org.au

Notes



Notes



"I look back over these years since

*I became hearing impaired and realise
that any efforts that I have made have
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*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
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