

The 2015

Libby Harricks

Memorial Oration



Libby Harricks Memorial Oration number 17

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

Elisabeth Ann Harricks AM 1945 – 1998



deafness forum of australia

The 2015 Libby Harricks Memorial Oration
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Towards a new Model for the Deaf Infusion of Leadership in
Early Hearing Detection and Intervention Services
Christine Yoshinaga-Itano
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Contents



Introduction	4
Towards a new Model for the Deaf Infusion of Leadership in Early Hearing Detection and Intervention Services	7
Deaf/Hard of Hearing Infusion in an existing EHDI system	9
Deaf/Hard of Hearing Role Models	11
Deaf Child Bill of Rights	14
Communication Plan	15
Deaf Mentors	15
Deaf Role Models	16
Cultural and Linguistic Brokers	17
Benchmarks	21
Medical Professionals	21
Deaf Parents as Mentors	22
References	24
Appendix	29
About Deafness Forum of Australia	30
Libby's Story	31
Libby Harricks Memorial Oration Series	33
The Libby Harricks Memorial Oration	35

Introduction to the 17th Libby Harricks Memorial Oration

Christopher Lind PhD, Chairperson, Libby Harricks Memorial Oration Committee



Welcome everyone to the 2015 Libby Harricks Memorial Oration held in conjunction with 8th Australasian Newborn Hearing Screening Conference here in Sydney. It is with great pride that I take this opportunity to open this session and welcome you all and our orator to this, the 17th in the series of Libby Harricks Memorial Orations.

There are several matters that precede our guest's presentation. I should note that this is the first time that I have had the privilege to introduce the oration as the new Chair of the Libby Harricks Memorial Oration committee. I wish to thank the Deafness Forum for the invitation to take on this role. I recognise that it is no mean task to follow on from the excellent work that Dr Jenny Rosen has undertaken as the Chair of the committee. Jenny was a close friend of Libby, and has been on the committee since its beginnings in 1999, taking over the chair in 2004. I thank Jenny for her efforts in maintaining this oration as one of the premier invited public presentations on hearing, hearing loss and related matters in Australia.

I would also like to acknowledge and thank the committee of the 8th Australasian Newborn Hearing Screening Conference, and in particular Professor Greg Leigh for the support in hosting this oration. The generosity of Greg's committee in their financial and organisational support for our Orator's visit to Australia and attendance at this conference is greatly appreciated. I also acknowledge and thank Cochlear Limited for their continuing support for the Libby Harricks Memorial Oration.

I now wish to speak briefly about the person who has been the inspiration for this series of orations, Libby Harricks. As some may know, Libby Harricks grew up with apparently normal hearing. Subsequently, as a young wife and mother, she developed a profound hearing loss. She not only educated herself with skills to manage her own hearing difficulties but soon became committed to advocating for all hearing impaired people. She was a founding



member and long-term President of Self Help for Hard of Hearing People, (SHHH Australia Inc.) and amongst many other challenges was the inaugural Chairperson of Deafness Forum of Australia. In all of these purely voluntary roles, she worked tirelessly to raise awareness of the need for equal inclusion in life activities for hearing impaired people, even travelling widely throughout Australia to lobby for this on their behalf. In recognition of her advocacy work, Libby was made a Member of the Order of Australia in 1990.

After her death in 1998, Deafness Forum of Australia, the national co-ordinating body for Deaf and hearing impaired issues, established the annual Libby Harricks Memorial Oration Series to honour her achievements. The Series aims to continue her vision of working towards gaining appropriate recognition, awareness, and access, for hearing impaired people. Over the years, orations have been presented across Australia, and the Oration Series has developed a well-deserved reputation for carrying forward Libby's commitment to raising awareness of issues relating to hearing impairment. The reputation of the Oration Series is undoubtedly due to the great contributions of our outstanding Orators who have presented on a wide range of relevant topics.

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. We are very gratified that it has been possible to provide the opportunity for audiences across Australia to hear the Orators, and to enable continuing availability of this valuable body of information via the on-going Monograph series. It is important to acknowledge the support of the Libby Harricks Memorial Oration Committee and the Deafness Forum's board of directors, and the sponsors and supporters for this event each year.

It is now my great pleasure to introduce to you all our 17th Libby Harricks Memorial Orator, Professor Christie Yoshinaga-Itano. Dr Yoshinaga-Itano is Professor Emeritus and Research Professor in the Department of Speech, Language and Hearing Sciences at the University of Colorado, in Boulder in the USA. Christie is both a Teacher of the Deaf and Hard of Hearing and an Audiologist and has been for many years internationally recognised and renowned for her work in Universal Neonatal

Hearing Screening. She was one of the pioneers of this work not only from an audiological assessment perspective but also from a systems view whereby districts, states and ultimately countries were able to plan for truly universal hearing screening for neonates. Christie's research work on the outcomes of early detection has had a tremendous influence on the uptake of screening services and their follow-up for newly diagnosed children. As a direct result of her work there are successful and sustainable programs in hearing screening in countries across the globe and we are both privileged and delighted that she took up our invitation to be the Libby Harricks Memorial orator for 2015.

I am sure you will find Christie's presentation both aspirational and inspirational as it articulates a vision of the ways in which deaf and hard of hearing professionals may provide support, guidance and leadership in the delivery of services to families of children newly diagnosed with hearing loss.

I would like you all to note that free copies of Christie's presentation in monograph form will be available as you leave this session this afternoon. A full list of previous orators and their oration titles is included in the monograph. Electronic copies of all monographs in the series can be accessed at the Events section of the Deafness Forum website (www.deafnessforum.org.au).

For her presentation entitled "Towards a new model for the deaf infusion of leadership in early hearing detection and intervention services" it is with great pleasure that I welcome Professor Christie Yoshinaga-Itano.

TOWARDS A NEW MODEL FOR THE DEAF INFUSION OF LEADERSHIP IN EARLY HEARING DETECTION AND INTERVENTION SERVICES

Christine Yoshinaga-Itano PhD

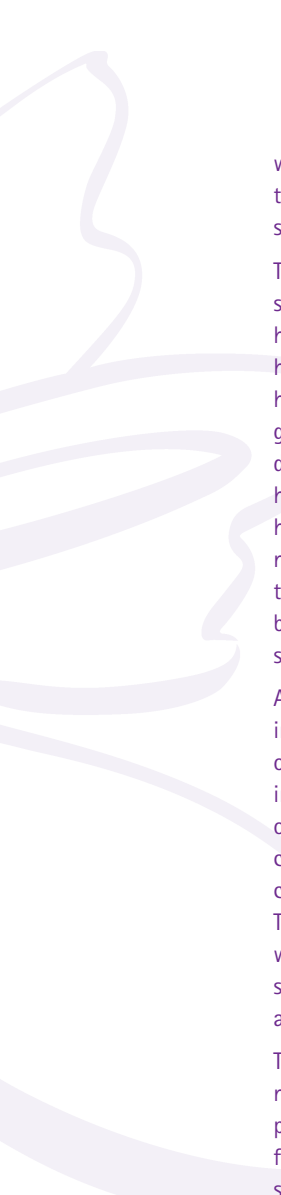


I am deeply honored to deliver the Libby Harricks Memorial Oration at the 8th Biennial Conference of the Australasian Newborn Hearing Screening Committee in Sydney, Australia. I chose this topic in honor of her advocacy and for her recognition as a Member of the Order of Australia. In this presentation, I will explore the role of individuals with deafness and hearing loss in supporting parents and young children who are identified through universal newborn hearing screening programs.

Universal newborn hearing screening programs have been initiated all over the world in order to provide children who are deaf or hard of hearing an opportunity to develop skills commensurate with their cognitive potential and able to compete with chronologically or cognitively matched peers who have normal hearing. This article will explore what the world would look like, if we truly succeed in accomplishing this goal.

Imagine a world, where a family with a newly diagnosed child with hearing loss, is provided services by a pediatrician who is him/herself deaf. Today, we have some examples of individuals with this level of education, but, if we are successful, these numbers will increase. Perhaps the Ear, Nose and Throat physician is also deaf or hard of hearing and the audiologist who diagnoses the hearing loss is deaf or hard of hearing. The parents are contacted by an early interventionist who is deaf or hard of hearing. The psychologist, social-worker, or counsellor who assesses the family's child or who assists them through their adaptation to the diagnosis is deaf or hard of hearing. Some of these individuals communicate exclusively through spoken language. Others switch from spoken language to sign language depending upon the conversational partner. Others communicate exclusively through sign language.

In this imagined world, parents would navigate through the health and educational systems being provided services by individuals who are themselves deaf or hard of hearing, as well as professionals



who are hearing. They are interacting with these individuals, not because they are deaf or hard of hearing, but because they have a significant service and expertise to provide the family.

Thus, we arrive at a concept of infusion into the fabric of the entire system. Many parents who have newborns diagnosed with hearing loss have never met or interacted with an individual who is deaf or hard of hearing. They may have only stereotypes of what it means to be deaf or hard of hearing. Their adaptation to the diagnosis which often involves grief and mourning, is influenced by their previous experience with deafness and hearing loss. If parents' initial interactions with the newborn hearing system happens to be with individuals who are deaf or hard of hearing, there to provide them with professional expertise, they will focus not on the deafness/hearing loss, but on the person who is supporting them. Knowledge about what a child who is deaf or hard of hearing could become and the things s/he could accomplish, can dramatically alter the sequence of the process of grieving.

As children who have benefited from early hearing detection and intervention (EHDI) systems grow up, there are an increasing number of them who are choosing to participate in the system as professionals in a variety of capacities. There are, for example, increasing numbers of children who are deaf or hard of hearing, users of hearing aids and cochlear implants, who have chosen to become audiologists. Some have chosen to become early intervention providers or teachers of the deaf. There is a growing number of individuals who are deaf or hard of hearing who have become allied health professionals, physicians, psychologists, social workers, teachers, pharmacists, dentists, occupational therapists, and speech/language therapists.

The journey for families typically starts at the referral from the universal newborn hearing screening (UNHS) in the hospital to either an out-patient re-screen or a diagnostic audiological evaluation. The anxiety of families arises when they are told that the child did not pass the hearing screening and increases at each level of the system and with the time that elapses until the family receives more information. For the family who is greeted by an audiologist who is a hearing aid, or a cochlear implant user or has chosen a visual communication without the use of amplification, the family begins, often for the first time, to establish an idea of what it means to grow up deaf or hard of hearing.



Deaf/Hard of Hearing Infusion in an existing EHHI system

In one metropolitan hospital system, two of the audiologists have congenital hearing loss. Families whose infants are tested by one of these audiologists would have the confirmation that the child is deaf or hard of hearing delivered by a professional who is deaf or hard of hearing. Immediately after the diagnosis from any audiologist at this hospital, the parents go to an office at the same hospital, where they are introduced to a professional who is profoundly deaf and who has cochlear implants but who used hearing aids for most of her life. She has worked as an early intervention professional for families who have infants and toddlers who are deaf or hard of hearing for over 25 years. This experienced professional provides counselling services immediately after the diagnosis of hearing loss to a significant proportion of families with newborns identified after UNHS in the state of Colorado, because she works in a pediatric hospital that is a center for excellence for pediatric patients with hearing loss.

Such interactions create a new "normal" for parents of newly-identified infants/children who are deaf or hard of hearing. Their perspective about deafness and hearing loss is now impacted by an individual who provides them support and professional services, knows what it is like to grow up as a deaf/hard of hearing individual and what it is like to live and work as an adult who is deaf.

If the family lives in the largest metropolitan city in this state, the first contact in early intervention is an educator of the deaf who specializes in early childhood deafness. She has a Master's degree in deaf education and also in Spanish. She grew up with a bilateral severe-to-profound hearing loss and received a cochlear implant as an adult. She is fluent in sign language, spoken English and spoken Spanish. She has extensive experience working with families with newly identified children who are deaf or hard of hearing. She is a Colorado Hearing Coordinator who is designated as the first contact for families in the most highly populated metropolitan area in the state.

This Colorado Hearing Coordinator provides families with the many options that are available for their family, including early intervention services focusing on language, cognition and social-emotional development and if the family chooses, sign language instruction in the home from an instructor who is deaf or hard of hearing and a native and/or fluent signer. These services can be provided weekly in the home, in addition to other intervention services and the family may include other members of the family or care providers. Though the families may not initially know,

the sign language instructor could be bilingually fluent in both spoken English and American Sign Language. The sign language instructors have found that the most effective instruction for families is through the visual modality only and it is often not until the deaf/hard of hearing instructors have established strong relationships with the family, that the family learns that this individual is also a fluent spoken English user. Families seem to have higher motivation to communicate visually, when they are not aware that they can switch to an auditory spoken language mode.

A parent of an early-identified child in the state of Colorado provided this quote: *"When we first received our son's diagnosis, I looked at the doctor, he was hearing. I looked at the audiologist, she was hearing. I looked at the nurse, she was hearing; and as we walked out, I looked back at the receptionist and she was hearing. I had no idea what this (raising a deaf or hard of hearing child) was going to look like until you (the deaf adult) walked in the door."*

In the weeks that follow, this professional provides parents with counseling support, intervention strategies, and educational information to respond to the families' many questions about deafness and hearing loss. A family's adaptation to the diagnosis is dependent upon the speed of skilled professional support and the information provided to them for the questions that the family has. It is therefore critical that the first contact be one of the most experienced individuals in early childhood deafness and hearing loss.

In all of the scenarios described above, the professionals who are deaf or hard of hearing, have professional training and experience in the professional service that they are providing to the family. In some cases, unless the professional identifies her/himself as a person who is deaf or hard of hearing, the family may not be aware or may not immediately realize that the professional is an individual who is deaf or hard of hearing.

While it is unlikely that any one family would see all of these professionals who are deaf or hard of hearing, the odds that they will encounter at least one of these professionals is quite high. On average, the families in Colorado will have interacted meaningfully with multiple and diverse professionals who are deaf or hard of hearing in the first few years of life.

In addition to these professionals, the Colorado Hearing Coordinator will offer the family a sign language instructor who is deaf or hard of hearing with fluent and/or native sign language ability. The family has



the opportunity to select an early intervention program and provider who will provide intervention services in the family's home. This trained early intervention professional could also be deaf or hard of hearing, although the vast majority of the early intervention providers are professionals with normal hearing.

In each of these situations, the family has an opportunity to ask these professionals questions about their personal stories and what it was like to grow up deaf or hard of hearing. Just as would occur with a hearing child, the family and child are exposed to a vast variety of diverse individuals, thus, providing a perspective early in the child's life that there is a world of opportunities available, things they can anticipate as their child grows up, as well as challenges that families and children face.

Deaf/Hard of Hearing Role Models

In some systems, individuals are trained as role models. This program is called Deaf Connections in the state of Colorado and is also available to families of children with hearing loss. The individuals were specifically trained to provide information about growing up and living in a hearing society. Some of these individuals have unilateral hearing losses, some are from families who are generational members of Deaf culture, some have cochlear implants, some are Deaf Plus with additional disabilities, while some are hearing aid users. The Deaf Connections program offers families and schools an opportunity to have a Deaf/Hard of Hearing Role Model visit them in their home or at the child's school. As deaf and hard of hearing individuals have become more infused into the system of health and educational services, families have requested this service less frequently because they have many social and professional interactions with deaf and hard of hearing individuals. However, the Deaf Connections program was an important step in establishing Deaf Infusion throughout the system.

The (role model) visit, for example, gave the family the opportunity to see that a deaf or hard of hearing person could be successful and could have different jobs/careers. Deaf Role Models have indicated that they felt that they were able to provide the family with resources that the family was not aware of, as well as giving family encouragement and understanding.

Parents often ask basic questions: *What's wrong with my child?*, *What will my child be like later?*, *What can be done to help my child?* (Bagnato, Neisworth, & Munson, 1997). Deaf and hard of hearing individuals with training are especially skilled at being able to respond to these families.

Questions reported by Hands & Voices organization indicate that some common questions that parents ask Deaf/Hard of Hearing Role Models are: 1) *I saw on the internet that deaf adults have a low reading level – is that true?* 2) *What will my child's speech be like?* 3) *You have good speech – how can I make sure my baby does?* 4) *Do you wear hearing aids? Why or why not?* 5) *Will you get an implant? Why or why not?* 6) *Should I stop playing my guitar?* 7) *Kids are cruel.... How can I make sure that my child won't be teased?* 8) *You have good self esteem – how do I develop that in my child?* 9) *When will I stop crying?* 10) *What about school... can my child go school with his sister? Or does he need a special school? Did you go to public school?* They often ask personal questions such as: 1) *Do you have kids? A spouse? Hearing or deaf?* 2) *What about sports?* 3) *Can you talk on the phone?* 4) *Can you drive?* 5) *How do you hear in the dark?* Parents appreciate a personal perspective from a D/deaf/hard of hearing role model. It increases the families' openness to examine issues in greater detail. Families report that interactions with D/deaf/hard of hearing individuals calm anxiety.

Parents often believe initially that they have lost a modality forever. Most parents of newly identified children do not realize how meeting a deaf or hard of hearing adult will help them until after they have had the opportunity. Systems must create opportunities for parents to meet deaf and hard of hearing adults through presentations, workshops, home visits, and social events. Deaf and hearing families interacting together in everyday social environments, such as birthday parties, family get-togethers, attending sports events (baseball, basketball, football) games, theater, and dances, should be a normal expectation of life for our children of the present and future. Parents who see D/deaf and hard of hearing adults as valuable members of their team, begin to understand the potential in their child. Often the D/deaf/hard of hearing adult is able to articulate what the child cannot yet. They lend ability and creditability for the child's upcoming/future needs. They assist the parents as they discover the potential and strengths of their child. They can give hope and encouragement through the inevitable ups and downs of those early years and they can assist the family in finding new ways of communicating and thinking and living with deafness and hearing loss becomes the new normal for families. Families have probably never thought about; 1) *driving with an inside car light on for visual cues*, 2) *looping the car, using FM assistive technology*, 3) *saying goodnight with the light on*, 4) *going upstairs facing the child and not speaking while climbing stairs without*

facing the child, 5) watching for opportunities to close the gap (incidental learning), 6) pointing out opportunities to cue the child to awareness of sound, or 7) using a vibrating alarm clock.



The deaf or hard of hearing child lives in a hearing world (family, church, neighbors). Meeting the deaf adult soon after diagnosis provides the family with an early opportunity to ask some of their questions and see these communication strategies modeled. The involvement of adults who are Deaf and Hard of Hearing should not be as token members, but leaders and trendsetters in our systems of care. Individuals who are D/deaf or hard of hearing can help families overcome family barriers to open, honest communication. They can provide families with examples of a sense of humor. They themselves provide an exceptional model for great inter-personal skills. Hearing professionals can benefit by inviting a role model to accompany them on family visits. However, if these individuals are serving a professional role, then there should be a mechanism for monetary compensation for their time and expertise. Deaf and hard of hearing individuals should be included in panel discussions and social opportunities. Play groups opportunities should include both deaf and hearing parents. In the Colorado system, the activities sponsored through our Families for Hands & Voices provide many opportunities for social and professional interactions with D/deaf and hard of hearing adults and their families.

Often, programs indicate that they don't have any D/deaf/hard of hearing individuals in their systems or that they can't find them. Start with the people you know and they will lead you to others. Remuneration can come from non-profit organizations, government and private agencies. Some states have been successful in writing grants for developing programs.

Effective Role Models have; 1) a written job description, 2) set appropriate expectations, 3) established policies and procedures, 4) a strength based program, strong role models, strong families, 5) a coordinator for the project, 6) training and an awareness of biases, 7) follow-up reports on effectiveness, 8) communication and interaction with other US states who have a program currently to find out what works. Overcoming cultural barriers includes not only the diversity among deaf, hard of hearing, spoken language users, and American Sign Language communicators, but also includes training role models in cultural sensitivity to meet the needs of the non-English speaking and culturally/ethnically diverse families.

Deaf Child Bill of Rights

A critical component of Deaf Infusion in the state of Colorado is the Deaf Child's Bill of Rights (http://www.cohandsandvoices.org/resources/coGuide/14_dcbr.htm; <http://nad.org/issues/education/k-12/bill-of-rights>). Colorado passed this bill in 1996. Seventeen states now have a Deaf Child's Bill of Rights. The components of the Deaf Child's Bill of Rights are:

- that each child's unique communication mode is respected, utilized, and developed to an appropriate level of proficiency,
- that teachers and other providers who work with children who are Deaf or Hard of Hearing are specifically trained for this population, including proficiency in the primary language mode of the children with whom they work,
- that an education with a sufficient number of language mode peers with whom direct communication is possible and who are of same age and ability level is available,
- that parent involvement and, where appropriate, people who are Deaf and Hard of Hearing, determine the extent, content, and purpose of educational programs,
- that children who are Deaf and Hard of Hearing benefit from an education in which they are exposed to Deaf and Hard of Hearing role models,
- that programs provide direct and appropriate access to all components of the educational process, including but not limited to recess, lunch, and extra-curricular activities,
- that programs provide for the unique vocational needs, including appropriate research, curricula, programs, staff, and outreach,
- that the least restrictive environment for each child who is Deaf or Hard of Hearing takes into consideration the legislative findings and declarations of this law, and
- that due to the unique communication needs of children who are Deaf and Hard of Hearing, the development and implementation of state and regional programs would be beneficial.



Communication Plan

A critical component of the Deaf Child's Bill of Rights is the Communication Plan.

The Individual Educational Plan (IEP) is required by legislation in the United States and the IEP team in Colorado must consider each area listed below, and cannot deny instructional opportunity based on the amount of the child's/student's residual hearing, the ability of the parent(s) to communicate, nor the child's/student's experience with other communication modes.

1. The child's/student's primary communication mode is one or more of the following: 1) aural, oral, speech-based, 2) American Sign Language, 3) English-based manual or sign system
2. The IEP team has considered the availability of deaf/hard of hearing adult role models and peer group of the child's/student's communication mode or language.
3. An explanation of all educational options provided by the administrative unit and available for the child/student has been provided.
4. The IEP plan must show that the educational environment has demonstrated proficiency in, and be able to accommodate for, the child's/student's primary communication mode or language.
5. The communication-accessible academic instruction, school services, and extracurricular activities the child/student will receive have been identified. The components of this accessibility must be included in the written plan.

Deaf Mentors

Watkins, Pittman and Walden (1998) published outcomes from the Experimental Deaf Mentor Program established in the 1990s. The program provided families with a Deaf Mentor who taught the families American Sign Language, information about deaf culture and their personal knowledge of deafness. The children receiving a Deaf Mentor in Utah were matched with children in a SKI-HI early intervention program in Tennessee who did not have a Deaf Mentor. They found that the children participating in the Deaf Mentor program had significantly higher scores on tests of early receptive and expressive language. Today, the Deaf Mentor program includes about 18 states but not all states have programs that provide services to all families who have children who are D/deaf

or hard of hearing who would like to learn American Sign Language. In addition, there are other states that have initiated sign language instruction programs including Arizona, Arkansas, Georgia, Hawaii, Illinois, Vermont, Minnesota and Wisconsin, New Mexico (Abrams & Gallegos, 2011), and outside the United States, Kenya. Some programs call these sign language instruction programs Deaf Role Model Programs, (Abrams & Gallegos, 2011, Mohay, Milton, Hindmarsh, Ganley, 1998, Parasnis & Fischer, 2005; Takala, Kuusela & Takala, 2001).

Deaf Role Models

Rogers and Young (2011) explored the experiences of deaf role models. This research was an evaluation of the deaf role model program established by the National Deaf Children's Society. Five focus groups were established and five key concepts were identified. They included reports about the value of training and the role model perceptions of the benefits for families and deaf young people. They felt that they managed parental expectations, addressed parental attitudes to deafness and had a personal impact of being a deaf role model. They concluded that recognizing and valuing d/Deaf adults' work with families of deaf children and young people would benefit not only the families and other professionals who work with them but also the d/Deaf adults themselves (Sutherland, Griggs & Young, 2003; Young, Griggs & Sutherland, 2000).

Johnson (2011) conducted a survey of 457 parents who had children who were deaf or hard of hearing. Four hundred and five of these 457 parents responded, reporting that 33% were educated in an auditory-verbal approach, 32% in an auditory-oral approach, 19% in a simultaneous/total communication approach, 13% in American Sign Language, 1% Cued Speech and 11% in other methods; 52% used hearing aids, while 15% had bilateral cochlear implants and 27% reported use of a cochlear implant. In this study, 56.2% indicated that deaf role models and mentors were very important, while 27.9% more indicated that it was moderately important; 47.9% indicated that access to adults who are deaf or hard of hearing was very important, and an additional 27.1% indicated that it was moderately important. Interestingly, parents of children with cochlear implants reported that they had good quality of access to these services, while parents of children with hearing aids reported a lower level of satisfaction in the quality of the service with 2.7 and 2.9 ratings as compared to 3.3 and 3.25 ratings by parents of children with cochlear implants. Deaf Role Models have also been proposed as an educational support to enhance a deaf child's awareness through literature (Schimmel & Monaghan, 1998).



Cultural and Linguistic Brokers

For families in the United States who represent ethnic/racial, linguistic and cultural minorities, cultural and linguistic brokers provide a number of important roles (Brown, Perry & Goode, 2003; Cross, Bazron, Dennis & Isaacs, 1998; Goode, 2001; Haynes & Smedley, 1998; Heifetz & Laurie, 1997; Jezewski, 1990; Jezewski & Sotnick, 2001; Phillips & Crowell, 1994; US Dept of Health & Human services, 2000; Wenger, 1995;). These roles include: 1) culture brokers as liaisons, 2) cultural brokers as cultural guides, 3) cultural brokers as mediators, and 4) cultural brokers as catalysts of change.

As a liaison, the cultural broker is knowledgeable about the health and educational values, beliefs, and practices within their cultural group and community. The cultural broker is knowledgeable about how to effectively navigate health and educational systems and can provide support to those families that they mentor.

As a cultural guide, the cultural broker can assist health and educational systems with the information that they need to be able to assist them in providing messages to families of diverse cultural and linguistic backgrounds that are articulated, through written, DVD, internet and website materials.

As mediators, the cultural broker addresses the historical and inherent mistrust that can exist between the cultural minority and the majority, in this case the hearing world. The cultural broker has the ability to establish and maintain trust and to establish meaningful relationships.

As catalysts of change, the cultural broker models and mentors behavioral change that can break down biases, prejudices and other institutional barriers that prevent meaningful relationships from occurring.

Cultural brokers must have the capacity to: 1) assess and understand their own cultural identities and value systems; 2) recognize the values that guide and mold attitudes and behaviors; 3) understand a community's traditional health beliefs, values, and practices and changes that occur through acculturation; 4) understand and practice the tenets of effective cross-cultural communication, including the cultural nuances of both verbal and non-verbal communication; and 5) advocate for the patient, to ensure the delivery of effective health services. Is there a place for this existing model of support in the United States or globally?

Calderon and Greenberg (2003) stated that deaf persons need to be involved in early intervention and education as teachers, psychologists, directors of schools, support staff, volunteers, and all other related positions. They also indicated the need to employ deaf persons at all levels in early intervention and education, including as members of the school advisory board and other decision-making bodies that set policy. Because these roles may not be considered standard teaching positions, for example, hiring deaf persons as professionals to offer American Sign Language and Deaf culture/history classes to deaf children, parents, and teachers, including the area of storytelling, the qualifications for hiring may have to be modified. As an example, when both parents and individuals who were deaf or hard of hearing were hired by the state department of health, some of them did not have college degrees or high school diplomas. However, these individuals were the most qualified for these positions. Because these exceptions sometimes applied to cultural brokers from diverse cultures and languages, deaf and hard-of-hearing individuals and parents, there was a diverse and large support for modifications to these job qualifications and that supportive coalition undoubtedly contributed to success. The Hands & Voices organization has a policy for the Infusion of Deaf/Hard of Hearing participation within Hands & Voices. This policy can be found at the following website: http://www.handsandvoices.org/articles/deafpersp/V15-2_deafinfusion.htm

In 2013, the Early Intervention Supplement to the Joint Committee on Infant Hearing Position statement 2007 was published (<http://pediatrics.aappublications.org/content/131/4/e1324.fullJCIH>, 2007). Two objectives dealt with deaf and hard of hearing individuals. Of the 11 objectives, three of them include objectives related to the topic of this presentation. The following discussion includes the exact wording of this Early Intervention Supplement, designed to be as recommended practice :

Goal 3a. (pg. e1328) Intervention services to teach American Sign Language (ASL) will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.

Goal 10. (pg. e1337) Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels. Their participation will be an expected and integral component of the EHDI systems and



Goal 11 (pg. e1338) All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH. This goal intends that families have access to meaningful interactions with adults who are deaf or hard of hearing who have the knowledge and skills to mentor, support, and guide families in culturally and linguistically sensitive ways and to serve as communication/language and social role models and mentors for deaf and hard of hearing children and their families.

The overarching goal is to have deaf and hard of hearing individuals woven into the fabric of EHDI systems at every level. Deaf and hard of hearing individuals know "what works" to meet their language and communication needs in a way that hearing people cannot. Since the support of language and communication of babies is intended to be the heart of EHDI systems, it is critical to include deaf and hard of hearing adults in these systems. Currently, there are few, if any, EHDI systems that include deaf and hard of hearing participants in a meaningful way. The system should have diversity of representation at many levels. Deaf and hard of hearing persons should be included, for example, as EHDI directors, EHDI advisory panel chairs and members, administrators, Part C coordinators, audiologists, pediatricians, counselors, mentors, sign language teachers, and in other roles.

All states, territories, and relevant Federal agencies will ensure the inclusion of deaf and hard of hearing individuals within EHDI systems as: 1) leaders in the establishment and implementation of EHDI systems at the Federal, State, and local levels, 2) active participants in the development of EHDI policies and practices at the Federal, State, and local levels; 3) professionals providing services to deaf and hard of hearing children and their families.

Partnerships of deaf and hard of hearing individuals in policy making and practitioner positions will help ensure that policy and practice is grounded in and responsive to the lives and experiences of deaf and hard of hearing people (Benedict & Sass-Lehrer, 2007). Providing hearing families opportunities to learn more about deaf and hard of hearing individuals reduces family stress and promotes family support of the child.

Although deaf and hard of hearing professionals should be included in a range of roles, an area where only a deaf or hard of hearing person will do is in the area of mentoring and sign language instruction. EHDI systems should offer qualified deaf and hard of hearing mentors and sign language instructors to all families. Standards for deaf and hard of hearing mentors and sign language instructors should be established at the state level.

Deaf and hard of hearing mentors and sign language instructors should be included in the state early intervention system of services and be paid competitive wages. Ensuring deaf and hard of hearing participation at all levels should start with data collection. States, territories, and relevant Federal agencies should survey staff and other program participants in all EHDI programs, including screening, identification, early intervention, medical home, and related programs to establish a baseline of how many of these individuals have been deaf or hard of hearing since birth, infancy, or toddlerhood. While adults with acquired hearing loss can provide valuable insight, it is critical that adults who are congenitally deaf or hard of hearing be included and infused within the system. Programs should include information about diversity of educational experiences, onset of deafness/hearing loss, language of communication, experience with technology use, and cause/type of deafness/hearing loss. States, territories, and Federal agencies should set goals to increase the number every year.

The Joint Committee on Infant Hearing Year 2007 Position Statement includes numerous recommendations supporting the inclusion of deaf and hard of hearing individuals in the lives of families with deaf and hard of hearing children (JCIH, 2007). The JCIH states:

"Almost all families choose at some time during their early childhood programs to seek out both adults and child peers who are deaf or hard of hearing. Programs should ensure that these opportunities are available and can be delivered to families through a variety of communication means, such as Web sites, e-mail, newsletters, videos, retreats, picnics and other social events, and educational forums for parents" (JCIH, 2007, p. 909)

Research demonstrates the benefits to families of connections with members of the deaf and hard of hearing community. Parents who have many contacts with deaf and hard of hearing adults exhibit a strong sense of competence in regard to raising their child (Hintermair, 2000). Hearing parents identify deaf parents as one of the most important sources of support (after teachers, therapists, and spouses) (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). Children from families who received deaf mentor services made greater language gains, had considerably larger vocabularies, and scored higher on measures of communication, language, and English syntax than similarly situated children without deaf mentor services (Pittman, 1998). Deaf community members are able to provide deaf children with something hearing parents cannot, experience as a deaf person.



Benchmarks

Programs are asked to determine the percentage of early intervention programs with professionals who are deaf or hard of hearing working in their systems in roles that include paid employment as administrators, therapists, teachers, and others and to report the percentage of families that have had meaningful interactions with individuals who are deaf or hard of hearing in a variety of roles (more than one). These roles might include: *a) the first contact, b) Deaf/hard of hearing mentor/role model, c) sign language instructor, d) early intervention provider who is deaf or hard of hearing e) counselor who is deaf or hard of hearing, f) or health professional who is deaf or hard of hearing (physician, audiologist, speech/language therapist.* Program staff are asked also to report whether their early intervention programs have developed systems of service provision that include trained and qualified deaf and hard of hearing individuals/mentors (or define mentors) from diverse backgrounds including linguistic, racial, ethnic, type and degree of hearing loss, use of communication strategies. These systems should guarantee that families have access regardless of their child's type or degree of hearing loss and their geographic location. Face-to-face visits as well as use of video-telephone technology can be explored. Systems should report the number of families each year who have had access to sign language instructors.

Medical Professionals

There is an association of medical professionals with hearing loss (AMPHL) <https://amphl.org/>. Though there is a critical need to increase the number of medical professionals who are deaf or hard of hearing, there are still too few physicians and medical professionals with the ability to communicate with patients who are deaf or hard of hearing (Levinson et al., 1997; McKee, Smith, Barnett & Pearson, 2013; Mervyn, 1998). In a survey conducted in 2010 (Moreland, Latimore, Sen & Zazove 2013); of 86 possible participants responded, fifty-six responded to the survey (31 trainees and 25 practitioners); nine of 22 medical students had a profound hearing loss, four of nine residents/fellows and 11 of 25 practicing physicians. Ten of 22 medical students; three of nine residents/fellows and 13 of 25 practicing physicians identified as either Deaf or deaf.

In 2015, a Johns Hopkins neuroscientist, J. Tilak Ratnanather, with expertise in brain mapping, received the Presidential Award of Excellence in Science, Mathematics and Engineering Mentoring, especially children who are deaf or hard of hearing. Dr. Ratnanather was educated at the

University College of London, Oxford University, and the City University of London and John Hopkins and he is dedicated to giving back to others who are deaf or hard of hearing.

We do not have a reliable survey of audiologists who are deaf or hard of hearing, speech/language pathologists or teachers of the deaf. We don't know how many early intervention providers are deaf or hard of hearing. But there is a great need in today's world to provide evidence that individuals who are deaf or hard of hearing can be included in every profession, including those that provide services to families who have children who are deaf or hard of hearing.

Deaf Parents as Mentors

In a study of 1000+ children across 12 states (Arizona, California, Idaho, Indiana, Maine, Minnesota, New Mexico, Oregon, Texas, Utah, Wisconsin, Wyoming), the language development of children who are deaf or hard of hearing with parents who are hearing was compared to the language development of children who are deaf or hard of hearing with parents who are deaf or hard of hearing (Sedey & Yoshinaga-Itano, 2013). All children had bilateral hearing loss and spoke English in the home. They had no additional disabilities. Three hundred and fifty children had assessments between the ages of 12 to 36 months of age from English-speaking homes: There were 370 Child Development Inventory assessments and 560 MacArthur-Bates Communicative Development Inventories. Fifty-five percent were boys and 45% were girls with a mean age of 24 months. The Child Development Inventory (Ireton, 1994) has 8 areas of development and is a parent-report. The MacArthur-Bates Communicative Development Inventory (Fenson et al., 1993) also is a parent questionnaire. The results are reported as Language Quotients (language age/chronological age) multiplied by 100. On the Expressive Language subscale, children with deaf or hard of hearing parents had language quotients of 98 as compared to those with hearing parents who had median language quotients of 88. On the Comprehension-Conceptual subscale, children who had deaf or hard of hearing parents had median language quotients of 87 as compared to children with hearing parents who had median language quotients of 80. On the MacArthur-Bates Communicative Development Inventories, children with deaf parents had median vocabulary quotients of 86 as compared to the children with hearing parents who had median language quotients of 78. There were significant differences between the language scores of children with deaf parents and children with hearing parents with those of deaf parents having significantly higher language levels.



Of the 45 children with deaf parents, 25 of them communicated in the home in American Sign Language, and 20 communicated in the home with spoken English. There was no significant difference in language quotients between children with deaf or hard of hearing parents who communicated with sign language and those who communicated with spoken English. Parents who are deaf or hard of hearing regardless of the language of communication in the home have knowledge and skills in providing language access for their children who are deaf or hard of hearing reinforcing the importance that individual who are deaf or hard of hearing should have a special role in early intervention programs. Thus, there is both a theoretical rationale, as well as evidence that the knowledge and skills of individuals who are deaf or hard of hearing provide valuable information to families with hearing who have children who are deaf or hard of hearing (Myers & Hulsebosch, 1997; Myers & Hulsebosch, 1999; Hulsebosch & Myers, 2002).

In summary, the purpose of EHDI systems is for children who are deaf or hard of hearing to have the opportunity to achieve their potential, to have comparable opportunities to children with hearing. When individuals who are deaf or hard of hearing are infused throughout our EHDI systems, so that children who are deaf or hard of hearing can decide to become doctors, psychologists, audiologists, teachers, social workers, early intervention providers, sign language instructors, or deaf role models, successful accomplishment of the goals of EHDI will be met. Providing families and children with the support they need to develop skills commensurate with their cognitive potential should result in a world of opportunity for the newborns that are identified. That world is within our reach.

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Appendix

Other resources for those interested in increasing the number of health professionals for deaf and hard of hearing people can also gain information from the following websites.

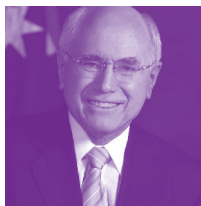
Task Force on Health Care Careers for Deaf and Hard-of-Hearing People:
<http://www.rit.edu/ntid/hccd>

Association of American Medical Colleges' Medical Students With Disabilities: A Generation of Practice (2005): https://members.aamc.org/eweb/DynamicPage.aspx?Action=Add&ObjectKeyFrom=1A83491A-9853-4C87-86A4-F7D95601C2E2&WebCode=PubDetailAdd&DoNotSave=yes&ParentObject=CentralizedOrderEntry&ParentDataObject=Invoice%20Detail&ivd_formkey=69202792-63d7-4ba2-bf4e-a0da41270555&ivd_prd_key=4E3A69D5-2E0B-49FA-BCCD-CD56B7F33688

Association of American Medical Colleges' Medical Students With Disabilities: Resources to Enhance Accessibility (2010): https://members.aamc.org/eweb/DynamicPage.aspx?Action=Add&ObjectKeyFrom=1A83491A-9853-4C87-86A4-D95601C2E2&WebCode=PubDetailAdd&DoNotSave=yes&ParentObject=CentralizedOrderEntry&ParentDataObject=Invoice%20Detail&ivd_formkey=69202792-63d7-4ba2-bf4e-a0da41270555&ivd_prd_key=11B97F0D-FFC9-4488-9A7A-295820D4A837



ABOUT DEAFNESS FORUM OF AUSTRALIA



Our Patron is The Honourable John Howard OM AC. He has worn two hearing aids throughout his professional career.

Deafness Forum Of Australia

The Australian Government funded the establishment of Deafness Forum in 1993 to provide quality advice to it on behalf of the entire deafness sector. This advice, offered consistently over two decades has informed government policy and played an important role in building a fairer and more inclusive nation.

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

- advocating for social change
- providing input to government policy and legislation
- generating public awareness
- being a forum for information sharing

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 1969 and 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", Turramurra 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.

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".

LIBBY HARRICKS MEMORIAL ORATION SERIES

Since 1999, orations have been presented annually across Australia by a series of outstanding orators. To achieve wider and more permanent coverage, the Oration Series is published by Deafness Forum in Monograph form. It is also available in e-copy on the Deafness Forum website www.deafnessforum.org.au.

In order, the Orations to date are:

- 1999:** *'Hearing Access Now!'*
Emeritus Professor Di Yerbury AM (Sydney)
- 2000:** *'Recent Advances in the Understanding of Meniere's Disease and Tinnitus'*
Professor William Gibson AM (International Federation of Hard of Hearing Conference, Sydney)
- 2001:** *'The Politics of Deafness'*
Senator Margaret Reid (National Press Club, Canberra)
- 2002:** *'The Prevalence, Risk Factors and Impacts of Hearing Impairment in an Older Australian Community: The Blue Mountains Study'*
Professor Paul Mitchell (XXVI International Conference of Audiology, Melbourne)
- 2003:** *'Disability Law and People with Hearing Loss: We've come a long way (but we're not there yet)'*
Ms Donna Sorkin MCP BA (Hons) (Macquarie University, Sydney)
- 2004:** *'A Sorry Business: Lack of Progress in Aboriginal Hearing Health'*
Dr Peter Carter (3rd National Deafness Summit, Brisbane)
- 2005:** *'Deafness and Disability Transformed: An Empowering Personal Context'*
Alex Jones (Blue Mountains NSW) (This Oration was presented in Auslan)
- 2006:** *'Hearing Loss: The Silent Epidemic: Who, why, and what can we do about it?'*
Professor Harvey Dillon (4th National Deafness Summit, Perth)

- 2007:** *'Hearing and Communication – A Primary Concern in Aged Care'*
Richard Osborn (9th Rural Health Conference, Albury)
- 2008:** *'Access, Equity and Hearing Loss in Australia in 2008'*
Professor Robert Cowan (5th National Deafness Summit, Canberra)
- 2009:** *'The Bionic Ear: From an Idea to Reality'*
Professor Graeme Clark AC (GP Continuing Education , Sydney)
- 2010:** *'Early Identification of Hearing Loss in Australia: Well Begun is not All Done'*
Professor Greg Leigh (6th National Deafness Summit, Sydney)
- 2011:** *'Molecules,Managers or Mentors: How Can We Minimize Noise Damage in the Worksite?'*
Dr Robert Patuzzi (11th National Rural Health Conference, Perth)
- 2012:** *'A Report Card on the Social Well-being of Deaf and Hearing Impaired People in Australia'*
Dr Anthony Hogan (7th National Deafness Summit, Melbourne)
- 2013:** *'The Consequences of Being Born Deaf in the 21st Century'*
Dr Laurie Eisenberg (Australian Hearing Hub Inaugural Conference Macquarie University Sydney)
- 2014:** *'Making Connections'* Professor Susan Brumby
(8th National Deafness Summit/XXXII World Audiology Congress, Brisbane)

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. Donation forms and general information regarding deafness can be obtained from:

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218 Northbourne Avenue
Braddon ACT 2612

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TTY: 02 6262 7809

Fax: 02 6262 7810

Email: info@deafnessforum.org.au

Web: www.deafnessforum.org.au



*"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 disability 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"*