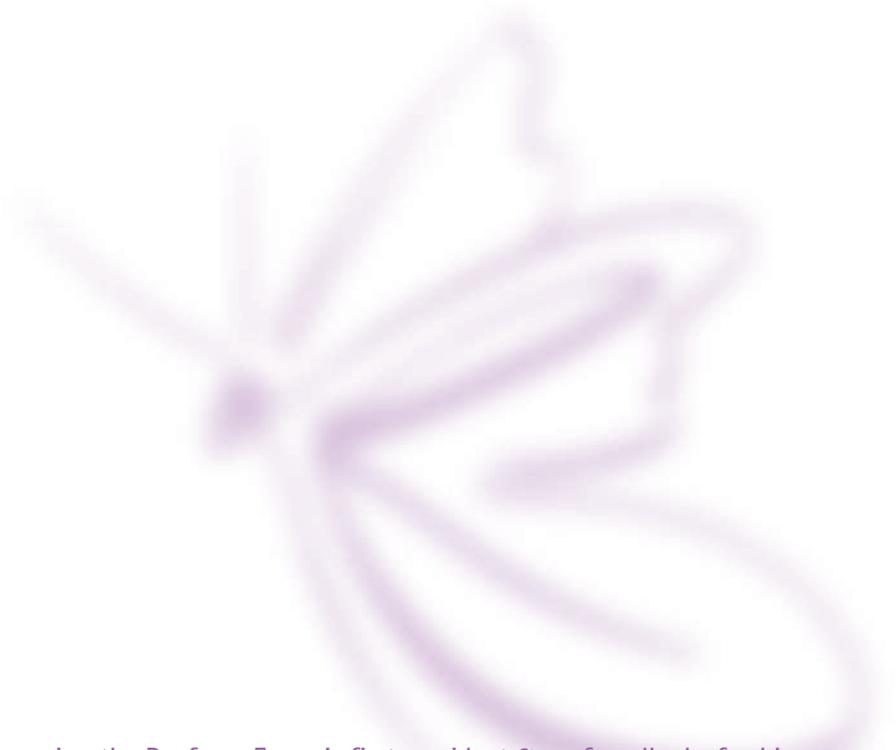




The 2010

Libby Harricks

Memorial Oration



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

Elisabeth Ann Harricks AM 1945 – 1998

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Introduction to the 12th Libby Harricks Memorial Oration

Dr Jenny Rosen, Chairman, Libby Harricks Memorial Oration Committee



Libby Harricks developed profound hearing impairment as a young wife and mother. She soon educated herself with skills to manage her own hearing difficulties and subsequently became a committed advocate for hearing impaired people. Amongst her many activities, Libby was a founding member and longterm President of SHHH Australia Inc (Self Help for Hard of Hearing People). In 1993 she was elected inaugural President of Deafness Forum of Australia, the national peak body in deafness and related issues.

In this voluntary role, she travelled widely throughout Australia raising awareness of the need, in various individual and community activities for hearing impaired people, and lobbying for this on their behalf. Amongst her many commitments, Libby served on the Board of Australian Hearing and represented hearing impaired people on the Sydney 2000 Olympics Access Committee. In 1990 in recognition of her many advocacy achievements, Libby was made a Member of the Order of Australia.

Libby died in 1998. Subsequently, Deafness Forum established the Libby Harricks Memorial Oration Series to honour her work. The aim of the Oration Series is to continue her commitment to achieving appropriate recognition, awareness, and access, for hearing impaired people. To further this aim in a more permanent form, the Oration Series is also published by Deafness Forum in a Monograph series.

Emeritus Professor Di Yerbury presented the first Oration, entitled 'Hearing Access Now!', in Sydney in 1999. At the International Federation of Hard of Hearing Conference in Sydney in 2000, Professor Bill Gibson gave the second Oration, focussing on tinnitus and Menieres Disease. In 2001, Senator Margaret Reid discussed 'The Politics of Deafness' in Canberra in. At the XXVI International Congress of Audiology in Melbourne in 2002 Professor Paul Mitchell presented findings of a major demographic study, the Blue Mountains Hearing Study, which addresses the prevalence and impact of hearing loss in a representative older Australian community. In 2003 as the keynote address to a full



day hearing access seminar at Macquarie University in Sydney, Donna Sorkin summarised progress in disability law and hearing loss from an international perspective.

At the 3rd National Deafness Sector Summit in Brisbane in 2004 Dr Peter Carter spoke on issues relating to Aboriginal ear health. In the Blue Mountains NSW in 2005, Alex Jones gave the first of the Orations to be presented in Auslan. With his message in 'Deafness and Disability Transformed: An Empowering Personal Context' this Oration had a very powerful impact indeed. For 2006, Professor Harvey Dillon presented his paper 'Hearing Loss: The Silent Epidemic' at the 4th National Deafness Sector Summit in Perth. In Albury in 2007, Rick Osborn educated the 9th Rural Health Conference with insights relating to 'Hearing and Communication – A Primary Concern in Aged Care.' In 2008 at the 5th National Deafness Summit in Canberra, Professor Robert Cowan spoke on 'Access, Equity and Hearing Loss in Australia in 2008' and in 2009 Professor Graeme Clark addressed General Practitioners at a Continuing Education Conference in Sydney, on the background and current status of cochlear implants.

The Oration Series undoubtedly has developed a well-deserved reputation for carrying forward Libby's commitment to raising awareness of issues relating to hearing impairment, and for furthering the aims of Deafness Forum. We sincerely appreciate the contributions of our outstanding Orators who have presented on such a wide range of relevant topics. We are equally gratified that it has also been possible to provide the opportunity for audiences across Australia to hear these Orators, as well as to enable continuing availability via the on-going Monograph series. I would like to acknowledge the support of the Libby Harricks Memorial Oration Committee, and also that of the Deafness Forum national secretariat. I am very pleased to also acknowledge our Oration sponsor for 2010, Cochlear Ltd. Without such sponsorships, neither presentation of the Oration nor preparation of the companion Monograph series would be possible. This year, we are privileged to welcome as our 12th Orator, Professor Greg Leigh PhD FACE.

Professor Leigh is Chair of RIDBC Renwick Centre, a centre for research for professional education administered by the Royal Institute for Deaf and Blind Children in affiliation with the University of Newcastle. The Centre undertakes research and provides programs of postgraduate study in the education of children with impaired hearing or vision. He is also Director of the Centre for Special Education and Disability Studies at the University of Newcastle.

He holds degrees in Education and Special Education from Griffith University in Queensland; a Master of Science (Speech and Hearing) degree from Washington University (Central Institute for the Deaf) in the USA; and a PhD in Special Education from Monash University in Victoria. In 2001 he was made a Fellow of the Australian College of Educators.

Professor Leigh has previously held a variety of positions in the education of deaf children including curriculum consultant in Queensland. He was previously Course Coordinator for the program in education of the deaf at Deakin University in Victoria and, in 2003, held the position of International Visiting Scholar at the National Technical Institute for the Deaf, Rochester Institute of Technology, New York. He is a member of the executive management team of the Royal Institute for Deaf and Blind Children.

Professor Leigh has published widely on aspects of the education of deaf children, including a co-edited book with Professor Des Power titled *Educating Deaf Students: Global Perspectives*. He is a member of the Editorial Boards of both *Deafness and Education International* and *Phonetics and Speech Sciences*. He is chairman of the Australasian Newborn Hearing Screening Committee and serves as a member of the New South Wales Health Minister's Standing Committee on Hearing. He has previously been National President of the Education Commission for the World Congress of the World Federation of the Deaf and is currently Chairman of the International Steering Committees of both the Asia-Pacific Congress on Deafness (APCD) and the International Congress on Education of the Deaf (ICED). He was Congress Chairman of the 19th ICED and 7th APCD in Sydney.

We are indeed fortunate that Greg was able to accept our invitation to bring us up to date on early identification of hearing loss in infants, and related issues. While his title relates this to Australia, it would be a hard task indeed to find anyone anywhere in the world better qualified in his area of expertise.

Would you please welcome Professor Greg Leigh.

Early identification of hearing loss in Australia: Well begun is not all done!

Professor Greg Leigh



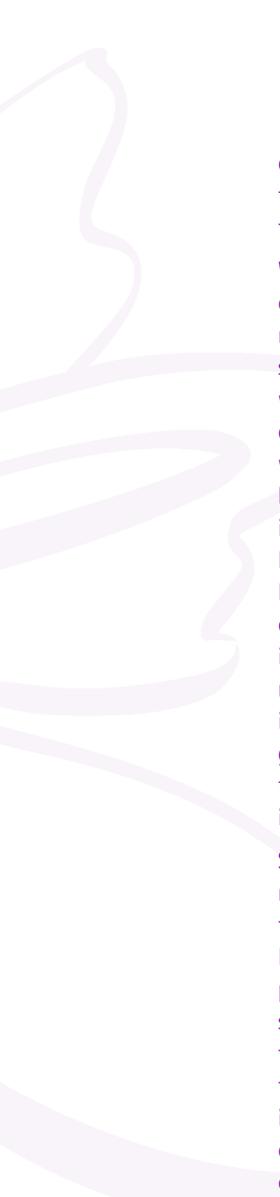
Introduction

It is an honour to be invited to deliver the 12th Libby Harricks Memorial Oration—an honour and an opportunity for which I am very grateful to the Oration Committee and to Deafness Forum more broadly.

Like so many of the people present for this oration, I had the pleasure of knowing Libby Harricks. Over many years I came to admire her for her boundless energy, sense of mission, and commitment to pursuing positive outcomes on many and varied issues related to deafness and hearing impairment in Australia. She was an extraordinary woman and a true force for good—the likes of which we only rarely see and even more rarely have the pleasure to know. There is no doubt that she would have been pleased that the orations over the last 11 years have reflected the diversity of the issues in our field and the continuing need for advocacy and action on so many fronts.

Clearly, in issuing the invitation to me to present this year's oration, it was the Committee's intention to consider yet another front—earlier identification of hearing loss and, in particular, newborn hearing screening and early intervention. For me, this was an invitation that required no second consideration. These issues have been at the centre of my focus for many years and, I would argue, are among the most important considerations in shaping the future of educational opportunities and outcomes for children with congenital hearing loss.

In his keynote speech to the 4th Australasian Newborn Hearing Screening Conference in Brisbane in 2007, Professor Karl White from the National Centre for Hearing Assessment and Management in Utah made reference to the proverb "Well begun is half done". The proverb is a modern variant on an adage first attributed to Aristotle but is perhaps better known as advice proffered by Mary Poppins. Regardless of its origin or its chief promoter, the wisdom in the words is patent—a strong beginning is a substantial



contribution to an effective outcome. There is, however, a logical corollary to this proverb. No matter how well a job is begun, there is always more to be done or, put simply, "well begun is not all done".

Where Universal Newborn Hearing Screening (UNHS) in Australia is concerned, there are two clear truths to the statement that "well begun is not all done". First, given that it is now more than 7 years since the first state-wide UNHS program was introduced, it is apparent that what was well begun in New South Wales in 2002 is certainly not yet "all done" on a national level. Quite simply, we are still yet to achieve a situation where every newborn Australian child is guaranteed the opportunity to have their hearing screened. Second, even though the available evidence indicates that earlier identification of hearing loss is linked to better language and educational outcomes for children with congenital hearing loss (Kennedy et al., 2006; Yoshinaga-Itano, 2004), it is abundantly clear that those benefits are not guaranteed simply by the act of early identification. From a developmental and educational perspective, the real benefits of earlier identification and confirmation of hearing loss lie in securing the basis for earlier intervention. The extent of the advantage gained by earlier identification still lies in the quality and timeliness of the interventions that proceed from that identification—not the act of identification itself.

So, in this brief presentation I would like to address both aspects of the notion that "well begun is not all done". First, I will take the opportunity to consider the background for, and current status of, UNHS in Australia. In this regard I will address briefly the urgent need to achieve full population coverage, the need for minimum national standards for service delivery and development, and the need for a national approach to data collection and management. Second, I would like to consider the continuing need for effective programs of early intervention and, in particular, the need for diversity in intervention services in order to capitalise on the benefits of early identification for all children with congenital hearing loss.

UNHS in Australia: Background and current status

In 2002, Professor Melissa Wake, the immediate past chair of the National Newborn Hearing Screening Committee, wrote:

"Australia does not do well in the early detection of hearing impairment. Only about 25% of infants born with hearing impairment are diagnosed by the age of 12 months and, for many children, deafness remains a disability leading to severe and lasting language impairment." (Wake, 2002, p. 172)



At that time there were no whole-of-population UNHS programs in Australia. Ironically, given that Western Australia and Victoria are the last two states to complete a full rollout of UNHS programs; those states were leaders in the introduction of hearing screening programs. In 2002 in Western Australia there were several hospitals operating a state-funded newborn hearing screening program for all newborns. In Victoria, the Victorian Infant Hearing Screening Program (VIHSP) had been operating since 1992. Under that program, infants identified with risk factors for hearing impairment were referred to diagnostic audiology as soon as a risk factor had been identified. By 2003, all infants that were admitted to Neonatal Intensive Care Units and Special Care Nurseries in four Victorian hospitals were being screened for hearing loss.

With regard to newborn hearing screening, the zeitgeist in Australia early in this decade was clearly very different to that which now prevails. In March 2001, the first National (now Australasian) Newborn Hearing Screening Conference was held at the Adelaide Women's and Children's Hospital. That meeting was styled as "A National Forum for Consensus and Implementation". There were 110 participants from all states and territories, including audiologists, teachers of the deaf, neonatologists, paediatricians, ear, nose and throat surgeons, nurses, nurse audiometrists, epidemiologists, and, importantly, parents of children with hearing impairment. The forum did reach consensus on the issue and produced the "Australian Consensus Statement on Universal Neonatal Hearing Screening" which was ratified in November of that year and was subsequently used extensively as the basis for lobbying governments around the country. Through the development of that statement, the National (now Australasian) Newborn Hearing Screening Committee was convened and began its work as a national lobby for action on UNHS. I take this opportunity to acknowledge the members of the Committee (see Appendix A), all of them volunteers, for their unstinting work towards the goals of that consensus statement over these many years.

The desideratum explicit in the Consensus Statement was that every child born in Australia would have his or her hearing screened and that appropriate interventions would be undertaken at the earliest possible time when required. In the context of a presentation such as this one—nine years later—an appropriate question to ask is where the nation now stands in relation to that desideratum. Unfortunately, without the benefit of a unified national system of delivery or a unified national approach to data collection, that is not an easy question to answer. In order to answer

the question it is necessary to rely on the combination of a small amount of publicly available data and the reports of key personnel involved in the screening processes within each state.

As can be seen from the population coverage map produced as Appendix B, it appears that we have reached a situation where five of the eight states and territories have achieved what the Joint Committee on Infant Hearing (JCIH) (2007) would describe as full population coverage (i.e., all babies born are offered the opportunity to have their hearing screened and greater than 95% of those babies complete the hearing screening process). The jurisdictions that are yet to achieve these benchmarks are Victoria, Western Australia, and the Northern Territory. Taken together, these state-level data indicate that, across Australia, the current proportion of newborn children who complete a hearing screen is approximately 88%. By any measure this is a huge step forward relative to 2001 but still remains well short of the objectives outlined in the original Consensus Statement. Considered another way, the current gap in population coverage by UNHS programs in Australia means that more than 36,000 newborns will not be screened for hearing impairment this year. This creates the potential for as many as 40 children to be born with significant hearing impairment that will not be identified until much later in their development (potentially not until after their second birthday).

In this context there was some very welcome political intervention on this issue last year. In June 2009, in the lead up to the meeting of the Council of Australian Governments in Darwin on July 2nd, the Office of the Prime Minister made the following announcement: "The Prime Minister will call on Premiers and Chief Ministers at the forthcoming Council of Australian Governments meeting to fast-track the introduction of universal and standardised newborn hearing screening" (Press Release, June 29th, 2009). That call was indeed made and the Premiers did agree to the timeline. There was a significant aspect to that agreement in addition to the decision to fast-track the slow rate of introduction of screening in some jurisdictions. Implicit in the agreement was the notion that there should be a "standardised" approach to newborn hearing screening in all states and territories. That call for a standardised approach to UNHS was entirely consistent with two issues that have been constantly on the agenda of the Australasian Newborn Hearing Screening Committee (ANHSC). Those issues are (a) the need for a national quality standards framework for UNHS programs, and (b) the need for a national data collection and management system. I will address each issue briefly in turn.

Towards a national quality standards framework

Internationally, there is a clearly understood need for systematic evaluation and monitoring of UNHS programs. Typically it is argued that such evaluation should be relative to a framework for quality assurance and associated service guidelines. In the United States, the JCIH (2007) has produced a set of guidelines that provide substantial guidance in this regard. On face value, it would appear that many, if not all, of the JCIH benchmarks for hearing screening programs are being met by many Australian jurisdictions. Certainly this would appear to be the case in regard to timeliness of screening and diagnostic audiology. Further, it is highly likely that Australian programs are world-leading in regard to the rates of follow-up that are being achieved in regard to timely completion of diagnostic audiology. Nevertheless, there remains a need for a framework to ensure that systems are actively monitored to these ends and also to ensure that targets for achievement do not become defaults. Continuous improvement should be a hallmark of all UNHS programs.

There is a patent need for Australian guidelines and an associated quality assurance framework to ensure that all aspects of all programs, not just issues of timeliness and population coverage, are in conformity with world's best practice. For example, in the area of family support and engagement, the JCIH guidelines suggest that any UNHS system should:

"...be family-centered with infant and family rights and privacy guaranteed through informed choice, shared decision making, and parental consent. Families should have access to information about all intervention and treatment options and counselling regarding hearing loss. The child and family should have immediate access to high-quality technology, including hearing aids, cochlear implants, and other assistive devices when appropriate." (Joint Committee on Infant Hearing, 2007, p. 901)

Evidence on how well programs in all Australian jurisdictions achieve in regard to these types of criteria is not currently available. Systems in place across the nation currently vary considerably and the availability and quality of early intervention programs is often heavily dependent on non-government (typically charitable) provision. This is an area where there is a particular need for strong evaluative mechanisms and further research to ensure that all of the necessary component follow-up services are in place and of high quality in regard to children who are identified with hearing loss and their families. To this end, advocacy by the ANHSC for the introduction of a national system of quality standards for system

development and evaluation has been constant. The Committee has argued consistently that such a national system is required to ensure that screening, diagnostic, and intervention services:

- are carried out to a high standard;
- are carried out in a timely fashion;
- communicate with families effectively and in a timely manner;
- provide comprehensive support post-diagnosis;
- have systems to ensure that recording, reporting and improvement of system performance occurs across the screening pathway; and
- capture and report data accurately and efficiently.

In this regard it is particularly pleasing to be able to report that these issues have been taken up by the Australian Health Ministers' Advisory Council (AHMAC) through their relevant subcommittee, the Australian Population Health Development Principal Committee (APHDPC). In March 2008, the APHDPC agreed to examine the feasibility of a national approach to neonatal hearing screening. In 2009, the APHDPC established the Neonatal Hearing Screening Working Group which was charged with the responsibility for the development of a set of draft national minimal standards for screening services and post screening follow-up in regard to audiology, medical intervention, family counselling, early intervention and education and, importantly, a draft national approach to data collection and management and data sharing. In the context of the Prime Minister's announcement that universal neonatal hearing screening would be available in all states and territories by the end of 2010, the work of this working group has taken on new significance.

The proposed standards are organised into seven areas that broadly represent the stages of the pathways for newborn hearing screening and intervention, as follows:

1. Recruitment/engagement with the Screening Process (identification of the target population, determination of eligibility, and population capture, antenatal/postnatal/community education about screening);
2. Screening (screening protocol, criteria for screening, target condition & consent);
3. Support for Families (screening to involvement in early intervention);
4. Diagnostics (audiological assessment and medical follow up);



5. Early intervention, management & long-term outcomes (transition to early intervention, ensuring engagement, availability and quality of program options and locations, outcome monitoring);
6. Co-ordination, monitoring & evaluation (program auditing, self-assessment, engagement with national data collection processes, and outcome measures); and
7. Professional education (training and maintenance of professional skills at all levels of the program).

The draft standards in each of these areas have already been through a process of community consultation and the final report and recommendations to the APHDPC (and ultimately to AHMAC) are being anxiously awaited. It is expected that AHMAC will receive the draft framework and standards by September of this year.

Towards a national approach to data collection, management and sharing

As I have already indicated, it appears that many Australian state and territory UNHS programs are achieving the benchmarks indicated by the JCIH for population coverage. Further, it is highly likely that most, if not all jurisdictions are meeting benchmarks for timeliness in delivering a number of elements of their screening programs. To the extent that state-based data collection systems are able to report on this process, these claims would certainly appear to be supportable. Nevertheless, it is possible that some children are being lost to follow-up at later points in the screening pathway. Without an effective system of data collection and data sharing the capacity to monitor potential loss to follow-up between points in the screening and service pathway is restricted. Moreover, the lack of nationally agreed and implemented processes for data collection limits the capacity to monitor the performance of UNHS systems in regard to a range of criteria that are only susceptible to investigation through the interrogation of well defined and carefully collected data at a range of levels. In this regard, I note that the JCIH suggested that data management systems should be designed and "used to measure outcomes and report the effectiveness of EHDI (UNHS) services at the patient, practice, community, state, and federal levels" (Joint Committee on Infant Hearing, 2007, p. 901). There is a patent need for attention to the issues of data management and information sharing in Australia at the national level. In this regard, the requirement for the Neonatal Hearing Screening Working Group to develop a draft approach to national data collection and management can be seen as a critical task.

There are several possible approaches to data collection that could be pursued nationally. Ideally, such a system would permit the collection and management of person-level data and would therefore provide:

- the capacity to accurately calculate the incidence and prevalence of Permanent Childhood Hearing Impairment (PCHI) in Australia;
- a basis for ensuring that children identified through UNHS programs are not lost to follow-up (i.e., that they receive the necessary intervention services and other supports that are required to capitalize on their early identification) regardless of their location or movement within Australia;
- access to a population database of children for research on aspects such as aetiology and epidemiology; and
- A basis for tracking the long-term outcomes and cost-effectiveness of UNHS.

Further work on these important issues is a critical next step in the development of UNHS programs in Australia and must be seen through to conclusion at the earliest possible time.

Before leaving the issue of advocacy for a unified national approach to screening and data collection, I should note one more issue that warrants national attention; that is, the need for continued monitoring and surveillance of children's hearing status across later childhood. The importance of this issue is patent when two available statistics are considered. First, based on the increasingly longer-term records available for the New South Wales UNHS program, it would appear that the average yield of true positive results from newborn hearing programs in Australia is likely to be approximately 1.15 per 1000 children screened (New South Wales Health Department, 2008, p. 8). Second, based on demographic information for children fitted with hearing aids in Australia, it is apparent that, by primary school age, more than three children per 1000 will have been fitted with a hearing aid (Australian Hearing, 2009). Given these facts, it is clearly apparent that neonatal hearing screening will not account for the timely identification of all children with hearing loss. Newborn screening will not identify children who will acquire a hearing loss at a later age or children who, for whatever reason, may have missed the opportunity for a hearing screen as newborns. In regard to the latter group, there is an obvious potential for children who arrive in Australia later in childhood (i.e., under the immigration program or as refugees) to not have been covered by a neonatal screening system in their country of origin.



A strong argument can and should be made for screening and assessment services to be available at later stages in childhood. Given that we know that many children with acquired hearing loss have their impairment confirmed around the time of school entry, serious consideration should be given to maintaining and/or reinstating early childhood hearing screening programs for pre-school age children. Children in some states do currently receive a hearing screen in the pre-primary years, but this is not available in all jurisdictions. Consideration should be given to the inclusion of an objective assessment of infant hearing as part of the child health check undertaken at or around 4 years-of-age. Further, at very least, there should be careful surveillance and provision of audiological assessments through early childhood for children who are identified as newborns as having risk factors for delayed-onset or progressive hearing loss (see Joint Committee on Infant Hearing, 2007, p. 921 for a comprehensive list of these factors). These are all matters that require serious consideration and should not be displaced by any complacency about the achievement of full population coverage by UNHS programs.

The need for quality and diversity in intervention services

As I indicated at the outset, there can be no assumption that earlier identification is, in and of itself, a solution for the amelioration of the myriad issues that attend significant permanent congenital hearing loss. At the conclusion of her presentation to the annual Leaders in Deaf Education Forum at RIDBC Renwick Centre last September, Professor Christie Yoshinaga-Itano made this same point. She concluded her presentation by noting that, where newborn hearing screening programs are concerned, "Optimal outcomes are made possible, but they are not guaranteed" (Yoshinaga-Itano, 2009). Early identification contributes significantly to the potential for optimal outcomes but ultimately outcomes will be mediated by a host of other factors.

When I was considering the theme for this presentation—"well begun is not all done"—I reflected on a chapter that I wrote recently for a book titled "Deaf Cognition: Foundations and Outcomes" (Marschark & Hauser, 2008). The chapter was titled "Changing Parameters in Deafness and Deaf Education: Greater Opportunity but Continuing Diversity". I'd like to use a quote from that chapter as an introduction to my remaining comments regarding early intervention in a post-UNHS environment. In that chapter I wrote:

"Developments in a number of related fields are providing greater opportunities for deaf children to access spoken language than at any time in history. Most notable among these developments have

been the advent of Universal Newborn Hearing Screening (UNHS) and the increasing accessibility of cochlear implantation. In addition, an increasing emphasis on inclusive education and continuing advances in understanding the foundations of learning by deaf children have served to dramatically alter expectations about both linguistic and educational outcomes for deaf children. Nevertheless, the outcomes of therapeutic and educational interventions with deaf and hard of hearing children continue to be characterised by considerable variability.” (Leigh, 2008, p. 24)

It is to the last sentence—the potential for continuing variability in outcomes for deaf and hearing impaired children who are identified through newborn hearing screening—that I will direct my remaining comments.

My starting premise for these comments is that the population of deaf and hearing impaired children is not, and never has been, a homogenous group. Without question, there are numerous factors that may account for diversity of outcomes within this population. Not least among such factors, and perhaps most commonly cited, is the degree of a child's hearing loss and the extent of their aided speech perception ability (Geers & Moog, 1989; Sininger, Grimes, & Christensen, 2010). Other factors that may influence outcomes for deaf children include, among others:

- concomitant disabilities—the degree and consequences of a range of additional disabilities have been shown to affect the rate and extent of growth in a number of outcomes measures for deaf children (Holt & Kirk, 2005 ; Knoors & Vervloed, 2003);
- cognitive ability—non-verbal cognitive ability has been shown to be predictive of speech perception (Geers, Brenner, & Davidson, 2003), language development (Geers, 2006), and reading abilities (Geers, 2003) in deaf children;
- social-emotional support and development—the emotional availability of parents, for example, has been shown to be associated with speech and language outcomes for deaf children (Pressman, Pipp-Siegel, Yoshinaga-Itano, Kubicek, & Emde, 2000);
- socioeconomic status—there are several issues of potential significance here, at least some of which impact families' capacities to fully engage in educational and therapeutic processes with their children (Powers, 2003);



- cultural and linguistic background—divergent home language backgrounds have been associated with differential levels of achievement in development of both spoken and signed language (Akamatsu & Cole, 2000);
- age at time of intervention (Kennedy et al., 2006; Sininger et al., 2010; Yoshinaga-Itano, 2004); and
- type and quality of intervention (Geers et al., 2003; Geers & Moog, 1989).

The final factor here might logically be broken down into two sub-factors: (a) the extent and timeliness of access to a fully available communication mode (regardless of whether that communication is spoken or signed), and (b) the type of assistive hearing device provided for the child and the age at which that device was effectively fitted (Sininger et al., 2010).

As indicated in the associated comments in the list above, each of these factors has been considered as a potential influence on developmental outcomes for deaf children. Notably, each factor has the potential for a broad range of variation across the population of early identified children with hearing loss. It is perhaps not surprising therefore that each of these factors is being considered as an independent variable in the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study currently being undertaken in Australia by the National Acoustic Laboratories. This large scale prospective study now includes 475 children as participants and aims to collect data on multiple assessments of those children at specific intervals (i.e., at 6 months post identification and then at 1-, 3-, 5- & 8-years-of-age) in order to monitor outcomes over time and to determine the effect of various factors on those outcomes (Ching, 2009). I will return to the LOCHI study later.

Having acknowledged the broad range of potential influences on deaf children's development, there are two factors that are increasingly receiving attention in regard to their potential to account for improved outcomes for children who are deaf or hearing impaired. Those factors are (a) age at time of identification/intervention, and (b) cochlear implantation (in particular, the age at which the implant is received). Regardless of the ongoing diversity among the population of children with hearing loss, the changed parameters in regard to these two factors since the advent of UNHS programs have resulted in them rightly coming under increasing scrutiny. I will now focus briefly on the impact of these two factors in a post-UNHS environment and the resultant changes in approaches to intervention.

Earlier identification

As I have already indicated, from a developmental and educational perspective, the real significance of UNHS programs lies in the potential for there to be even earlier intervention for children with congenital hearing loss. Although still mixed in nature, the available evidence suggests that earlier intervention is linked to better language and educational outcomes for children born with permanent hearing loss (Kennedy et al., 2006; Yoshinaga-Itano, 2004). The advantages of early identification have been shown to extend to development across a range of areas. Yoshinaga-Itano, Coulter, and Thomson (2000) found that children whose hearing loss was diagnosed early had significantly better general language development and vocabulary knowledge than those whose hearing loss was diagnosed after the age of 6 months. Similarly, Apuzzo & Yoshinaga-Itano (1995) and Yoshinaga-Itano et al. (2000) found that early identified children had superior speech intelligibility. The early evidence available from the LOCHI study is also supportive of the claim that earlier identification is associated with better outcomes although, at this stage, the results remain inconclusive. The data that has been analysed to date suggests that early identification results in significant advantages for earlier versus later identification for children in the six months immediately after identification of their hearing loss (Ching, Dillon, Day, & Crowe, 2007). The longer term impacts of earlier versus later identification in the children involved in the LOCHI study are, however, less clear. Clarification of that issue requires significantly more data to be subjected to analysis.

Earlier cochlear implantation

For some time, the literature has been positive regarding the potential for an improved rate and level of spoken language development in children with severe to profound sensory-neural deafness who receive a cochlear implant (Geers, Nicholas, & Sedey, 2003; Svirsky, Robbins, Iler-Kirk, Pisoni, & Miyamoto, 2000). The literature now emerging, however, suggests that the prospects for positive outcomes associated with cochlear implantation are even greater when the implant is provided earlier in the child's development. This is perhaps unsurprising given the considerable theoretical and evidence-based support for the concept of an optimal (but not finite) period for development of speech perception abilities in early infancy (Mayberry, Locke, & Kazmi, 2002; Werker & Tees, 2005) and also theories proposing a "sensitive period" for plasticity of the developing neurological system (Kral & Tillein, 2006; Sharma, Dorman, & Spahr, 2002).



A recent Australian study illustrates this point. Dettman, Pinder, Briggs, Dowell, and Leigh (2007) compared the language development scores for 11 children who received their implants before the age of 12 months (mean age 0.88 years) with those for 36 children who were implanted between 12 and 24 months (mean age 1.6 years). Scores were collected for two or more yearly administrations of the expressive and receptive scales of the *Rossetti Infant-Toddler Language Scale* in order to calculate average rates of growth over time. A significant difference was found in favour of the early implant group for the average rate of language growth for both expression and reception of language. Indeed, the mean rate of language growth for the children who received cochlear implants before the age of 12 months was consistent with the growth rate expected for hearing children.

Emerging evidence from the LOCHI study also suggests that there is likely to be an impact of earlier application of cochlear implant technology. Ching (2009) reported briefly on the Preschool Language Scale (PLS-4) scores for 69 children in the study—27 who were implanted prior to the age of 12 months and 42 who received their implant after 12 months of age. In all cases, the results were for assessments 12 months after the receipt of the implant. In regard to both expressive and receptive language skills the early implant group scored significantly better than the later implanted group. Similar comparisons for smaller groups of children—52 children who had their implants for three years and 33 children that had their implants for 5 years—also showed higher average PLS scores for the early implanted groups, however the differences in these cases were not statistically significant. These trends are still under observation and will continue to be monitored as more data become available. Even acknowledging the limited data currently available from the LOCHI study, there is still considerable support in the literature for the conclusion that earlier cochlear implantation (made possible by earlier identification of hearing loss through UNHS) stands to impact outcomes for children with congenital permanent hearing impairment.

Earlier identification and implantation in practice

Having noted the likely positive consequences of the confluence of earlier identification and cochlear implantation, it is appropriate to observe that in Australia we are very much on track for that pattern of action to become the standard response for an increasing majority of children with severe or profound hearing loss. It would appear that the power of the theoretical argument for earlier implantation and the type of data that

are emerging from current research of the type reported here is a potent combination in terms of influencing intervention decisions and practice. The situation in New South Wales provides a good illustration of how this confluence is currently being realised.

The UNHS program in New South Wales has been fully operational since very early in 2003 and accounts for more than 98% of all births (New South Wales Health Department, 2008). By using the data available for all children under the age of 24 months of age who received an implant at the Sydney Cochlear Implant Centre from 1998–2007 (a total of 148 children), it is possible to examine the pattern of implantation for infant children for a period before and after the introduction of UNHS in 2003. Figure 1 shows the relative ages at which children received implants from 1998 to 2007. The number of children implanted in each of those years is shown for three groups—those under 12 months; 13–18 months; and 19–24 months. The trend towards earlier implantation following the full availability of UNHS in 2003 is obvious.

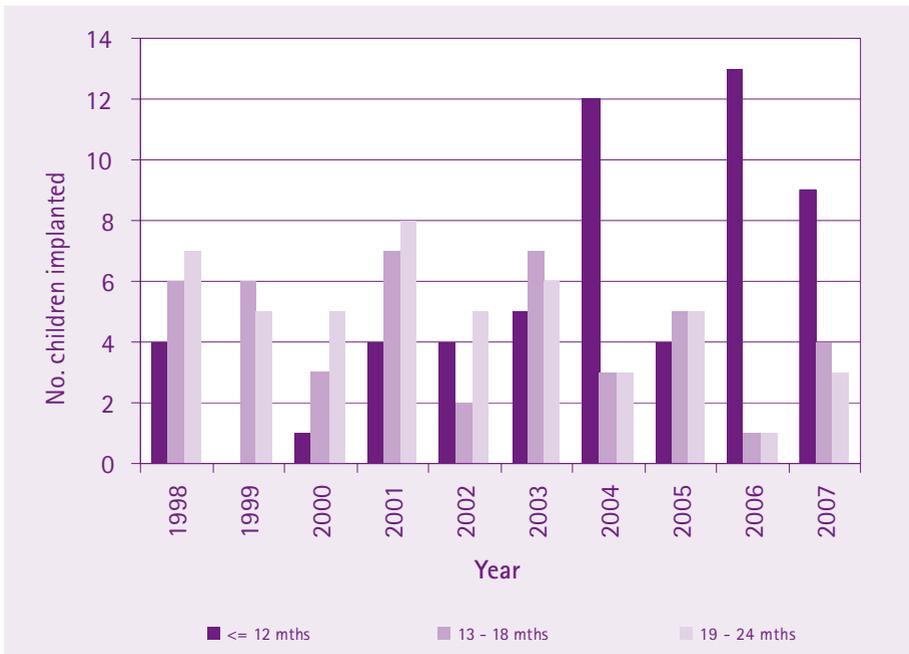


Figure 1. Infant children (< 24 months) implanted at Sydney Cochlear Implant Centre, 1998 – 2007 (n = 148), by age of implantation.



Continuing diversity

Even with the evidence supporting earlier implantation, it must be recognised that the emerging nexus between earlier identification and increasingly earlier implantation will not entirely ameliorate the diversity in outcomes among children with congenital hearing loss. The potential impacts of the factors that I have already identified will undoubtedly remain. In her précis of the data presented in the latest update report of the LOCHI study, Ching noted that there are "many confounding factors still to be allowed for" (Ching, 2009, slide 23). She concluded by saying that it is apparent that "multiple factors affect level of attainment and rate of development" for children in the study (Ching, 2009, slide 24). I would argue that the important issue here is recognizing the continuing diversity of needs in this population and **not** assuming that we have entered a new era where the playing field has been levelled to the point where all children are going to achieve normalised outcomes or where a single approach to intervention is going to serve the needs of all children equally well.

For the majority of children with hearing loss who are identified early and receive a cochlear implant at a very early age, the most appropriate approach to intervention will unquestionably be one that is based on the optimal development of their listening and speaking skills. Nevertheless, there will be children—however few and for whatever reasons—for whom a different pathway to language and communication will be required or desired. For some children, the most appropriate approach will be one that incorporates the development of sign language. For other children the appropriate response might be one that incorporates the use of some form of alternative or augmentative communication in addition to spoken English. Alternatively, some children's circumstances might determine the need to pursue a strategy that involves the use of signed communication to augment their early receptive auditory communication abilities en route to the development of listening and spoken language skills.

Having made this point, it should be noted that catering for such diversity presents at least three challenges for the field of early intervention. These challenges are:

- to ensure that early intervention professionals are in a position to make decisions (i.e., to assist parents to make decisions) about program type and intervention approach *at the earliest possible time*.

This demands improved capacity to assess and monitor very early development in a range of areas including auditory and vocal development;

- to maintain a viable range of program options to support children for whom an alternative pathway is necessary or desirable, regardless of how small those groups of learners may ultimately be; and
- to ensure that the professionals who will work in early intervention programs have the skills necessary to assess children's language and communication needs (in spoken and/or signed language) and the ability to deliver the full range of alternative programs effectively (in spoken language, signed language, or in some cases a combination of approaches).

To address each of these three issues in adequate detail would go way beyond the scope of this oration. In the remaining space and time, I would like to address the first point and then, in closing, to make some brief comments about the latter two issues.

The need for early and timely assessment and monitoring

Like just about everything else in a post-UNHS era, the need for early assessment and monitoring of children's development places demands on professional knowledge and capabilities that did not previously occur. Prior to UNHS, the focus for intervention was on children who were considerably older than those who are now engaged in early intervention programs. In that context, the techniques and instruments for measuring and monitoring the development of auditory and vocal abilities tended to focus on the assessment and monitoring of development well beyond the first year of life. If the benefits of earlier identification are to be achieved for all children, then we must determine their most appropriate path to the development of language and communication skills at the earliest possible time. Determination of the appropriateness of our approaches cannot be left to the assessment of language and communication outcomes later in childhood. Waiting until an approach has failed before changing to an alternative will, quite simply, squander the benefits that are offered by newborn hearing screening.

An illustration of the consequences of delayed decision making might help to illustrate the issue here. Several years ago I was engaged in a project with two colleagues, Professors Phil Foreman and Trevor Johnston, to investigate the principles, practices, and outcomes of a sign language-based program for deaf children here in New South Wales. The program extended from early intervention to secondary school. In our research into



the outcomes of the program we noted a series of factors that appeared to be working against positive linguistic and academic outcomes for some of the children in the program. Significant among those negative influences was a factor that we labelled "late arrival"—the tendency for children to commence in the program at increasingly later ages.

Under the program model adopted by the school it was intended that children entering the preschool and primary school levels of the program should have age-appropriate communication skills in sign language as a basis for their negotiation of the school curriculum. What we discovered, however, was that this was true for only a minority of children. Many of the children only commenced in the program in the latter part of their early childhood or even at school age. In many cases this late engagement with the program was only after a period of unsuccessful engagement with an early intervention program where the approach was designed to develop auditory-oral communication skills exclusively. Those children only commenced learning their principal language and communication skills at that time, rather than having learned them through early intervention and bringing those skills to school. Much of their time in school was expended in learning sign language rather than negotiating the general curriculum or developing their English literacy skills (Leigh & Johnston, 2004). The effect of this delayed sign language intervention was most apparent when we examined the outcomes for these children in terms of their English literacy skills. There was a significant negative correlation between the average age at which the children had commenced in the program and their achievement of English literacy skills. The children who had accessed the program very early in childhood had significantly better outcomes in regard to literacy.

The point here is a simple one. For those children who require an alternative pathway; waiting until they fail to achieve language and communication skills in spoken language before modifying a program or providing access to an alternative communication mode will create a delay in access to language and learning and will likely mean that the benefits offered by newborn hearing screening and early identification of their hearing loss will have been squandered. The literature on this issue is unequivocal. It doesn't matter which language or approach to communication a child will ultimately develop; the consequences of early versus later intervention and provision of language learning opportunities in that language and communication mode are significant.

Indeed, the case for the existence of a "sensitive period" for development of perceptual and related linguistic systems can be made for all forms of perceptual stimulation.

If the benefits of earlier identification are not to be squandered by waiting to determine the effectiveness of interventions later in infancy or early childhood, then we need to develop new approaches to assessment that are capable of raising concerns about lack of progress well within the first year of a child's life. We must be in the best possible position to ensure that the right intervention approaches are in place for all children so as to ensure that development in crucial areas such as cognition and social-emotional well-being is not compromised by failure to develop effective language and communication skills at an early age. At very least we need to be in a good position to identify children who *might* require an alternative approach (perhaps a dual approach) to language and communication development to ensure that neither cognitive nor emotional development is compromised.

At RIDBC Renwick Centre my colleague, Dr Robyn Cantle Moore, began a process several years ago to develop a strategy for monitoring pre-lexical vocal productions in very young children with hearing loss, particularly in the first 6 to 12 months of a child's life. This research is seen as one part of a response required to ensure that we can provide earlier and more clinically consistent information about the auditory and vocal skill development of all early identified children. That strategy has become a pilot instrument which is now known as the Infant Monitor of vocal Production (IMP). Effectively the IMP is a questionnaire that is designed to be administered in an interview process with parents or caregivers who are closest to the child in question (Moore, 2009).

The IMP is premised on the notion that family observations should be recognised as an important part of the process of gathering data on infant development. This approach is also consistent with the view put by Berlin, Morlet, and Hood (2008) that we have few tools available to identify issues such as auditory pathology that might compromise progress in very young infants "other than history, watchful waiting and re-testing routinely with ABR (Auditory Brainstem Response)" (p. 38). The IMP seeks to provide careful structure to such observations. In the process, the instrument aims to assist parents to better understand the nature and pace of their child's auditory and vocal development, particularly subsequent to receiving a cochlear implant. This is an exciting and promising development that is being viewed with great interest by the field, both here in Australia and internationally. Further development



and validation of the IMP is continuing and is to be encouraged, as are all efforts to ensure improvement in the capacity to monitor the development of children with hearing loss in very early infancy.

The continuing need for diversity of program options and professional skills

The provision of alternative program options for deaf and hearing impaired children and their families is often cast as a matter of "choice". Certainly, there is, and should remain, an element of choice in regard to language and communication decisions made by parents in regard to their children. The availability of options in regard to language and communication type in education is an important principle, particularly for parents who themselves are deaf or hearing impaired. In the context of the position that I have put in this oration, however, it is equally important to recognise that the provision of alternative program types (or pathways within programs) is primarily about responding appropriately to the particular needs of individual children who are deaf or hearing impaired and their families. Even for Deaf families the issues are not simple and are heavily mediated by individual differences. For an increasing number of Deaf families the most appropriate program is one that is able to cater for their child's development and use of sign language in the context of their choice to pursue the simultaneous development of their child's spoken language (i.e., including their listening and speaking abilities as aided by cochlear implantation). For other children and families, as I have endeavoured to make clear, the decision to pursue a path to language and communication that involves some use of signed language (or the combination of spoken and signed language) is more frequently dictated by factors which are outside their control and are not just a matter of preference.

Even though the number of children who may need to pursue such alternative program types may be small, the ongoing need for alternative provisions is clearly apparent. There is insufficient space and time here to address the questions of what the full range of program options should be, or where or how they should be offered. There are, however, two points that are worthy of comment before I leave this issue. First, in the context of an approach to early intervention that involves very early monitoring and rigorous ongoing assessment of children's development, it is important that all programs are open in acknowledging all available intervention approaches. Different programs (and different pathways through programs) for some children should be valued as viable alternatives that are entirely dependent upon the needs and requirements

of particular children and families. It is to be earnestly desired that, in the context of such acceptance and open sharing of information, the transition of children into or between alternative program types will be less likely to be seen (inappropriately) in terms of success or failure and also less likely to be subject to unnecessary delay.

Second, regardless of the intervention approach being used, there clearly is a need for a strong commitment on the part of all programs to the skilled application of the best evidence-based techniques available. In the case of spoken language interventions, this means a consistent emphasis by skilled staff on children's development of speech, auditory and spoken language skills. In the case of children who may require the additional use of signed communication, or the use of sign language, this means the deployment of staff with very high levels of skill in the use of sign(ed) language and associated intervention techniques and pedagogies. In either case, the provision of effective early intervention services requires the engagement of personnel with highly specialised skills. It is to this point that I will address my final comments.

The provision of highly specialized staff to fulfill roles in early intervention is premised on two assumptions. First, that there are opportunities for professional staff to acquire the necessary skills through either (or both) initial professional preparation or continuing professional development programs. Second, given the diversity of program possibilities and the diverse range of roles that they may be required to fulfil, that there is (a) the opportunity for professionals to acquire specialized knowledge and skills, and (b) careful attention on the part of intervention programs (as employers) to ensure that prospective professionals have the competencies that are required for the various roles to which they are to be deployed. Elsewhere, I have argued that this second issue demands a high level of cooperation between training institutions and intervention programs to ensure that: (a) a full list of competencies is documented for each of the possible roles; and (b) there is a system in place to ensure that prospective professionals "have either completed a postgraduate course specifically aimed at development of those competencies or can demonstrate that they have acquired these competencies through alternative training or experience" (Leigh, 2010, p. 429).

The diversity among children with hearing loss and the associated diversity of program types necessary to meet all of their needs demands a system of professional education that provides highly specialized skills for professionals. We should expect nothing less than highly trained and highly capable professionals as the deliverers of the various specialized



program options. This is a challenge for both the field of service delivery and, importantly, the field of initial and continuing education for professionals in that field (Leigh, 2010).

Conclusion

In the introduction to this oration I said that, where Universal Newborn Hearing Screening in Australia is concerned, there are two truths to the statement that "well begun is not all done". First, even though it has been seven years since the introduction of the first state-wide UNHS program, I pointed out that we have yet to achieve a situation where every child born in Australia is guaranteed to have his or her hearing screened as a newborn. Having acknowledged that there is more to be done on this front, I will conclude this issue by saying that there is also much to be proud of in regard to the achievements that have been made. Second, I have noted that earlier identification is not, in and of itself, a solution for the amelioration of the myriad issues that attend significant permanent congenital hearing loss. There will always be more to be done. Here again, however, there is much to be proud of. By any measure we are fortunate in Australia to have robust and well developed systems of audiological, medical, and educational interventions available for children with hearing loss and their families. In this address I hope to have made the case strongly for continuing the effort to ensure quality and, in particular, to ensure that programs of early intervention are highly responsive to the broad diversity of needs among the population of newly identified children with hearing loss.

We may not yet be "all done" but the challenges are apparent and the capacity for us to respond effectively on all of these fronts is clearly evident.

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Appendix A

Australasian Newborn Hearing Screening Committee Members, 2010

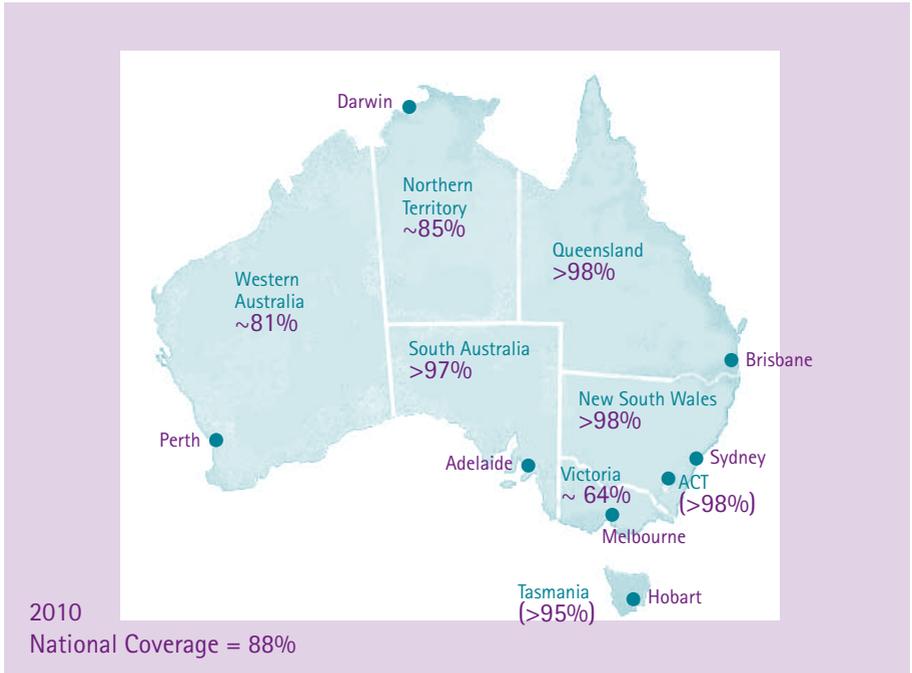


Paediatrics/Child Health:	Damien Mansfield (SA), Melissa Wake (Vic)
Otolaryngology:	Harvey Coates (WA), Fiona Panizza (Qld)
Population Health:	Peter Baghurst (SA)
Education:	Greg Leigh (NSW) (Chair)
Audiology:	Kirsty Gardner-Berry (NSW), Nina Swiderski (SA)
State UNHS Program Representatives:	Shirley Glennon (Qld), Isobel Bishop (NSW), Zeffie Poulakis (Vic), Lee Kethel (Tas), Raelene Kelly-Grindle/Michelle Forte (SA), Janet MacLean (WA), Renee Garuccio (NT)
Australian Hearing:	Alison King (Vic)
Deafness Forum:	Kathy Challinor (NSW)
Parent Representatives:	Tina Carter (Qld), Jo Quayle (Vic)
NZ UNHSEIP:	Vickie Rydz (NZ)
Project HEIDI:	Janet Digby (NZ)



Appendix B

State and National UNHS Program Coverage 2010 (% of newborns offered screening)





About the Deafness Forum

Introduction

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

Structure

Deafness Forum is divided into four classes.

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

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

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

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

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

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



Objectives

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

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

Community Involvement

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

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

Libby's Story



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

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

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

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

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

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



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

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

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

Unfortunately, Libby faced another hurdle when she was diagnosed with breast cancer in 1995. Following surgery, she continued her family and volunteer work with undiminished vigour. She would wickedly show off her wig at public functions after her chemotherapy, and talked openly of her "mean disease". She died peacefully on 1 August 1998 and was honoured by hundreds who attended her Thanksgiving Service on 6 August.

In her own words, Libby related her outlook:

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

The Libby Harricks Memorial Oration

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

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

Deafness Forum of Australia
218 Northbourne Avenue
Braddon ACT 2612

Tel: 02 6262 7808

TTY: 02 6262 7809

Fax: 02 6262 7810

Email: info@deafnessforum.org.au

Web: www.deafnessforum.org.au