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**A SURVEY OF THE DISTRIBUTION OF
INFORMATION REGARDING HEARING
LOSS TO PARENTS BY HOSPITALS AND
PEDIATRICIANS IN THE ST. LOUIS AREA**

by

Karen Layton

**An independent study submitted in partial
fulfillment of the requirements for the degree of**

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Emphasis in Audiology

**Washington University
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Approved by: Brad Stach, Ph.D., Independent Study Advisor

The last thing that crosses most expecting parents' minds is whether or not their child will have normal hearing. Yet, the loss of hearing sensitivity affects a substantial number of children each year. The exact incidence of hearing impairment has not been described, but Healthy People 2000, published by the U.S. Department of Health and Human Services in 1993 approximated that 1 newborn out of every 1,000 live births will be born with a bilateral severe hearing loss. Yet the new health agenda, Healthy People 2010, notes recent research suggesting the figure could be as high as 2 to 3 per 1,000 births. (National Institute on Deafness and Other Communicative Disorders, 2000). This does not include the children who acquire hearing loss throughout their childhood. For every 1,000 children in school in the United States, 83 have what is termed as educationally significant hearing loss. If all children who have any degree of hearing loss are accounted for, the incidence rate rises to 1 out of every 25 children (Tye-Murray, 1998).

Universal Newborn Hearing Screening Programs

With the acknowledgement that many newborns with hearing loss were going undiagnosed at the time of birth, universal newborn hearing screening programs began to be established in the 1980s. Such programs present an equal opportunity for all children, not just those with symptoms in the high-risk registry, to be diagnosed and receive rehabilitation for hearing impairment at an early age. It has taken up to 20 years for many states to adopt such a program as a part of legislation, and many still do not have a program in place.

Early identification of newborn hearing loss was first accepted in the 1960s with the acknowledgement that the best time to test infants for hearing loss was right after birth. It was reasoned that most infants are at no other time as readily available for testing than right after

birth. Yet, at this time many complications with the method of hearing screening were encountered by the first pilot programs. The increased awareness for the need of neonatal screening led to the development of the Joint Committee on Infant Hearing Screening (JCIH) in 1969. At this time, the JCIH did not support universal screening of infants, but encouraged research in this area. From this research, the high-risk registry for hearing impairment was developed and later adopted by the JCIH. At that time, the committee recommended screening of infants born with symptoms that included them in this list of possible contributors to hearing loss by age two. Later in 1982, additional high-risk symptoms were added to the list, and the committee decreased the recommended age for screening from two years to before six months of age.

In the early 1990s, several events occurred allowing the idea of universal screening of every newborn to become a more realistic goal. The first event was the issuance of Healthy People 2000 drafted by the U.S. Department of Health and Human Services. This document laid out goals for the identification and intervention of services for those born with hearing loss. One of these goals was to "reduce the average age at which children with significant hearing impairment are identified to no more than 12 months". The second major event that occurred in the 1990s was the development of effective screening tools. During this time, both the automated auditory brainstem response and transient otoacoustic emissions were documented in research as being an effective means for screening neonatal hearing impairment. Another document published in the early 1990s again highlighted the importance of screening all infants for hearing loss. In 1993, the National Institutes for Health (NIH) held a conference on the topic of Early Identification of Hearing Impairment in Young Children. From this meeting a consensus statement was drafted emphasizing the importance of universal screening and

recommending a model for such a program. The final major event in the early nineties that was instrumental in bringing universal screening programs into life was a position statement published by the Joint Committee on Infant Hearing (JCIH) in 1994. With support from numerous medical associations, the comprehensive statement stressed the importance of universal hearing screening and recommended an ideal program.

Now in the year 2001, it is well documented that as a whole, we have fallen significantly short of the goals set by the Joint Committee on Infant Hearing in 1994. Research has indicated a significant lag between the time at which hearing loss is suspected, diagnosed and intervention is begun both in healthy and high risk infants from wide range of environments (Harrison & Roush, 1996). Unlike other diseases, which are readily diagnosed at birth due to the apparent physiological characteristics that express themselves, hearing impairment can go undiagnosed because of the lack of symptoms apparent at birth. Only fifty percent of children born with hearing impairment will present symptoms that include them in the high-risk registry for hearing loss. The other half of children affected by congenital hearing impairment each year present no symptoms of the loss at the time of birth. It is only through comprehensive hearing screening of every newborn that hearing loss can be diagnosed within the first few weeks after birth in all children.

Acquired Hearing Loss

Besides the 4,800 children who are born with some form of hearing impairment each year, many others will acquire hearing loss during their early childhood (Downs, 1986). Marion Downs reported in 1986 that 33% of all children will have had three or more attacks of middle ear effusion by three years old, each of which can cause as much as 26-31 dB of hearing loss on

average. For children, even a mild loss due to middle ear effusion can be significant due to its impact on speech and language development. In 1986, Eimas and Clark conducted a study on 11 children with recurrent otitis media. The results showed children with recurrent middle ear infections demonstrated difficulties discriminating speech-sounds when compared to their noninfected peers. They concluded that this inability would have a long-term affect on the children's speech perception abilities. "The effects of the abnormal auditory input (impaired phonologic discrimination) persisted after the episodes of otitis media" (Bishop & Magford, 1993). These long-term effects are a result of a speech signal that is frequently degraded and fluctuant during early childhood, a time critical for language learning. Gravel and Wallace presented a model of the potential effects of the hearing loss accompanying otitis media on child development. The model includes "possible early auditory deprivation, aberrant perception of the auditory-linguistic code of language resulting in inadequate mental representations, and longer-term age and situation dependent auditory-based deficits in higher-order listening and language processing" (Bess, 1998). These negative effects can lead to poorer academic outcomes, behavioral and attention difficulties, and impaired binaural abilities when compared to peers that have not been affected by otitis media.

Effects of Hearing Loss on Speech and Language

A child born with mild hearing loss can miss up to 25-40% of a speech signal. Often this amount of hearing loss can go undiagnosed until the child reaches school age due to the close proximity a child often experiences to his primary caregivers during their infant and toddler years. When a child enters an academic environment, he or she is surrounded by unfamiliar speakers and competing noise. These can exacerbate the effects of the hearing loss causing

miss up to 50% of class discussions, which can cause the child's learning environment to become stressful.

A moderate hearing loss will often severely limit the child's conversational abilities unless the person is standing within a few feet of the child. A child with this degree of hearing loss is likely to display delays in syntax, a limited vocabulary, imperfect speech production, and an atonal voice quality. These abnormalities in the child's communication abilities will make socialization with their peers difficult.

A severe to profound hearing loss that goes undiagnosed allows the child to only hear loud voices or environmental sounds without amplification. With such a significant hearing loss, it is likely that oral speech and language will not develop spontaneously. This is observable within the first few months of hearing impaired child's life. Stoel-Gammon and Otomo in 1996, reported differences in the quality and quantity of hearing impaired infants' vocalizations compared to those produced by normal hearing infants. They reported much smaller verbal repertoires for the deaf children. In the hearing impaired babies, babbling decreased with age and fewer multisyllable utterances with consonants were produced compared to normal hearing infants. Additionally, the emergence of the first word and two word combinations by hearing impaired infants often significantly lagged behind the normally hearing child (Mogford & Gregory, 1981). These delays in early development continue on for the hearing impaired child throughout his or her life. Markides in 1970, found in a study of 110 hearing impaired children, lay listeners rated 64% of the children as 'very difficult to follow' or 'unintelligible'. These serious delays can cause the child to be isolated from family and peers and from the speaking world in general.

A child with undiagnosed hearing impairment will present delays in receptive and expressive speech and language abilities. These delays not only present themselves in the child's spoken language abilities but also contribute to literacy difficulties. As a general rule, children with severe hearing impairment do not exhibit sufficient knowledge of language to ensure a basis for normal development of reading abilities. Their delays in the vocabulary, syntax, and figurative language lead to reading levels far below the norms for children with normal hearing. Generally, reading skills slowly increase between the ages of 8-14 years, and level off during the early teen years. Trybus and Karchmer (1977) reported data from Standard Achievement Test (SAT) scores of hearing impaired children. The median score for students age 20 and above was grade 4.5. The highest reading achievement was at or above the eighth grade level.

Suspicion, Diagnosis and Early Intervention

In light of the detrimental effects that hearing loss can have on a child's development, it is increasingly important a child with hearing loss be diagnosed early and intervention begun soon after diagnosis. Existing data reveals that for most children the suspicion of a hearing loss occurs weeks or months prior to identification. Also, the diagnosis of hearing loss may span over a period of time, and the intervention, which includes fitting of amplification and receiving special services, do not always coincide. All of these factors delay the child receiving amplified auditory input to assist in his or her speech and language development.

Casto and Mastropieri (1986) concluded that early intervention provided modest gains in cognitive, linguistic, and academic development for a variety of handicapped populations. More specifically to hearing loss, it has been reported that the age of intervention is significantly related to receptive language ability during the first year of intervention (Musselman, Wilson, &

Lindsay, 1988). Additionally, children with either normal or impaired cognitive development whose hearing losses are identified by six months of age have significantly better language development than children whose hearing losses are identified after six months of age when intervention begins immediately after diagnosis (Yoshinga-Itano, 1998).

In a study with 112 prelingually deaf children enrolled in an early intervention program at a mean age of 1.83 years, a “significant negative correlation was found between age of enrollment and language outcomes at five years of age” (Moeller, 2000). The mild to profoundly hearing impaired children that were enrolled earliest in the intervention program demonstrated significantly better vocabulary and verbal reasoning skills at age five. Additionally, results demonstrated that regardless of the degree of hearing loss, early-enrolled children achieved scores that better approximated scores of the hearing children in the control group. Results also indicated that early enrollment benefited children across all levels of family involvement (Moeller, 2000).

Unfortunately, a significant lag between the age at which hearing loss is first suspected and the initiation of early intervention services occurs in too many cases (Harrison & Roush, 1996). This is a trend that has been continuously documented over the past 18 years. In 1983, Stein, Clark and Kraus studied 108 infants and children under 3 years of age enrolled in a parent-infant program for the hearing impaired. Results showed the median age of the first suspicion of hearing loss ranged from 3 months to 14 months for children in the neonatal intensive care unit (NICU) and well baby nursery combined. Yet, a median age for enrollment in habilitation was 20 months for NICU babies and 24 months for well nursery babies. The results from this study were idealistic compared to other studies published at the time. The Deaf Division of the Bureau of the Physically Handicapped, Chicago Board of Education stated, “more than 60% of all deaf

children enroll in classes for the hearing impaired at 3-6 years of age without any form of prior habilitation”.

In a follow up study published by Stein et al. in 1990, similar results to those printed in 1983, were reported. This study included data on 107 infants enrolled in the same program as Stein's previous study from 1983-1988. The age of first suspicion of hearing loss was significantly earlier for children in the NICU versus those in the well baby nursery. The babies that graduated from the NICU were first suspected to have hearing loss at a median age of 4 months and the well baby graduates were first suspected to have hearing loss at a median age of 15 months. The median ages for enrollment in interventions services were 20 months for the NICU babies and 19.6 months for the well nursery babies. Despite the large age difference between the two groups at the time of suspicion of the hearing loss, any advantages the NICU babies may have gained was lost by the long lag time between suspicion and intervention. The results reported by Stein in 1990 showed no major improvement in decreasing the age at which a child with hearing loss is enrolled in intervention.

Other studies published more recently support the finding that some apparent gains have been made in the identification of hearing loss at an earlier age, but there remains a disappointing delay between suspicion, diagnosis and intervention. In 1996, Harrison & Roush reported data from 331 parental surveys from across the country. Their data showed an average of 7 months delay between the time of suspicion and diagnosis. An average of 6 months elapsed between the diagnosis and the time intervention began for children with mild to moderate hearing loss with no known risk factors. Parents of children with severe to profound hearing loss with no known risk factors reported a lag time of 3 months between the time of diagnosis and intervention. They also reported that children with known risk factors were suspected 4 months earlier, diagnosed

5.5 months earlier, and intervention begun 3 months earlier than children with the same degree of hearing loss with no known risk factors.

The time that expires between suspicion and diagnosis of hearing loss is crucial in terms of the child's language development. White and White (1986) reported significantly better language scores for a group of children diagnosed at a mean age of 11.9 months versus a group diagnosed around 19 months. In a study with 150 deaf and hard of hearing children, Yoshinaga-Itano (1998) reported children with hearing losses identified before 6 months of age demonstrated significantly better receptive and expressive language skills than did children identified after 6 months of age. This advantage was shown across age, gender, socioeconomic status, ethnicity, cognitive status, degree of hearing loss, mode of communication and presence or absence of other disabilities.

A 1991 study that reviewed at the medical records of 123 children at the Boys Town National Research Hospital found that the average age for familial referral regarding hearing loss is 2.75 years. It was also reported that the average age of identification for children who were referred by their pediatricians is 1.71 years. Both of these statistics are well beyond the age of identification recommended by the Joint Committee on Infant Hearing in 1990. From the Stein, and Harrison and Roush studies it can be said that hearing loss is generally suspected by the child's primary caregiver long before a diagnosis is made. Therefore, it would be assumed that significant time elapses before a child is referred for testing from the time the parents first suspect hearing loss.

The parents in Harrison and Roush's study reported that the time lapses between the diagnosis and intervention can most often be accounted for by delays due to third party payment, the child's illness, the necessity for further audiological testing, and delays due to obtaining a

proper hearing aid fitting. These time lapses may be difficult for a professional to overcome because that two out of the four reasons are out of an audiologist's control. On the other hand, Mace et al. (1991) postulated that lapses between suspicion and diagnosis of hearing loss might be due to the lack of concern by parents regarding hearing until speech and language development seemed to be delayed or that parents are uneducated to the fact that children can receive audiological testing at a very early age.

The key factor is that a parent, uneducated about hearing loss, can cause their child to lose valuable time in their speech and language development. The months that elapse between a parent's suspicion of hearing loss and identification of the impairment may be reduced through educating parents on risk factors, developmental milestones, and hearing assessment procedures. With this important fact in mind, it is up to professionals to supply parents with the information they need to make educated decisions about their child's hearing welfare.

Method

This qualitative survey examines what, if any, information pediatricians and hospitals in the St. Louis metro area distribute to parents regarding hearing loss in their children. Data were collected through an informal phone survey. The head nurse, at the pediatricians' office or on the birthing floor in the hospital, or the pediatricians themselves primarily gave the information. The pediatricians were selected randomly through the phone directory, and all major hospitals in the St. Louis area that administer care to pediatric patients were contacted. Eighteen out of sixty pediatricians' offices and eight of thirteen hospitals responded to the survey.

Three primary questions and one follow up question were asked of each of the pediatricians' offices. The questions were as follows:

- 1) Do you give out written information to parents regarding hearing loss?

If you give out information to parents, when is the information distributed?

- 2) Do you perform any hearing testing or screening at your office?
- 3) Who is your referral source when there were concerns about a child's hearing?

Each of the hospitals was also asked three primary questions and two follow up questions.

The questions were as follows:

- 1) Do parents who have children in the NICU receive information regarding hearing loss?

When do parents receive this information?

- 2) Do parents who have children in the well baby nursery receive information regarding hearing loss?

When do parents receive this information?

- 3) Are all babies born in your hospital currently screened for hearing loss?

Results

Table 1.1 shows only four or 22% of the 18 physicians surveyed do not give out any written information to parents regarding hearing loss. When questioned further it was determined that two of these pediatricians distributed information when the parents displayed concerns regarding hearing loss in their children. The other two pediatricians disbursed information when the child was seen for his or her annual physical at three years of age. Both of the physicians who gave out information at this time did so after an in-office hearing screening was conducted during the three-year checkup. An additional two pediatricians attested to performing a hearing screening in the office as part of an annual physical exam. The mean age of the initiation of the screening

was three years of age. The other fourteen pediatricians' offices surveyed reported parents did not receive any information from them regarding hearing loss. All of pediatricians surveyed reported routinely referring to other professionals when the parent expresses concerns about the hearing loss. The majority of referrals went either audiologists or Otolaryngologists.

Under the current insurance system, many Americans rely on their primary physician or pediatrician as the gatekeeper to other medical services. These physicians often are needed to issue a referral to other medical -personnel in order to have the cost of the care covered by a person's insurance. Therefore, the pediatrician often becomes the primary link to which parents turn in regards to the health of their children. With this in mind, the fact that only 22% of pediatricians ever address the issue of hearing loss with the parents of their patients seems disconcerting. Additionally, of the pediatricians that do address the issue of hearing loss, none include it routinely in their practice before the child is three years old or until the parent expresses concern about his or her child's hearing ability. It is well documented that language learning begins well before the age of three years old. Children with normal hearing will often be speaking in short sentences and have a significant vocabulary by this age. The incidental learning that the child has acquired up to this point has been monumental in the development of the child's language. A child who has a hearing loss that goes undiagnosed up until this time has been deprived of speech and language input for so long that much effort will be required to assist in development of communication abilities.

Of the eight St. Louis metro area hospitals that responded to the survey, three stated a current policy of screening every baby born at their facility. The type of screening procedure currently differs among hospitals and is noted in Table 1.2. Two hospitals currently use auditory brain responses as the screening tool, and the other hospital performs otoacoustic emissions as

part of the screening protocol. Of the remaining five hospitals, three only screened newborns in the neonatal intensive care unit (NICU) for hearing impairment. The other two hospitals did not screen any of the children in their hospital.

In three of the participating hospitals, information regarding hearing loss was given to all parents of newborns in the NICU. Alternatively, another three hospitals reported information given to parents only when their child fell into a certain criteria. In two these medical facilities, only parents of newborns who failed the ABR screening were given information addressing the possibility of hearing loss. In the third hospital, only parents of the children who are placed on ototoxic medications are given information on hearing loss.

Parents of newborns placed in the well-baby nursery after being born had less chance receiving information on hearing loss versus those in placed in the neonatal intensive care unit. Only three hospitals reported distributing information regarding hearing loss to parents of newborns in the well-baby nursery. Two-thirds of these hospitals gave out the information when the child was discharged from the hospital. It was noted that this information is usually included into a packet of information on a variety of topics given to parents before their child is discharged. Therefore, no direct reference is made to the parents regarding hearing loss. The third hospital distributed the information following the child's otoacoustic emissions screening. The remaining five hospitals reported that parents of babies in the well-baby nursery were given no information on hearing impairment before they took their newborns home from the hospital.

Discussion

The results of the survey can serve as a representative sample of the current practice of pediatricians and hospitals throughout the St. Louis metro area. The current practice of medical

services in regards to hearing loss seems to be lacking. Both a majority of the pediatricians and hospitals that responded to the survey reported they do not give information on hearing loss to parents. This majority holds true with the exception of parents who have newborns placed in the neonatal intensive care unit.

Another discouraging realization that was made during the collection of data was the apparent confusion between professionals about who was discussing hearing loss with parents. More than once physicians' offices answered that it was not policy to give out information regarding hearing loss because they believed the issue had already been covered by the hospital staff. Conversely, the opposite comment was made by the nurses who worked in the nurseries. One nurse commented that the issue is never brought up because it is left up to the pediatrician's discretion whether or not to mention hearing loss to the parents. This confusion about whose current responsibility it is to distribute information on hearing impairment can leave parents ignorant to the issue altogether.

According to Bess (1998), the data published in regards to early identification of hearing loss can provide us with an indication of the current state of affairs nationally. Taken together the studies are in agreement that we obviously fall well beyond the optimistic goal set by the Joint Committee on Infant Hearing in 1994 to identify hearing loss and to begin intervention by six months of age. Yet, all of the studies demonstrate large amounts of variability in the reported data among the subjects. In all the current studies, there are babies who are diagnosed and receive intervention at ages well below and well above the norm. This leads me to conclude that some parents are being educated about the possibility of hearing loss in their children and some are not. In order to achieve a time when all babies are diagnosed within the first six months, information must be made available to all parents.

The results of the survey indicated that three out of the eight participating hospitals currently have universal hearing screening programs in their facilities. By examining the policy of these hospitals it is possible to make some assumptions on how parent education regarding hearing loss might change in the future. In January of 2002, the universal newborn hearing screening law takes effect in Missouri. At this time, the law requires that every baby born in Missouri be screened for hearing loss. If the three hospitals that currently have such programs intact serve as a model as what is to come, the news is encouraging. All three of the hospitals distributed information to parents regarding hearing impairment before the child was discharged from the hospital.

When newborn hearing screening laws take effect the focus of parental education in regards to hearing loss needs to change. With every child being screened for hearing loss immediately after birth the focus of education may need to switch to follow up care if needed and the possibility of acquired hearing loss later in childhood. Audiologists should take an active role in ensuring parents are receiving accurate and easily understood materials regarding hearing loss. They should also work to ensure parents understand the urgency in regards to follow up care due to the detrimental effects hearing impairment can have on speech and language development. Additionally, as advocates for hearing welfare we must make it our responsibility to continually work with pediatricians and pediatric hospitals to develop and implement successful newborn hearing screening programs which include the parents as active participants in the process.

At first glance the results of this survey seem discouraging when measured against the goal set by the Joint Committee on Infant Hearing in 1994. If the participating pediatricians and hospitals were used as a model of the current practices in the St. Louis area today, it would seem

that this goal is unattainable. Yet, in the near future many changes are going to take place in medical facilities that serve pediatric patients. With the enactment on the newborn hearing screening law this January, it seems many more hospitals will be taking the responsibility for educating parents regarding hearing loss. Such a program allows children with hearing to be diagnosed within the first few days of life. Therefore, as professionals we must then take on the goal of educating parents to the intervention services necessary to foster normal speech and language development in their children throughout their childhood.

Subject	Do you give out information to parents regarding hearing loss?	If you give information to parents, when do you distribute the information?	Do you do any hearing testing at your office?	Who do you refer a parent concerned about hearing loss to?
1	no		no	ENT
2	yes	when parent has concerns	no	otolaryngologist
3	no		no	ENT
4	no		yes	hospital
5	yes	at 3 years old	yes	audiologist
6	no		no	audiologist
7	no		no	ENT
8	yes	parental concerns	no	hospital
9	yes	at 3 years old	yes	ENT
10	no		no	hospital
11	no		yes	audiologist
12	no		yes	audiologist
13	no		no	ENT
14	no		no	ENT
15	no		no	
16	no		no	audiologist/ENT
17	no		no	audiologist/ENT
18	no		no	hospital

TABLE 1.1 Results from pediatrician survey

Hospital Name	Do parents who have children born in the NICU receive information regarding hearing loss?	When do parents receive this information?	Do parents who have children in the well-baby nursery receive information regarding hearing loss?	When do parents receive this information?	Do parents who have children in the well-baby nursery receive information regarding hearing loss?	When do parents receive this information?	Are all babies born in your hospital screened for hearing loss at this time?
St. John's Mercy	yes	if their child fails an ABR	yes		yes	when are discharged	yes
Barnes Jewish St. Peters	no		yes		yes	when are discharged	no
Christian Northwest	yes	if their child fails an ABR	no		no		yes
DePere	no		no		no		no
St. Anthony's	yes	after screening	no		no		no
St. Elizabeth's	yes	following OAE screen	yes		yes	following OAE screen	yes
St. Lukes	some (ototoxic meds)	following ABR screen	no		no		no
Cardinal Glennon	yes	following ABR screen	no		no		no

TABLE 1.2 Results from hospital survey

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