

Information for Families with Young Deaf and Hard of Hearing Children: Reports from Parents and Pediatric Audiologists

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Introduction

Parents' needs regarding information at the time of diagnosis has been a topic of discussion and investigation for more than two decades. In 1982, Williams and Darbyshire invited a small sample ($n = 25$) of parents to complete a questionnaire and be interviewed regarding their experiences surrounding the diagnosis of their child's hearing loss. Although small, the sample was demographically diverse. Among the reported findings, it was noted that 88% of the parents expressed a need for factual information about hearing loss and its effects on their child's development. When asked to restate the audiologist's explanation of hearing loss and what it would mean to their child, 40% were unable to do so and another 24% responded inaccurately. Parents consistently expressed a need for better counseling at the time of diagnosis and later in regard to educational and behavioral needs.

In 1987, Martin, George, O'Neal and Daley surveyed 500 parents of children with hearing loss and 500 audiologists. Parents were asked to respond to questions regarding their feelings and reactions to the ways they were told about their child's hearing loss. Audiologists were asked about current practices in parent counseling at diagnosis and the perceptions of audiologists about parents' reactions and counseling needs at the time of diagnosis. Parents reported that they wanted professionals to provide them with more information about the hearing loss, ramifications regarding education, communication, habilitation measures, and realistic expectations for the future. Parents preferred professionals who exhibited

a willingness to spend time with them, who listen and answer questions, and provide them with information, support, and hope. A substantial proportion of parents felt they accepted the diagnosis of deafness very quickly and wanted to move forward to implement intervention for their child. In contrast, very few of the audiologists had a similar impression of the parents. Furthermore, while most of the audiologists saw themselves as well qualified to provide counseling and emotional support, few parents considered the audiologists well suited for this role.

Parents' lack of confidence in the counseling skills of audiologist may be due in part to lack of educational preparation. Crandell (1997) examined the availability of counseling instruction within graduate audiology programs. Responses from 77 programs indicated that fewer than one-half offered a course in counseling and, among those that did, the course was required in only 27% of the programs.

In a study of the services rendered by audiologists and early intervention specialists, Roush and Harrison (1998) invited 400 parents to respond to an open-ended survey. Repeatedly, parents asked for more and better information about their child's hearing loss and the full range of intervention options. There was a recurring emphasis on the need for professionals to have a greater understanding of the emotional impact of the diagnosis.

These studies and others reflect a need to further explore what parents want, not only at the time of diagnosis but also in the weeks and months that follow. The need to identify parent priorities at two specific points in time was based on the finding of Martin et al. (1987) who reported that most parents felt they readily accepted their child's hearing loss and were soon ready to move ahead. If that is indeed the case, parent's needs for information are likely to change

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within the first few months following audiologic confirmation of the hearing loss.

Luterman (1979, 1985; Luterman and Kurtzer-White 1999) has repeatedly emphasized the importance of allowing families to pace themselves with regard to informational content and timing of delivery. But few studies have sought to determine the specific information desired by families at the time of diagnosis in the weeks and months that follow. In an effort to identify parents' priorities for information at the time of diagnosis and in the ensuing months, a checklist of topics was developed for distribution to parents of young children with hearing loss. Parents were asked to respond to two lists, first as the parents of a newly identified child and a second time as they might have responded a few months following confirmation of their child's hearing loss. The lists were identical with the exception of four items, which reflected priorities a few months after confirmation of hearing loss. Parents were also given the option of adding topics not listed. They were asked to assign a high, medium, or low priority for each topic, and to indicate the preferred format. Choices were, print, video, web-based, and "other". Following completion of each checklist, parents were asked to rank their top four priorities, generating two lists of priorities, once at time of diagnosis and a second time for priorities a few months following diagnosis. Parents were also given the opportunity to respond to several open-ended questions regarding other issues they believed to be important. Demographic information regarding both the child and the family was also collected (see Appendix A).

A similar instrument in the same format was designed for pediatric audiologists. The wording was changed slightly to make the items less specific to a particular child. For example, the item, "How might this affect my other children" was changed to, "How might this affect other children in the family." Pediatric audiologists were also asked to respond to questions regarding years of experience, academic degrees, and caseloads (see Appendix B).

Parent Respondents

In November, 2000, questionnaires were mailed to 611 parents whose children had been diagnosed with hearing loss. These parents were receiving a free introductory subscription to *Volta Voices*, a publication of the A.G. Bell Association for the Deaf. Follow-

ing review of the project by the executive director, parents' names and mailing addresses were provided to the investigators. Parents were asked to complete and return the questionnaire if their child had been born between January 1995, and October 2000. Parents' whose responses were included in the final analysis all had children between three months and five years 10 months of age. Of those returned, 118 were complete and met the above criteria. The return rate was 31%. Forty-one states were represented by at least one parent respondent.

Parents' Descriptions of their Children

Sixty percent of the parents reported no identifiable cause of hearing loss. Among the 40% who did specify a cause, 14% listed a specific syndrome or illness. Another 8% had hearing loss associated with prematurity; and 8% were identified with a genetic hearing loss. Meningitis and trauma at birth each accounted for 5% of the babies with a known cause of hearing loss.

The degree of hearing loss reported in this sample was not representative of the total population of children with hearing loss. Thirty-two percent of the children were described by their parents as having a mild-to-moderate hearing loss. Sixty-eight percent were described as having a severe-to-profound loss. Among all children with hearing loss in the United States this proportion is approximately the opposite. The proportionally high number of children with severe-to-profound hearing loss is most likely a function of the sample, composed of parents with children whose hearing losses were considered developmentally or educationally significant.

Parents were asked to indicate whether or not their child's hearing had been screened at birth. Nearly half (46%) of the children in the sample had their hearing screened prior to leaving the hospital. The remaining 54% had been referred for audiologic evaluation between birth and five-and-one-half years of age.

Parents of Children with Mild-to-Moderate Hearing Loss: Selected Priorities

Table 1 lists the priorities selected by parents of children with mild-to-moderate hearing loss at the time of diagnosis and a few months later. Two topics, *realistic timelines for learning speech and language*

Table 1. Parent priorities for children with mild-to-moderate hearing loss.

Priorities at the Time of Diagnosis

Learning about the causes of hearing loss
Understanding the audiogram
Realistic timelines for learning speech and language
Understanding the ear and hearing
Coping with the emotional aspects of hearing loss

Priorities a Few Months Later

Learning to listen and speak
Realistic timelines for learning speech and language
Responsibilities of early intervention agencies
Legal rights of children with hearing loss

and *understanding the ear and hearing*, were selected as equally important at the time of diagnosis.

Priorities at the Time of Diagnosis

Approximately one-third of the respondents described their child's hearing loss as mild to moderate. For those parents, topics pertaining to information, rather than the emotional aspects of hearing loss, received the greatest emphasis. The priority most frequently listed was *learning about the causes of hearing loss*. The next highest priority listed by this group of parents was, *understanding the audiogram*. Months and even years after a child's hearing loss is diagnosed, parents may still be mystified by their child's audiogram. As time goes by they may be less willing to ask for clarification of the abstract symbols and acronyms with which professionals appear so familiar. Careful explanation of a child's audiogram each time hearing is assessed is desired by many families and may facilitate their understanding of the hearing loss (and limitations of the audiogram). Professional acknowledgement that the information presented on an audiogram is abstract and difficult to comprehend may allow the parents to feel more comfortable asking questions.

Two topics were selected with the same frequency: *realistic timelines for developing speech and language* and *understanding the ear and hearing*. Both were identified as important information for parents of children with mild-to-moderate hearing loss and both reflect the parents desire to become active and knowledgeable in their child's habilitation.

Coping with the emotional aspects of hearing loss

was also selected as an important topic by this group. Although the emotional aspects of hearing loss on the entire family have been well documented (Bernheimer, Gallimore and Weisner 1990; Luterman 1996; McLinden 1990; Moses 1985) for many of the parents surveyed it was a lower priority than the informational topics. A possible explanation is the relatively mild degree of hearing loss for these children. To some degree this finding supports the assumption that parents, particularly those of children with milder degrees of hearing loss, are indeed ready to move more quickly into a proactive stage than we might have expected. However, it is important to remember that every family is unique. A situation one family might deal with easily can be overwhelming to another. Thus, diagnosis of a mild hearing loss can be as devastating to a family as diagnosis of a profound loss is to another.

Priorities a Few Months Later

To investigate whether or not parent's needs for information change during the first few months following diagnosis, parents were asked to respond a second time to the same list of topics. This time they were encouraged to focus on topics they felt were important a few months *after* confirmation of their child's hearing loss. Analysis of parent responses revealed that priorities for information were, indeed, different.

The first two priorities selected by most parents a few months following diagnosis were related to the development of audition and spoken language for their children. These were *learning to listen and speak* and *realistic timelines for developing speech and language*. Both of these priorities would seem to reflect the fact that this group of children has significant residual hearing and the ability to develop auditory, speech, and language skills. Provided with competent pediatric audiologic management and early intervention with a specialist in oral language development, many of these children should acquire speech and language within a developmentally appropriate timeframe.

The other two priorities selected were related to public policy and the provision of intervention/educational services. Specifically, the third priority was *responsibilities of early intervention agencies* and *legal rights of children with hearing loss*. These topics are consistent with issues cited by parents in another survey of parents who responded to questions

regarding the provision of early intervention services (Roush 2000). In that study, parents indicated 1) a need for professionals to provide information about all intervention options available, and 2) information about and referrals to services available in their communities. Parents want to be able to pursue intervention options armed with as much information as possible. Initially, parents may look to professionals for more guidance in making choices, but over time, given complete and unbiased information presented in a comprehensible format, most parents will become knowledgeable and effective advocates for their child.

Parents of Children with Severe-to-Profound Hearing Loss: Selected Priorities

Table 2 shows the priorities selected by parents whose children had been diagnosed with severe-to-profound hearing loss at the time of diagnosis and a few months later.

Table 2. Parent priorities for children with severe-to-profound hearing loss.

Priorities at the Time of Diagnosis

Learning about the causes of hearing loss
Coping with the emotional aspects of hearing loss
Learning to listen and speak
Understanding the ear and hearing

Priorities a Few Months Later

Learning to listen and speak
Cochlear implants
Communication options
Realistic timelines for learning speech and language

Priorities at the Time of Diagnosis

Like parents of children with milder degrees of hearing loss, parents whose children had been diagnosed with severe to profound hearing loss rated *causes of hearing loss* as their highest informational priority. As one parent noted, “All parents grieve and feel guilty, wonder what they did wrong, and even feel guilty about feeling guilty.” The concern parents expressed regarding cause of hearing loss is pervasive. A father wrote, “You try so hard to do all the right things for your children. When something like this happens that you can’t explain or point to a cause for it, your mind just won’t leave it alone. You keep

going back to it over and over.” At the present time, approximately 50% of the diagnoses of pediatric hearing loss have a known etiology (Fortnum and Davis 1993). Thus, it could be speculated that about half of all parents struggle, sometimes for years, with the question of causality. This percentage should decline in the future as more families elect to pursue genetic testing.

Coping with the emotional aspects of hearing loss was also ranked among the highest priorities. A diagnosis of severe-to-profound hearing loss is life changing for many families. One mother wrote, “The day and many days after our son’s diagnosis were some of the worst days of our lives. It was as though someone had died.” Similar comments were made by many parents. The emotional upheaval parents experience at the time of diagnosis, and for some time afterward, is substantial. Although parents may accept their child’s hearing loss and want information and materials to begin helping their child (Martin et al. 1987), the emotional aspects of loss or change continue throughout childhood in various ways (Luterman 1979). The manner in which the audiologist responds can be instrumental in helping parents deal positively with their feelings and their specific situations, or can create a barrier to the development of a collaborative relationship between parents and professionals. Unfortunately, little seems to be changing in the curricula regarding the level of counseling skills and knowledge in audiology or speech-language pathology. Culpepper, Mendel and McCarthy (1994) indicated there had been almost no change in the number of counseling courses in training programs from a similar study eight years earlier. At the same time, Culpepper and colleagues reported that almost everyone involved in these programs believes counseling is an important component of successful intervention.

Another highly ranked priority was *learning to listen and speak*. As newborn hearing screening becomes implemented across the United States, babies are being identified, diagnosed, and fitted with hearing aids at a very young age. Even children with severe-profound hearing loss are experiencing unprecedented success in language, speech, and auditory development. While optimal hearing aid fitting is fundamental to achieving these outcomes, parents are instrumental as language facilitators, models, and communication partners. A collaborative partnership that includes the family, the audiologist, the speech-language pathologist, and early intervention

personnel knowledgeable in communication and hearing loss, is likely to achieve the best outcomes. When such a team is unavailable, parents frequently turn to their audiologist as a resource for materials about speech and language development. Tools such as the IT-MAIS (Robbins, Renshaw and Berry 1991) or Auditory-Verbal Ages and Stages of Development (Estabrooks 1998) are easy for parents to read and implement with minimal guidance.

Understanding the ear and hearing was also important for parents of children with severe to profound hearing loss. "Shortly after our son's diagnosis we were bombarded by two things: our emotions and grieving, and the need to find out as much information as possible." Information regarding how the ear processes sound is available in both print and video formats. For families with access to a computer a wealth of information is available on websites such as those maintained by the Early Hearing Detection and Intervention Resource Center <http://www.infantheating.org/ehdi/index.html> at Utah State University or the Marion Downs Center, <http://www.colorado.edu/slhs/mdnc/> at the University of Colorado.

Priorities a Few Months Later

As seen in table 2, a few months after diagnosis parents rate *learning to listen and speak* as an even higher priority. It is interesting to note that while *causes of hearing loss* and *coping with the emotional aspects of hearing loss* were initially the highest priorities, after several months there was a shift toward topics related to communication or to technologies that might facilitate acquisition of auditory, speech, or language learning.

Luterman (1979, 1996) and Moses (1983) have long advocated that parents be allowed to determine the pace of intervention and to decide what they need to know and when they need to know it. It appears that the needs of at least some parents do change, and the ability of professionals to respond to those changing needs may be a critical factor in maintaining a collaborative relationship with families.

Pediatric Audiologists

The membership list of the National Association of Children's Hospitals and Related Institutions was the source of the mailing list for the professional questionnaire. Questionnaires were addressed to the

"pediatric audiologist" at each hospital. A total of 121 were mailed and 48 were returned for a return rate of 40%. Of those returning the questionnaire, 74% had earned a master's degree, 15% had a Ph.D., and 11% had an Au.D. degree. Most of the audiologists (75%) had more than 5 years of experience. Nine percent had 1–2 years and 16% had 3–5 years of experience.

Reported caseloads ranged from 1 child to 100 children. Forty percent of the audiologists reported caseloads between 1 and 15 children; 53% reported a range of 16–30 children in their caseloads and 6% provided services for 31–100 children. One percent indicated caseloads of more than 100 children.

Hospital based pediatric audiologists were asked to respond to a questionnaire almost identical to the questionnaire sent to parents. Like the parent respondents, the audiologists were asked to indicate their priorities for information to share with families at the time of diagnosis of hearing loss and then again a few months later. However, they did not respond based upon the child's degree of hearing loss. Thus, one set of priorities was reported for each point in time.

Pediatric Audiologists' Priorities

The priorities selected by pediatric audiologists are listed in table 3.

Table 3. Priorities selected by audiologists.

Priorities at the Time of Diagnosis

Coping with the emotional aspects of hearing loss
Explaining the cause of hearing loss
Understanding the audiogram
Understanding the ear and hearing

Priorities a Few Months Later

Learning to listen and speak
What to expect from hearing aids
Realistic timelines for learning speech and language
Coping with the emotional aspects of deafness

Priorities at the Time of Diagnosis

Audiologists have, at times, been criticized for lack of empathy and emotional support at the time of diagnosis. In particular, parents have been critical of professionals' insensitivity to their feelings when conveying diagnostic information (Corcoran, Stewart,

Glynn and Woodman 2000). They have also indicated that some professionals distance themselves by using technical jargon and unfamiliar terminology (Sjoblad, Harrison, Roush and McWilliam 2001). Those reports are clearly inconsistent with the number one priority selected by this sample of audiologists: *coping with emotional aspects of hearing loss*. Sample selection may be a critical factor that serves to explain the difference between the experiences reported by many families and the priorities of audiologists represented here. The audiologists represented in this study all worked in children's hospitals and most had more than five years of experience working with children and their families. Thus, their sensitivity and level of skill in working with families of newly diagnosed children was likely to be different from that of audiologists whose primary clinical experience is with adults and older children.

Priorities a Few Months Later

The goal of assisting a child in *learning to listen and to speak* was assigned the highest priority by audiologists. From a clinical perspective, much is changing in the role audiologists play in providing service to infants and toddlers with hearing loss and their families. Optimal hearing aid fitting continues to be a fundamental component of the pediatric audiologist's role. In addition, new technologies have provided more children the potential for developing normal, or near normal, speech and language. We believe the priority audiologists assigned to *learning to listen and speak* reflects optimism among professionals regarding outcomes for young children. Pediatric audiologists are clearly aware that they can and do have a vital role in early intervention.

What to expect from hearing aids was the second priority identified by audiologists. A study by Sjoblad et al. (2001) is of particular relevance to this priority. Parents were asked a series of questions regarding their concerns at the time their child's hearing aids were fitted. Three areas were identified: (1) hearing aid maintenance, (2) appearance of the hearing aids, and (3) potential benefit provided by the hearing aids. Nearly three-fourths of the parents reported anxiety related to aspects of hearing aid management, ranging from inserting and cleaning earmolds, to monitoring hearing aid function. Two-thirds indicated that appearance of their child's hearing aids had originally been a concern to them and almost half were worried that their child might be socially rejected following

hearing aid fitting. The audiologist's experiences with the benefits amplification can provide in development of speech and language may minimize their sensitivity to issues of appearance for the families. Among the most compelling findings of Sjoblad and colleagues was the report that only 12% of the parents felt their expectations for their child's hearing aids had been met within a few weeks of hearing aid fitting. When asked if expectations had been met over a period of months or even years, only 25% of parents responded positively. When parents are not satisfied with hearing aids they may be less invested in having the child use them consistently. Clearly, issues surrounding the fitting of hearing aids and what to expect from them, are important priorities for pediatric audiologists and the families they serve. For some parents, simply acknowledging that appearance and maintenance of the hearing aid can be stressful may be an important step in creating an atmosphere of support and trust. Of at least equal importance is the need for audiologists to be realistic about the benefits amplification can provide and the amount of time and intervention necessary to achieve those outcomes.

Realistic timelines for learning speech and language was the topic ranked third by the audiologists who responded to this survey. This topic is closely related to the highest priority in the months following diagnosis, *learning to listen and to speak*. Early detection of hearing loss is a cornerstone to age-appropriate development of speech and language. Appropriate audiologic management, including timely selection and fitting of hearing aids or a cochlear implant, is equally crucial. Only when these components are in place can the child begin to use developmental patterns of listening, language, and speech for communication. Audition, speech, and language move through predictable and hierarchical levels beginning with detection and continuing through multiple levels of comprehension and production. Familiarity with materials describing the stages of development by the audiologist is essential to a child's success. Without that information the audiologist cannot determine if reasonable progress is being made. A collaborative, family-centered relationship with a speech-language pathologist, auditory-verbal therapist, or a teacher of the hearing impaired who is knowledgeable about oral language development, will facilitate the most positive developmental outcomes.

Pediatric audiologists ranked *coping with the emotional aspects of hearing loss* as the fourth most

Table 4. Comparison of priorities for parents of children with mild-to-moderate hearing loss, parents of children with severe-to-profound hearing loss, and audiologists.

Mild-to-Moderate	Severe-to-Profound	Pediatric Audiologists
Causes of hearing loss	Causes of hearing loss	Emotional aspects
Understand audiogram	Emotional aspects	Causes of hearing loss
= Understand ear & hearing	Learn to listen & speak	Understand audiogram
= Realistic timelines for learning to listen & speak		
Emotional aspects	Understand ear & hearing	Understand ear & hearing

important topic in the months following diagnosis. This finding is consistent with previous reports (Harrison, Dannhardt and Roush 1996; Roush and Harrison 1998; Roush and Matkin 1994), emphasizing the need for professionals to bring greater understanding of the emotional impact created by a diagnosis of permanent hearing loss and the effects on the entire family. Parents often express a need for professionals to be aware of and supportive of the grieving process, an honest but positive approach in describing the child's hearing loss, and recognition of each child and family as unique. Although some parents want to move into a proactive stage as quickly as possible, many report that the emotional aspects linger for years. The response of one parent is typical; "There was also a long grieving process for us—that even now five years later will resurface at times" (Roush and Matkin 1994). For many parents there may be an on-going conflict between accepting the hearing loss and dealing with the emotions attached to any loss. Awareness of recurring or unresolved grieving periods is a critical component of a successful family-centered partnership. As a group, the experienced pediatric audiologists sampled here seem to appreciate the importance of attending to the emotional aspects of a child's hearing loss beyond the initial point of diagnosis.

Comparing Parent and Professional Priorities

Table 4 lists the top priorities selected by parents of children with mild-to-moderate hearing loss, those selected by parents of children with severe-to-profound hearing loss, and those selected by the pediatric audiologists. It is striking that the priorities selected by pediatric audiologists are very similar to those selected by the parents. Although the rankings vary slightly, with only one exception the priorities

selected by each group are identical. The one topic not selected by all groups was a priority of parents of children with mild-to-moderate hearing loss: *realistic timelines for learning to listen and speak*.

The congruence of priorities expressed by parents and experienced pediatric audiologists is, in our opinion, an indication of the need to establish specialized pediatric audiology centers where families can be served by an experienced team of professionals. We believe that audiologists who specialize in management of pediatric hearing loss, in addition to being well versed in the technical aspects of pediatric audiology, are most likely to be aware of and sensitive to the emotional impact of hearing loss on the entire family.

As newborn hearing screening becomes fully implemented, a greater percentage of children with hearing loss will be identified at or near birth. The need for pediatric teams that include audiologists, speech-language pathologists, early intervention personnel, and medical specialists, must grow proportionally. Collaborative service delivery models have the potential to match families' needs for information, support, and specialized services with the resources needed to insure optimal outcomes for young children and their families.

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Appendix A

Parents often express a desire to have information to take home after talking to the audiologist when they first learn about their child’s hearing loss. Below is a list of topics about hearing loss. Please rate each topic according to what you feel families need **AT THE TIME THE HEARING LOSS IS IDENTIFIED**.

Circle “H” (High priority), “M” (Medium priority), or “L” (Low priority).
 Next circle the format that might best present the information:
 P = Printed materials, V = Video, W = Web resources. If “other”, please explain.

What information should be provided WHEN THE HEARING LOSS IS IDENTIFIED?

Priority	Topic	Best Format—Circle One
1. H M L	The ear and hearing	P V W other _____
2. H M L	Causes of hearing loss	P V W other _____
3. H M L	Learning to listen and speak	P V W other _____
4. H M L	Understanding the audiogram	P V W other _____
5. H M L	Types of hearing aids	P V W other _____
6. H M L	How hearing aids work	P V W other _____
7. H M L	What to expect from hearing aids	P V W other _____
8. H M L	Care and maintenance of hearing aids	P V W other _____
9. H M L	FM systems	P V W other _____
10. H M L	Cochlear implants	P V W other _____
11. H M L	Coping with the emotional aspects of hearing loss	P V W other _____
12. H M L	Opportunities to interact with other parents	P V W other _____
13. H M L	Descriptions of parent organizations	P V W other _____
14. H M L	Responsibilities of early intervention agencies	P V W other _____
15. H M L	Audiology services	P V W other _____
16. H M L	Speech language pathology services	P V W other _____
18. H M L	Legal rights of children with hearing loss	P V W other _____
19. H M L	Financial issues related to hearing aid purchase	P V W other _____
20. H M L	Communication Options (e.g., sign language, oral)	P V W other _____
20. H M L	Other _____	P V W other _____
21. H M L	Other _____	P V W other _____

From the numbered list above, please indicate the *four* most important topics at the time the hearing loss is identified.

1. # _____ 2. # _____ 3. # _____ 4. # _____

Now think about the **FIRST FEW MONTHS AFTER the hearing loss is identified**. What information do you think would be most helpful to families at that time?

Priority	Topic	Best Format—Circle One
1. H M L	The ear and hearing	P V W other _____
2. H M L	Causes of hearing loss	P V W other _____
3. H M L	Learning to listen and speak	P V W other _____
4. H M L	Understanding the audiogram	P V W other _____
5. H M L	Types of hearing aids	P V W other _____
6. H M L	How hearing aids work	P V W other _____
7. H M L	What to expect from hearing aids	P V W other _____
8. H M L	Care and maintenance of hearing aids	P V W other _____
9. H M L	FM systems	P V W other _____
10. H M L	Cochlear implants	P V W other _____
11. H M L	Coping with the emotional aspects of hearing loss	P V W other _____
12. H M L	Opportunities to interact with other parents	P V W other _____
13. H M L	Descriptions of parent organizations	P V W other _____
14. H M L	Responsibilities of early intervention agencies	P V W other _____
15. H M L	Audiology services	P V W other _____
16. H M L	Speech language pathology services	P V W other _____
17. H M L	Communication Options (e.g., sign language, oral)	P V W other _____
18. H M L	Legal rights of children with hearing loss	P V W other _____
19. H M L	Financial issues related to hearing aid purchase	P V W other _____
20. H M L	Local schools' responsibility for meeting the child's needs	P V W other _____
21. H M L	How might this affect other children in the family	P V W other _____
22. H M L	Assistive listening devices	P V W other _____
23. H M L	Realistic timelines for learning speech and language	P V W other _____
24. H M L	Other _____	P V W other _____

From the numbered list above, indicate the *four* most important topics in the first few months after the hearing loss is identified.

1. # _____ 2. # _____ 3. # _____ 4. # _____

Have we forgotten anything that is important to you?

If you were designing a “parent information kit” for families with a newly identified infant, what would you put in it (for example, pamphlets, battery tester, etc)?

The following questions are about your child and his/her hearing loss.

1. How old is your child this month (November, 2000) ___ years ___ months

2. Do you know or suspect the cause of your child’s hearing impairment?

- unknown meningitis maternal rubella
 heredity prematurity trauma at birth
 other (please specify) _____

3. How has your child’s hearing loss been described to you?

- Mild (20–40 dBHL) Severe (70–90 dBHL)
 Moderate (40–70 dBHL) Profound (90 +) I don’t know

4. Was your child admitted to the Neonatal Intensive Care Unit (NICU)? ___ yes ___ no

If yes, please tell us why and for how long.

5. What state did you live in when your child's hearing loss was confirmed? _____
6. Was your child's hearing screened at birth? ___ yes ___ no
7. If yes, was it because: ___ Hospital policy to screen all newborns ___ Admission to NICU
8. If yes, did your child pass the newborn screening? ___ yes ___ no
9. If your child's hearing was *NOT* screened at birth, who referred you for a hearing test?
____ self ____ Pediatrician/Other physician ____ other
____ child care ____ Early Intervention Specialist (please explain)

For the following questions, if you do not remember exact ages, please answer as accurately as you can.

10. How old was your child when the hearing loss was confirmed by an audiologist?
___ years and ___ months
11. How old was your child when she/he was fitted with hearing aids?
___ years and ___ months
12. Is your child participating in an early intervention program? ___ yes ___ no
If yes, How old was your child when he/she started the program? ___ years and ___ months
13. If more than one month passed between the identification of the hearing loss and fitting of hearing aids, please describe the reasons.
- _____
- _____
- _____
- _____
- _____
- _____

Please answer these questions about your family.

1. The person filling out this survey is the child's
____ mother ____ grandparent ____ stepparent
____ father ____ foster mother ____ other, please specify your relationship to the child
-

2. How would you describe the area where you live?

rural large city
 suburban small city

3. How would you describe your ethnic background?

White African-American Hispanic
 Asian Other (please specify) _____

4. Mother's education:

less than 12th grade jr. college some college college graduate
 high school graduate technical school graduate or professional

5. Mother's occupation: _____

6. Father's education:

less than 12th grade jr. college some college college graduate
 high school graduate technical school graduate or professional

7. Father's occupation: _____

8. Do you have a computer in your home with Internet access? yes no

9. If yes, Have you used the web for information regarding hearing loss? yes no

Have you found **Volta Voices**, AG Bell's monthly magazine, to be a useful resource? Why or why not. _____

What topics would you like to see covered in **Voices** ?

May we quote you? Not by name, of course, but we would like to compile some parent-to-parent quotations. If you had the opportunity to speak with parents on the day their child's hearing loss was diagnosed, what comments, suggestions, or other advice would you share? Please write them in the space below. Our plan is to compile these remarks in a small booklet that could be included with materials given to parents on the day of diagnosis or shortly after. Thank you!

Appendix B

Parents often express a desire to have information to take home after talking to the audiologist when they first learn about their child’s hearing loss. Below is a list of topics about hearing loss. Please rate each topic according to what you feel families need **AT THE TIME THE HEARING LOSS IS IDENTIFIED.**

Circle “H” (High priority), “M” (Medium priority), or “L” (Low priority).

Next circle the format that might best present the information:

P = Printed materials, V = Video, W = Web resources. If “other”, please explain.

What information should be provided WHEN THE HEARING LOSS IS IDENTIFIED?

Priority	Topic	Best Format—Circle One
1. H M L	The ear and hearing	P V W other _____
2. H M L	Causes of hearing loss	P V W other _____
3. H M L	Learning to listen and speak	P V W other _____
4. H M L	Understanding the audiogram	P V W other _____
5. H M L	Types of hearing aids	P V W other _____
6. H M L	How hearing aids work	P V W other _____
7. H M L	What to expect from hearing aids	P V W other _____
8. H M L	Care and maintenance of hearing aids	P V W other _____
9. H M L	FM systems	P V W other _____
10. H M L	Cochlear implants	P V W other _____
11. H M L	Coping with the emotional aspects of hearing loss	P V W other _____
12. H M L	Opportunities to interact with other parents	P V W other _____
13. H M L	Descriptions of parent organizations	P V W other _____
14. H M L	Responsibilities of early intervention agencies	P V W other _____
15. H M L	Audiology services	P V W other _____
16. H M L	Speech language pathology services	P V W other _____
17. H M L	Communication Options (e.g., sign language, oral)	P V W other _____
18. H M L	Legal rights of children with hearing loss	P V W other _____
19. H M L	Financial issues related to hearing aid purchase	P V W other _____
20. H M L	Other _____	P V W other _____
21. H M L	Other _____	P V W other _____

From the numbered list above, please indicate the *four* most important topics at the time the hearing loss is identified.

1. # _____ 2. # _____ 3. # _____ 4. # _____

Now think about the **FIRST FEW MONTHS AFTER the hearing loss is identified**. What information do you think would be most helpful to families at that time?

Priority	Topic	Best Format—Circle One
1. H M L	The ear and hearing	P V W other _____
2. H M L	Causes of hearing loss	P V W other _____
3. H M L	Learning to listen and speak	P V W other _____
4. H M L	Understanding the audiogram	P V W other _____
5. H M L	Types of hearing aids	P V W other _____
6. H M L	How hearing aids work	P V W other _____
7. H M L	What to expect from hearing aids	P V W other _____
8. H M L	Care and maintenance of hearing aids	P V W other _____
9. H M L	FM systems	P V W other _____
10. H M L	Cochlear implants	P V W other _____
11. H M L	Coping with the emotional aspects of hearing loss	P V W other _____
12. H M L	Opportunities to interact with other parents	P V W other _____
13. H M L	Descriptions of parent organizations	P V W other _____
14. H M L	Responsibilities of early intervention agencies	P V W other _____
15. H M L	Audiology services	P V W other _____
16. H M L	Speech language pathology services	P V W other _____
17. H M L	Communication Options (e.g., sign language, oral)	P V W other _____
18. H M L	Legal rights of children with hearing loss	P V W other _____
19. H M L	Financial issues related to hearing aid purchase	P V W other _____
20. H M L	Local schools' responsibility for meeting the child's needs	P V W other _____
21. H M L	How might this affect other children in the family	P V W other _____
22. H M L	Assistive listening devices	P V W other _____
23. H M L	Realistic timelines for learning speech and language	P V W other _____
24. H M L	Other _____	P V W other _____

From the numbered list above, indicate the *four* most important topics in the first few months after the hearing loss is identified.

1. # _____ 2. # _____ 3. # _____ 4. # _____

The Joint Committee on Infant Hearing *Year 2000 Position Statement* recommends that infants with no medical contraindications begin use of amplification within one month after confirmation of hearing loss. (assuming parents concur)

Do you agree with this goal? (circle one) Yes No

If no, why?

When there is a delay of more than one month between diagnosis and hearing aid fitting, what are the most common reasons?

What are the greatest challenges to you as an audiologist in providing services to newly identified infants?

What specific recommendations do you have for facilitating audiologic management from diagnosis to intervention?

If you were designing a “parent information kit” for families of a newly identified infant, what would you include?

How many years of experience do you have with children with who have hearing loss? Check one

___ 1–2 years ___ 3–5 years ___ 6–10 years ___ 11 + years

Please *estimate* the number of children birth-12 months currently on your caseload _____

What is your highest degree? ___ Master’s ___ Ph.D. ___ Au.D.

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