

# **Strategies for Educating Physicians About Newborn Hearing Screening**

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The benefits associated with universal Newborn Hearing Screening (NHS) are most likely to be achieved when screening is linked to timely and effective interventions. Well-informed primary care physicians (PCPs) are in a key position to educate families about the importance and most effective ways of following-up for infants who do not pass the NHS test. Unfortunately, little information has been systematically collected to document physicians' current knowledge and needs, nor the methods for addressing them. This study combined qualitative methods (focus groups) with a national survey to gain an understanding of physicians' attitudes, knowledge, and practices related to NHS. The project also developed tailored resources for this professional group.

Newborn Hearing Screening (NHS) has become a standard of care throughout the United States (White, 2003), and recent statistics indicate that 93% of newborns are screened for hearing prior to hospital discharge (National Center for Hearing Assessment and Management [NCHAM], 2006). This nationwide effort has led to a reduction in the average age of identification of infants with hearing loss (Vohr, Carty, Moore, & Letourneau, 1998), and provides the potential for proactive intervention efforts that may prevent or minimize the impact of hearing loss

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on the learning of spoken language (Kennedy et al., 2006; Moeller, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). However, the ultimate success of these efforts is dependent on diagnosed children receiving timely and effective interventions. As states fully implement their NHS programs, a variety of challenges to follow-up have been reported. For some states, high rates of loss to follow-up threaten to undermine program effectiveness (Prieve et al., 2000).

As conceptualized in the medical home model (American Academy of Pediatrics [AAP], 2002), physicians play a key role in promoting follow-up and appropriate referral of infants who do not pass the newborn hearing screen. Families of newborns typically see physicians on a regular well-child appointment schedule during the first 2 years of a child's life, and they seek advice from healthcare professionals on multiple aspects of development. These well-child appointments are ideal times to monitor auditory and language development and to guide families in needed follow-up procedures for their infants. It is therefore vital that Primary Care Physicians (PCPs) have an understanding of NHS as well as an appreciation for the impact hearing loss has on speech and language development. Unfortunately, little information has been systematically collected about what physicians already know, what they need or want to know, or how they would prefer to learn about currently recommended practices for children who are deaf or hard of hearing.

Effective collaborations between audiologists and the medical home are needed to promote timely follow-up testing and early access to communication interventions. Reports from parents, audiologists, and state NHS program coordinators indicate that some physicians or other healthcare providers have minimized the failed screening to parents of newborns or have counseled parents to "wait and see" rather than pursue further testing (Kittrell & Arjmand, 1997). Concerned audiologists wishing to improve collaborative services to infants and their families will therefore benefit from better understanding physicians' perspectives on neonatal hearing loss and NHS and learning what methods are effective in shaping positive practices. Direct research with physicians will guide audiologists toward more effective strategies for information dissemination.

The current research project focused on identification of physician attitudes as well as knowledge related to NHS. This approach is based on a health communication model known as the *theory of reasoned action* (Glanz, Marcus Lewis, & Rimer, 1997). Within this theory it is asserted that the most important determinant of a person's behavior is *behavioral intention*. Intentions result from *attitudes toward performing the behavior* and the *individual's subjective norms* related to the behavior (Ajzen & Fishbein, 1980). Attitude is determined by an individual's beliefs about outcomes weighted by an evaluation of outcomes (Glanz et al., 1997). So, if a physician has a strong belief that a referral for hearing testing will benefit the patient and experience verifies that, the physician will have positive attitudes about referral. Conversely, negative beliefs regarding universal

NHS (e.g., concern about or experience with a high percentage of false positive screening results; and/or an underestimation of the impact of infant hearing loss on learning), will result in negative attitudes toward the referral behavior. The theory also asserts that an individual's subjective norm is determined by normative beliefs. A normative belief relates to social influences, such as a physician's philosophical alignment with important spokespersons or agencies that influence standard of care (e.g., AAP). Finally, the theory of reasoned action suggests that identification of knowledge gaps alone may not lead to practice changes. Rather, it is important to consider beliefs, experiences (or lack thereof), and affiliations that may influence attitudes and motivation to implement a new practice.

This study employed focus groups and a national survey to address three primary questions: (a) What are physician attitudes and/or experiences related to NHS, (b) do physicians perceive and/or demonstrate gaps in their knowledge related to NHS and follow-up, and (c) how do physicians want to be informed about this topic? This paper describes the results of the focus group work, along with supporting data from the survey work published elsewhere (Moeller, White, & Shisler, 2006). This discussion is followed by practical suggestions for audiologists who strive to educate and collaborate with physicians on NHS to improve the continuity of hearing care for infants and children.

## METHOD

The research was implemented in two stages: (a) focus group sessions analyzed with qualitative methods, and (b) empirical evaluation of the perspectives expressed in the initial focus groups through a nation-wide survey of 1,968 PCPs (see Moeller et al., 2006 for full details on the survey). To ensure the success of these efforts, staff at Boys Town National Research Hospital (BTNRH) and the NCHAM established collaborations with several organizations, including the AAP, a market research firm (Discover Why), and the Public Administration Program at the University of Nebraska. Both phases of the project were approved by the BTNRH Institutional Review Board.

### *Focus Group Participants*

A total of 32 pediatricians representing nine different states participated in three separate focus group sessions. Five pediatricians from a metropolitan practice group were recruited into a pilot focus group session. The purposes were to field test and refine a moderator's script to be used in the second and third focus group sessions. Physicians were recruited into the second focus group through mailings and e-mails to the Nebraska Chapter of the AAP. The session was limited to the first 14 physicians who responded. The third focus group was formed by recruiting in collaboration with the national office of AAP in order to broaden the geographic representation of the sample. AAP was hosting a Pediatric Update workshop in Breckenridge, CO. Recruiting materials were mailed to pedia-

tricians who were registered for the workshop. The first 13 volunteers (all non-Nebraskans) were enrolled in the focus group session, which was held on the evening prior to the workshop. The size of focus groups was purposely limited to ensure active participation by all involved.

During the recruiting process, participants were informed that the researchers planned to create resources on NHS for the medical community and needed input from physicians on this important topic. Meals were provided, physicians were paid for their participation, and they received a complimentary packet of educational resources. Twelve participants were female, 20 were male. Twenty-five were from metropolitan area pediatric practices and 7 were from practices in small towns or rural communities.

### ***Focus Group Procedures***

Focus group discussions were structured to gain an understanding of physicians' knowledge, beliefs/attitudes, and experiences related to NHS. Another primary goal was to determine how physicians prefer to access information on newborn screening procedures. Pilot versions of physician-oriented resources on NHS were field-tested with the groups to assess their perceived utility.

Sessions were facilitated by a communications research specialist with input and collaboration from the authors. Questions used to guide the discussions are included in Appendix A. The facilitator clarified points from the discussion, worked to determine if there was consensus on main points, and encouraged the expression of alternate viewpoints. All sessions were audio recorded. Verbatim transcripts were prepared and coded by two of the researchers to identify discussion themes. Common themes were then identified across the three groups, with input from all authors. Preliminary analyses were examined and discussed by the authors before reaching final agreement on important and consistent themes.

### ***Survey Procedures***

A four-page paper survey was created based on analysis of the focus group results (Moeller et al., 2006). Early Hearing Detection and Intervention (EHDI) coordinators from all 50 states and U.S. territories were invited by NCHAM to participate in surveying physicians in their respective states. Twenty-one states and Puerto Rico agreed to mail surveys to a random sample of at least 200 physicians in their states for a total of 12,211 mailed surveys.

### ***Survey Participants***

A total of 1,968 physicians returned completed surveys, which was a response rate of 16.1%. The majority of respondents were pediatricians (58.6%), with family practitioners making up the second largest group (27%). A limited number of responses came from otolaryngologists (2.9%), neonatologists (2.7%), ob-

stetricians (0.5%), residents (1.7%), or other/unknown specialists (6.6%). Participants were well distributed by gender (49.4% male, 43.4% female, 7.2% unknown) and by practice location (57% metropolitan, 22% small town, 12.1% rural, 8.8% unknown).

## RESULTS AND DISCUSSION

### *Support for NHS*

In the sections that follow, results from focus group discussions are presented in conjunction with the survey results. This provides detail about the degree to which the broader survey confirmed the focus group themes. Primary themes identified from the focus group analysis also are provided in summary form in Table 1.

The majority of physicians participating in focus groups voiced support for NHS. One physician stated, "I wasn't very good at screening for hearing loss. I

**Table 1**

Primary Themes Identified Across the Focus Group Sessions ( $n = 32$ )

<b>Support for NHS</b>	<b>Knowledge needs</b>
Concept of NHS supported	Desire for information on NHS
Concerns for system issues	Preference for concise, just in time resources
	Immediate follow up guides
<b>Costs and cost/benefit</b>	<b>Strategies and sources for learning</b>
Hearing loss a low incidence and lower priority medical issue	Preference for: <ul style="list-style-type: none"> <li>• evidence-based materials</li> <li>• recognized medical journals</li> <li>• trusted sources (such as AAP)</li> <li>• easy-to-read guidelines</li> <li>• management algorithms</li> </ul>
Concern over resource allocation	
Concern for high false positive rates	
Limited familiarity with actual costs of screening	
<b>Role perceptions</b>	<b>Other suggestions</b>
Patient management <ul style="list-style-type: none"> <li>• Improve communication among hospitals, physicians, parents</li> </ul>	Use clear terminology <ul style="list-style-type: none"> <li>• Improve cross-disciplinary communication</li> </ul>
Making appropriate referrals to specialists	Make parent resources available
Developmental surveillance <ul style="list-style-type: none"> <li>• Including methods to identify late-onset losses</li> </ul>	Educate other medical providers <ul style="list-style-type: none"> <li>• nurses</li> <li>• family practice physicians</li> </ul>
Counseling & educating families	

*Note.* NHS = Newborn Hearing Screening; AAP = American Academy of Pediatrics.

focused on the general state of the baby. It is easy to miss hearing loss and families can miss it for a long time too.” Another pediatrician noted,

NHS has been wonderful. In the previous thirty-five years we've been through bells and whistles and everything that didn't work. I can honestly say that I've gotten burned on every one I have had in thirty years, and did not pick them up soon enough.

These responses suggest that previous experiences were shaping present attitudes. The majority of survey respondents supported the positive views of the focus group participants, with 81.6% indicating that it was *very important* to screen for hearing loss at birth. Only 4.4% stated that NHS was unimportant.

In general, our data suggest that physicians support the *concept* of screening. However, they voiced many concerns about practical issues, including costs, system breakdowns, inconsistent care coordination, and need for more evidence about benefits. Some physicians made statements that showed a tendency to underestimate the consequences of partial hearing loss on infants. These issues and their implications are reviewed in the sections that follow.

### ***Costs and Cost/Benefit***

Cost was a main theme identified in the focus group transcripts. Physician statements included concerns about the costs to patients (both emotional and financial), costs to hospitals, and limited reimbursement to practices and hospitals. These issues influence physician beliefs about the cost/benefit ratio for newborn screening. One pediatrician stated, “I don't doubt that we get a better outcome from early identification, but what is the cost? Are we developing another industry to use scarce medical resources? Is there a better allocation in some other area?” This statement suggests that infant hearing loss is a low priority health issue for some physicians. This may occur because most physicians see few children who are deaf or hard of hearing and, compared to other health conditions, infant hearing loss appears to have less obvious impact. It may also be because the long-term negative repercussions of hearing loss are not physically debilitating, per se, but are instead manifest in the areas of language, communication, and education (Spencer & Marschark, 2006). These perceptions need to be addressed through education and by providing evidence about the consequences of all degrees of hearing loss on infants. Provision of epidemiological data also may help. In the national survey, 23.4% of physicians were unsure or unconvinced that benefits of early hearing loss detection outweighed the costs of NHS. This suggests the need to increase education about the effects of hearing loss on communication and learning *and* empirical evidence in support of early detection and intervention.

Other cost-related concerns included lost time for the physician and the stress on families when an infant fails the hearing screening. For example, a physician from a rural practice explained that a parent kept him on the phone for 90 min

following her newborn's failed hearing screening. The infant subsequently passed the second screening. In addition to expressing concern for the anxiety experienced by the parent, he also stated, "I do not get reimbursed for that time." In the national survey, however, 84.7% of physicians stated that NHS did NOT cause undue anxiety for families. This perception may be influenced by physicians' mounting experience with parental relief once a referred infant passes the second screening. In reality, parental responses to NHS may be highly variable (Young & Tattersall, 2005).

Perceptions about the cost/benefit ratio are influenced by physician experience with false positive screening results. For example, a physician stated,

The other part of the cost thing that bothers some of us is that if there was a substance in the baby's ears and the test did not work, the baby gets referred for more formal hearing evaluation and I've yet to see one of those come back where there really was a true hearing problem.

National survey participants also expressed concern about high false positive rates. Notably, physicians admit that high false positive rates can lead to complacency about failed screening and a lack of trust in the procedure. Staff at the primary care office may advise parents not to worry because "all the babies pass the second test." Information about acceptable false positive/refer rates and ways to achieve them will be valuable for physicians (Clemens, Davis, & Bailey, 2000). Some physicians in the focus groups reported that their hospitals made substantial improvement over time in reducing their false positive result rates. Peer-reports like this may be valuable to include in physician-oriented educational resources, because research demonstrates that such reports are influential (Davis, 1999). Ultimately, it is important to consider how unacceptably high false positive rates can negatively influence attitudes and practices of physicians.

A final caveat should be considered when interpreting issues around cost. The national survey results indicated that not all physicians are familiar with the actual costs associated with NHS. It is known that the cost per infant for a newborn screening test in hospitals with at least 1,000 births is \$30 or less (Kezirian, White, Yueh, & Sullivan, 2001; Weirather, Korth, White, Down, & Woods-Kershner, 1997). Yet, 35.6% of the respondents estimated the costs at \$100 or greater. Provision of actual cost information at their specific hospital(s) will be helpful to physicians. In the final analysis, a number of factors appear to influence physician beliefs about the cost/benefits of NHS.

### ***Role Perceptions***

Pediatric PCPs typically see newborns and infants on an established periodicity schedule (<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;105/3/645.pdf>), maintaining regular contacts with families during infancy and early childhood. Given their credibility with the parents and regular face-to-face contact, informed physicians are in an ideal position to encourage follow-up to NHS.

Physicians' comments in focus groups reflected four primary roles: (a) overall patient management (i.e., serving as a medical home for the child), (b) making appropriate referrals, (c) developmental surveillance, and (d) counseling and educating families. System challenges and informational gaps that threaten the ability to function effectively in these roles were also noted by the focus group participants.

**Overall patient management.** Physicians reported the need to be better informed about the training and qualifications of healthcare providers who administer NHS screenings. One pediatrician noted, "Who is doing the testing and is this person trained?" Another said,

We have every single nurse testing. Are they appropriately talking to parents? How is the nurse going to tell a parent that the baby did not pass? The parent thinks this is a sophisticated tester. Where am I in that loop?

These statements reflect skepticism about test accuracy and a concern for the physician's role in case management. There was consensus that the doctor needs to be notified of the results and that better channels of communication are needed between hospitals, medical practices/clinics, and parents. One participant stated, "If information does not get to the doctor, it is useless." Another added, "We need a better plan for how to get results." In the national survey, 12% of pediatricians and 17% of family physicians indicated that they receive NHS results on <50% of their patients. Increased confidence in the training of screeners and better communication about results would support physicians in their patient management roles.

**Making appropriate referrals.** Physicians expect to refer children with suspected or confirmed hearing loss to appropriate specialists. Potential barriers to appropriate referrals included: knowledge gaps about hearing loss etiologies, lack of a comprehensive follow-up protocol, and knowledge gaps about what happens in early intervention for infants with hearing loss. Participants in both the focus groups and the survey indicated the need for more information on causes of hearing loss and the genetics of hearing loss. Specific protocols for follow-up/referral were viewed as a *great need* by 66% of the survey respondents. Survey respondents were asked to list the specialists to whom they would refer infants who were diagnosed with a permanent hearing loss. Although otolaryngologists and audiologists were frequently listed, relatively few stated the need to refer to early intervention (11.4%), genetics (8.9%), or ophthalmology (0.9%). Wider dissemination of resources such as an algorithm chart developed by the AAP and NCHAM, which includes specific protocol steps for follow-up to NHS (available at <http://www.medicalhomeinfo.org/screening/hearing.html>), will support physicians in their referral role.

Results also showed that improved communication about strategies and goals of early intervention are needed. A focus group participant asked, "Okay so you've got this baby with hearing loss. What can we do right now? Or what time



does intervention need to be implemented?" Another stated, "Sometimes we'll have problems with parents being bombarded with all this information and we don't know how reliable the information is." A third observed, "I think the interventions I've heard of at one and a half or two (years of age) are basically helping the parents understand the rudiments of signing. But I haven't seen them go to other measures." These comments and questions indicate uncertainty about interventions and their timing. Further evidence came from the national survey, where 41.6% of physicians assumed incorrectly that infants cannot begin wearing hearing aids until *later than 6 months* (18.1% responded > 12 months). Audiologists are in a good position to address this issue. By communicating regularly with PCPs about interventions being provided to infants and young children, audiologists can help physicians better serve as the medical home for their patients while also educating them about the intervention process in general. A physician expressed it well in saying, "It's a long time before we find out what happens with those children. It would be really nice to get some feedback." Concise and timely feedback with limited technical jargon goes a long way in educating physicians about interventions.

Some focus group participants reported that they were well connected with early intervention teams. In those cases, physicians stated a clear appreciation for working with developmental specialists. One pediatrician stated, "Developmental specialists use a holistic approach to assessment. They do a much better job than I could possibly do, and so I tend to rely on them." This type of effective collaboration between the medical home and early intervention teams is a goal worth pursuing.

Two additional comments were relevant to understanding the early intervention process. One physician observed, "Hearing loss includes such a variety of kids. We need to be better educated about the various paths for this diverse set of kids." Another stated, "Parents look to us to see if their children are getting the education they need. It would be good to know the level of expertise of the intervention programs."

***Developmental surveillance.*** Physicians in focus groups also noted the importance of their role in ongoing monitoring. One stated,

We are actually screening every time we see the child. I mean if you have that articulate two-year old who is already speaking in six-word sentences, you are not going to waste time doing an audiogram. One thing we always hone in on is their speech (articulation and vocabulary).

Another reported that hearing loss would be suspected if a "baby has been babbling and all of a sudden they stop." The various comments revealed consistent attention to developmental landmarks. One physician added, "We need to be constantly assessing if the parent is raising a concern." However, physicians agreed that updated evidence-based information on speech, language, and auditory landmarks would support this role in surveillance. In addition, they reported

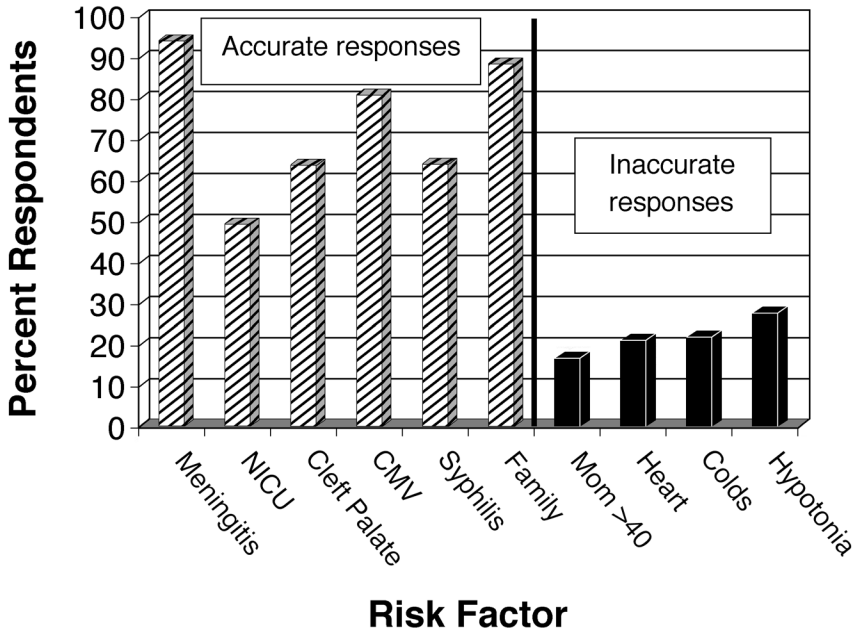


Figure 1. Percentage of respondents indicating that the respective conditions placed a child at risk for late-onset permanent hearing loss.

a need for tools for screening for late-onset hearing loss.<sup>1</sup> This need was supported by national survey results, illustrated in Figure 1. These results indicate informational gaps related to etiologies that may be associated with late-onset hearing loss. Another physician stated, “I need guidelines for identifying progressive hearing loss. It would help to have a set of specific questions to ask the mother and a better developmental checklist.”

**Counseling families.** Several focus group participants requested information on how to support the family when the infant does not pass the hearing screenings. One physician noted, “I need some guidance for when I am sitting with a parent. How worried should they be about this?” Another stated, “I would appreciate information on how to support the family, when they’ve expected an infant with normal hearing.” Pediatricians in focus groups were clear that severe and profound hearing loss had consequences for articulation and language. They were less certain about consequences of unilateral and mild-moderate hearing losses. A family physician reported, “Most of my kids with unilateral hearing loss are doing okay. Some have a hearing aid, but at least half of them will not wear it. So I don’t know if treatment is as necessary.” In contrast, a pediatrician

<sup>1</sup>An example of a Fact Sheet resource developed (by Leisha Eiten) in response to this need is included in Appendix B.

stated, “Some of these children have behavior problems. If he hears just some of the time, or he’s having trouble expressing his feelings or needs . . . you have subsequent developmental problems.” Provision of evidence-based summaries on consequences of mild-moderate and unilateral hearing loss would be a great help to physicians in counseling families.

Parents of children diagnosed with hearing loss may raise complex topics with their physicians, such as whether a cochlear implant is needed or which communication method should be used. Our focus group and survey results indicate that physicians lack confidence in discussing these topics with parents. Figure 2 illustrates how survey participants rated their confidence levels for a variety of topics. Given the complexity of these topics, it is probably unrealistic to expect that all physicians would become knowledgeable enough to counsel families in these areas. Perhaps the most realistic goal would be to educate physicians that decision-making related to cochlear implantation or communication methods are complicated, personal, and dependent on the individual characteristics of children and families; while at the same time providing the physician with access to basic, factual information (such as the type of hearing loss that would potentially qualify a child for a cochlear implant – an area where the survey revealed a basic lack of knowledge). Many decisions related to intervention options are best addressed with collaborative input from a variety of professionals.

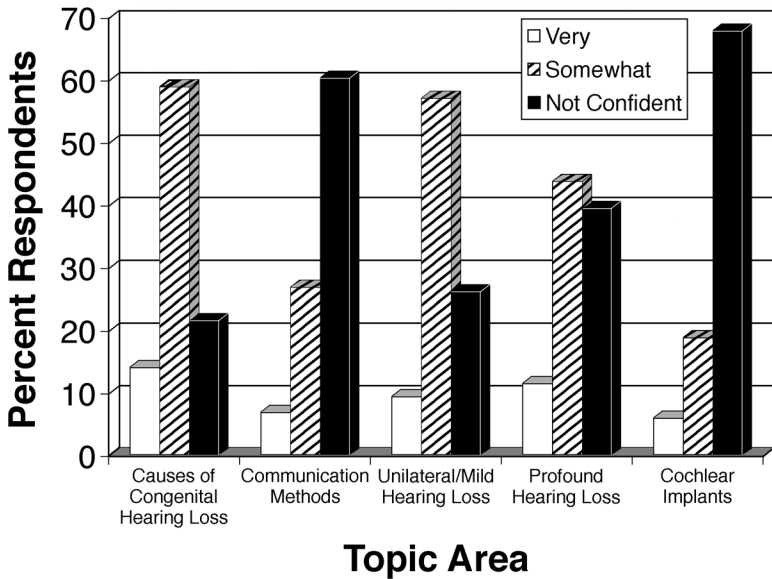


Figure 2. Confidence levels of survey respondents about counseling parents regarding various topics.

### *Physician Perception of Knowledge Needs*

A key conclusion from both the focus groups and the survey was that the typical PCP's contact with permanent childhood hearing loss is relatively infrequent and this influences knowledge and attitudes about current practices. Estimates suggest that the average pediatrician encounters a minimum of 12 children with severe or profound sensorineural hearing loss (SNHL) in the course of a practice lifetime. Our survey asked physicians to report the number of young children with SNHL they had seen in the past 3 years. Pediatricians reported an average of 3.32 children ( $SD = 4.9$ ), but family practice physicians reported an average of 1.25 ( $SD = 2.7$ ), which was a significant difference ( $t = 8.82, p < .001$ ). Given these data, some physicians (especially family practice doctors) may not perceive an immediate need for information on SNHL in children.

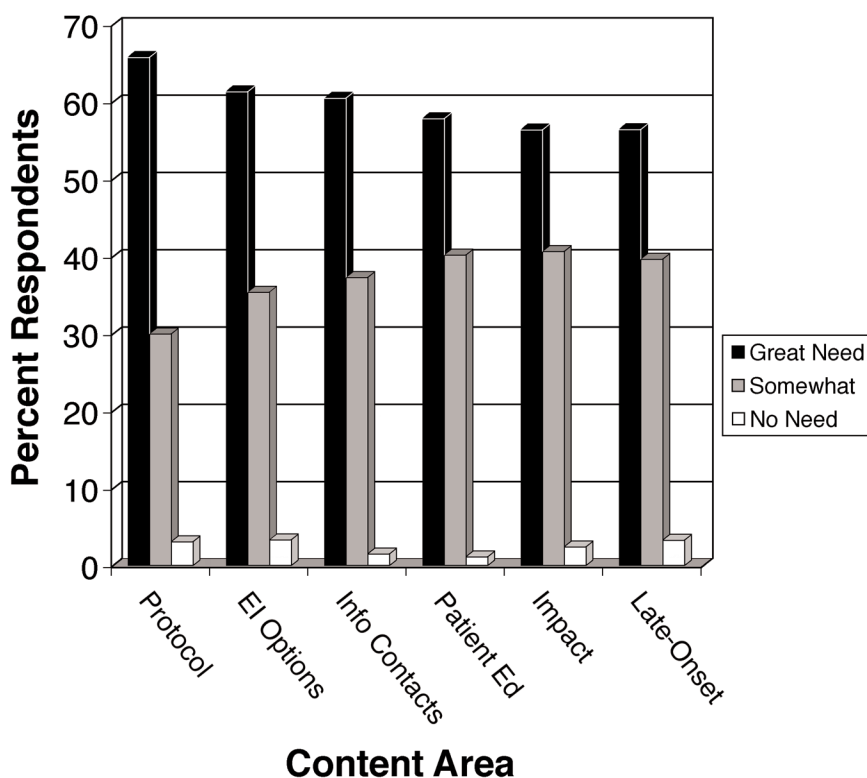
Further, the time constraints of daily practice life dictate the need for access to practical, understandable resources that provide evidence-based guidance for action. It was not uncommon to hear that 35 children were seen daily in a busy practice. Pediatricians identified the need for resources that could be read quickly, were provided "just in time," and that outlined specific activities (including parent counseling) that could be used when an infant fails screening or presents with hearing loss. Just in time resources are those that can be accessed efficiently when there is a need for them, and they provide information that directly relates to management of care. A participant stated, "We need an immediate follow-up guide. If we only see 1/1000 babies, we cannot remember the protocol." Physicians pointed to other screening models, like PKU and Down Syndrome, where specific follow-up steps are provided to the physician. In addition, physicians reported that they lacked the time to "become an expert" on childhood hearing loss. Although audiologists may be motivated to share in-depth information on the topic, this is an impractical approach to take with PCPs.

Physicians also noted that they had received very little information about childhood hearing loss in their medical training or residency programs. Only 14% of the national survey respondents stated that their medical training prepared them to care for infants with hearing loss. Survey respondents were in strong agreement with focus group physicians about NHS topics of highest need. Responses to the top six priorities are summarized in Figure 3. In addition to these topics, physicians also recognized a need for information on methods for screening children at well-child visits, hearing aids and cochlear implants, genetics of hearing loss, and guidelines for informing families about screening and diagnostic results.

### *Preferred Strategies and Sources for Learning*

The results of both the focus groups and the survey supported previous health communication research (Cronenwett, 1995; Freemantle & Watt, 1994; Moulding, Silagy, & Weller, 1999; Mowatt, Thomson, Grimshaw, & Grant, 1998; Thomson O'Brien, Freemantle, & Oxman, 2001), documenting the need for a variety of approaches to educate physicians (e.g., multiple strategies, multiple con-

tacts). Focus group discussions revealed individual differences in preferred strategies for accessing information. For example, several physicians in the focus groups expressed that they rarely accessed medical information on the internet. In the survey, 51.7% of physicians indicated that they use the internet for medical information, but access of information on NHS was rare. One physician stated, “I do not search the internet for a topic like this. However, I do look for infor-



*Figure 3.* Top six content areas identified in physician survey as needed resources. Protocol = algorithm or guide for steps to take following screening and diagnosis; EI Options = information on accessing early interventions and understanding procedures; Info contacts = useful contacts for more information on the topic; Patient Education = brochures to use in guiding families (that may be accessed when needed); Impact = information on the impact of varying degrees of hearing loss on infant speech and language learning; Late-Onset = guidelines to support surveillance for late-onset hearing losses in children. Adapted from: “Primary Care Physicians’ Knowledge, Attitudes and Practices Related to Newborn Hearing Screening,” by M.P. Moeller, K.R. White, and L. Shisler, 2006, *Pediatrics*, 118(4), pp. 1357-1370. Copyright 2006 by The American Academy of Pediatrics.

mation on the AAP website. There is a difference.” This comment speaks to the importance of disseminating information through trusted sources. Focus group participants indicated a preference for receiving information from credible sources, including other physicians, medical journals, and the AAP. There was strong agreement that resources provided by the AAP were valued. Collaborations with AAP and other nationally-recognized medical organizations in the dissemination of information on NHS are likely to be more effective than independent efforts. Audiologists who are seeking ways to collaborate with physicians need to be aware of the information already accessible from these trusted sources.

In general, pediatricians in focus groups were skeptical of anecdotal evidence and expressed a strong preference for information that was supported by credible evidence. They voiced the need for multi-center trials and for consensus among specialists that what is being done is truly beneficial. One stated,

We have to find deaf kids, but we do not have a lot of information to say if you find a deaf kid before 1 year of age, he will be bigger, stronger, brighter. We don't have a lot of data to say that a kid picked up in the nursery vs. one picked up by the pediatrician will be bigger, brighter, smarter. The literature is sparse.

Physicians indicated a preference for informational resources that present scientific evidence related to screening accuracy and benefits of early interventions.

A variety of resources were field tested with physicians during the focus group sessions. Their feedback was particularly helpful in determining ways to package information for physician audiences. For example, participants had a negative reaction to a videotape where a mother of a late-identified child stressed the need for doctors to listen to parents. This was perceived as anecdotal and not evidence-based. Consumer feedback resources with a *positive* focus (e.g., contrasting examples of early and late-identified children; consumer feedback illustrating the benefits of early identification) were positively received by the focus groups. Developmental contrasts (outcomes for early vs. late-identified children) needed to be clear, explicit, and well controlled (i.e., children matched on background variables) to be useful. When these conditions were met, the video clips had obvious impact.

Finally, when asked to indicate preferred modes of information delivery, physicians gave a range of responses, illustrated in Figure 4. The most consistent response was a preference for materials to use in Grand Rounds lectures or in self-study. Physicians indicated that Grand Rounds provides a forum for physician information exchange and CME credits. Such materials should include statistics and specific developmental guidelines. Physicians indicated interest in parent education materials that would demonstrate the value of complying with interventions. A video format was suggested for parent education, but physicians have limited time to use this type of material. Print materials should be quick to read and should provide guidelines, such as management algorithms. Pediatricians recommended that information dissemination efforts also target family practice

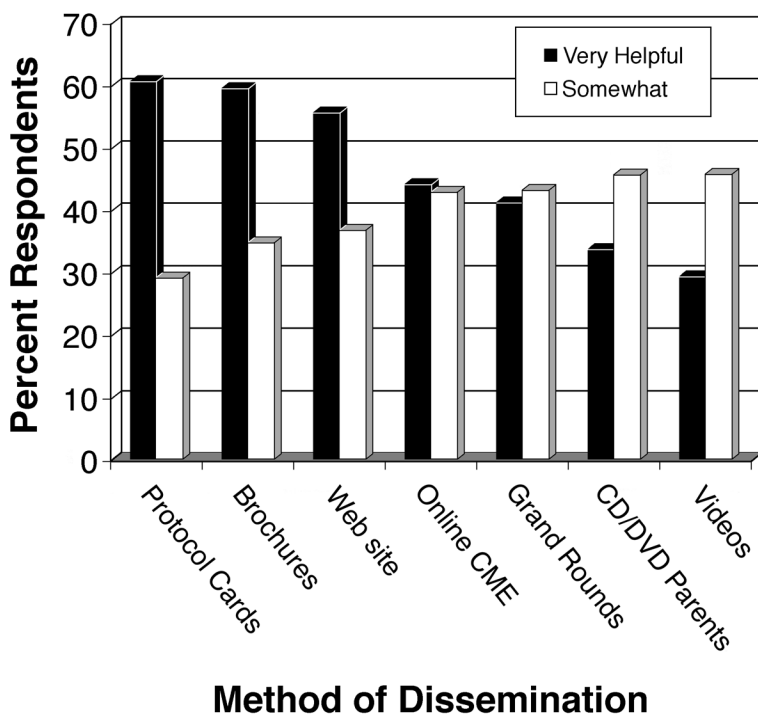


Figure 4. Survey physician perceptions about the usefulness of various methods of information dissemination on newborn hearing screening and childhood hearing loss.

physicians and nurses. Importantly, previous research has demonstrated that unsolicited mailings of informational materials have little impact on physician behaviors (Moorjani & Fortnum, 2004). Underscoring the importance of using various approaches for ongoing education about this topic, it is noteworthy that of the seven different approaches listed in Figure 4, every one was chosen by almost 30% of the respondents as being “very helpful,” and by almost 30% more of the respondents as being “somewhat helpful.”

#### ***Addressing Identified Needs***

As a result of this project, our research dissemination team created the following resources, which are available on the internet ([www.infanthearing.org](http://www.infanthearing.org) and [www.babyhearing.org](http://www.babyhearing.org)) or on request (contact the first author).

1. Grand Rounds CD on NHS. This material includes movies of a physician conferring with a family following screening and diagnosis. It also includes developmental contrasts of early and late-identified children, as well as current evidence on the effectiveness of early

intervention. AAP has provided this resource to a contact person in all of the AAP Chapters throughout the US. The AAP identified a pediatrician in each state (Chapter Champion) who was willing to take the lead in disseminating information on NHS to other physicians. See [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org) for a listing of the AAP Chapter Champions.

2. Focused Fact Sheets. Topics include: Comparison of OAE and ABR, Methods for identifying late-onset hearing loss (see example in Appendix B), and Cochlear Implants.
3. Web based informational resources. Our team worked with the AAP to develop modules on their online learning resource, [www.pedialink.org](http://www.pedialink.org). In addition, our team is expanding [www.babyhearing.org](http://www.babyhearing.org) to contain physician-oriented sections.
4. Training materials for educating health care professionals on steps in implementing an OAE screening program (<http://www.infanthearing.org/earlychildhood/hcs.html>).

### IMPLICATIONS FOR AUDIOLOGISTS

When this project began, we had naïve ideas about how to communicate with physicians about NHS and follow-up. For example, the first author envisioned sending out a CD that included multimedia elements (i.e., hearing loss simulation). In the first focus group, physicians said, “Oh we get that kind of stuff all the time. We throw it away.” This initial experience helped us appreciate the importance of listening to physician experiences and views before creating resources. It also was important to validate individual focus group comments through the survey work. Notably, 75 to 85% of the survey respondents indicated interest in CD/DVD resources. Two key points emerge from the findings: (a) multiple resources are needed to address the varied needs and learning styles of physicians, and (b) unsolicited materials created without consideration of physicians’ views may be unsuccessful (Moorjani & Fortnum, 2004).

We conclude with some suggestions for audiologists who are working to collaborate with and educate physicians about NHS and management of infants with hearing loss.

1. Consider the time constraints of daily practice and the limited frequency with which PCPs encounter infants with permanent childhood hearing loss. Arm them with information about how to access relevant, practical guidance when they see children who do not pass NHS or who have been diagnosed with permanent hearing loss.
2. Avoid dense, complex information designed to make the physician an expert. Provide protocols (like the AAP algorithm) and time efficient



Fact Sheets (i.e., National Institute on Deafness and Other Communication Disorders [NIDCD] Fact Sheet, 2003).

3. Where possible, provide evidence-based resources. There is an ongoing need to continue to build the evidence base that early detection and intervention matter.
4. Use formats (e.g., Grand Rounds, patient education materials, algorithms) and language (e.g., surveillance, periodicity schedule) that are familiar to physicians.
5. Create resources that address identified gaps in knowledge.
6. Increase the awareness and availability of internet resources. Include multimedia resources that enhance the learning (e.g., hearing loss simulations).

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**APPENDIX A*****NEWBORN HEARING SCREENING DEVELOPMENT RESEARCH*****FOCUS GROUP****MODERATOR'S SCRIPT**

Intro 5 minutes

1. Introduction. First names (and professional role if mixture of pediatricians and other job titles), purpose of research, statement of how comments will be used, and pledge of confidentiality. Acknowledge recording, and observers if present.

Knowledge, Beliefs, Experiences – 20 minutes?

2. What do you know about hearing loss in infancy? (Probe: Incidence rate? Types? Causes? Consequences of profound hearing loss? What about mild hearing loss? Medical and educational interventions? Parental needs for information and decision making support? If hearing loss in infancy is not a concern, why not?)
3. How common is it to screen newborns for hearing loss? (Probe: Were you aware that it is now done for most babies born in the US?)
4. How has newborn screening affected (or will that affect) what you do as a physician? (Probe: Have you been contacted by hospitals regarding screening efforts or results of screening for individual patients? Would you want to receive results on all your patients or only those who fail the screening and need followup? Why?)
5. What do you know about newborn hearing screening procedures? (Probe: technologies like ABR, OAE, One stage vs. two stage screening protocol, and appropriate next steps)
6. How were you trained to deal with this situation? How confident are you that you know what to do? That you can speak knowledgeably with parents? (Probe: What do you see as the appropriate steps for diagnosis? Intervention?)
7. Have you had any infants with hearing loss in your practice? If so, what happened?
8. Assume a baby in your practice is diagnosed with a profound bilateral hearing loss. Are there specialists to whom you would always refer the family (e.g., ophthalmology, genetics, cardiology, neurology, otolaryngology)? If so, what kinds of specialists would you routinely refer to and why? If not why not?
9. How confident are you in the accuracy of the newborn hearing screening tests that are available? (Probe: Incidence of false positives? What issues does this raise? What about false negatives?)

Information and Delivery Needs – 30 minutes?

10. What would be most helpful to you and your colleagues in becoming better informed about newborn hearing screening? For educating parents on screening test results? (Probe: Where do you look first for information on low-incidence conditions? What kind of information is most useful? What have been your primary sources [e.g., medical school curricula, Grand Rounds, journal articles, Internet]? What sources do you trust most? Which are you most likely to use? How can it be delivered [amount and medium] so that you are most likely to be aware of and use it?)
11. What kinds of information and resources would be most helpful to you in working with infants with hearing loss in your practice? What are the best ways of making you aware of its availability? Of actually delivering it to you? To parents?
12. How useful would an Internet-based curriculum be for addressing infant hearing screening and interventions? What other kinds of information or courses have you turned to the Internet for? Are there particular sites or courses you thought were particularly worthwhile? Have you ever used AAP's Pedialink?

Ongoing Assessment – 10 minutes?

13. Do you currently assess hearing health as part of each child's regular healthcare checkups? If so how? (e.g., talk to parents about language development milestones, use handheld equipment, make noise and note response, etc.)
14. How would you screen for late onset sensorineural hearing loss (e.g., enlarged vestibular aqueduct or meningitis) in your practice? (Probe: Do you see this as a more or less serious concern than hearing loss in infancy? Do you have the knowledge and resources you need to identify and intervene appropriately? If not, what is missing?)

Video Review – 15 minutes?

15. Review of video and discussion about usefulness and appropriateness for training.

## **APPENDIX B**

### ***FACT SHEET ON IDENTIFYING LATE ONSET HEARING LOSS***

#### **BEYOND NEWBORN HEARING SCREENING: RECOGNIZING THE SIGNS OF LATE-ONSET HEARING LOSS IN INFANTS AND YOUNG CHILDREN**

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With 39 out of 50 states mandating universal newborn hearing screening (UNHS), and newborn hearing screening data being collected from 40 states, it would be easy to assume that the identification of permanent childhood hearing loss is guaranteed. Yet, the fact is that some childhood hearing losses have a later onset and will not be identified through newborn screening methods. This article responds to some basic questions about late-onset hearing loss in infancy and childhood.

#### **What is the prevalence of childhood hearing loss?**

Current UNHS statistics indicate an overall hearing loss prevalence rate of 1-2 per 1000 at birth. These prevalence statistics are consistent across the US and are not dependent on the particular hearing screening method being used. Statistical information about the prevalence of hearing loss in older children is difficult to find and interpret for a number of reasons. Late onset or progressive hearing loss can be due to hereditary factors, infection, trauma, noise exposure or teratogens. Studies also vary in how "significant hearing loss" is defined. As a result, the prevalence of late onset hearing loss is not well defined. In general there is a trend toward increasing rates of hearing loss as children get older.

#### **Can newborn hearing screening miss hearing loss that is present at birth?**

It is possible for some children to have a mild hearing loss at birth and pass universal hearing screening. This is due, at least in part, to the underlying assumptions about newborn hearing screening. Any type of universal screening program needs to achieve a low false-alarm rate and a high "hit" rate. The goal for UNHS is that few children are referred for additional, more expensive testing who do not need it and those who are referred have a high likelihood of having hearing loss. To meet these requirements, current UNHS methods may not identify children with mild hearing losses. If no further audiological monitoring is being completed within the child's medical home, the result could be late identification of milder degrees of hearing loss.

In some instances, mild hearing loss that is present at birth may progress to more severe hearing loss after the child goes home from the hospital. Rapidly progressive hearing loss can be associated with

several congenital conditions, including Cytomegalovirus (CMV) and Large Vestibular Aqueduct (LVA) as well as some genetically inherited losses.

**What are the most common causes of late-onset hearing loss?**

The major categories of late-onset loss are acquired, structural, and genetic.

**Acquired:** Among acquired late-onset losses, congenital CMV (both symptomatic and non-symptomatic) is the most common and accounts for around 1/3 of all hearing loss in children. Hearing loss associated with CMV may be both late onset and progressive within the first years of life. Even asymptomatic congenital CMV infection carries an increased risk of hearing loss. Hearing loss prevalence rates of 7-15% in asymptomatic cases have been reported. Congenital symptomatic CMV infection carries greater risk for hearing loss and a higher percentage of children with active CMV symptoms at birth have hearing loss identified through UNHS, with further progression reported within the first 2-3 years (Fowler et al., 1997; Barbi et al., 2003). Other childhood illnesses may also cause hearing loss. These include viral or bacterial meningitis, mumps and other viral infections that cause a high fever or central sequelae. Head trauma with skull fracture is one type of traumatic late-onset loss. Chemotherapeutic agents containing platinum, such as cisplatin, are among the best known ototoxic medications.

**Structural:** Structural causes of late-onset hearing loss may occur with a number of syndromes. Structural deformities of the cochlea such as LVA and Mondini malformation are congenital but not always related to a specific syndrome. Cochlear malformations affect hearing differently in different children. Some hearing losses may occur earlier and others may not present until later childhood. Structural malformations of the inner ear are associated with sudden and extreme progression and fluctuation of hearing.

**Genetic:** Genetic causes of late-onset hearing loss may be syndromic or non-syndromic. Full explanations of specific syndrome characteristics can be found online on OMIM, the Online Mendelian Index in Man at <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>.

**Syndromic losses include:**

- Pendred's Syndrome, which is associated with LVA
- Branchio-Oto-Renal Syndrome (BOR), associated with Mondini deformities
- Alports Syndrome with progressive renal failure and late occurring, progressive hearing loss
- Stickler Syndrome, a connective tissue syndrome with late occurring vision problems and hearing loss
- Usher Syndrome with progressive blindness and deafness. Usher Type I is associated with more severe hearing loss, lack of vestibular function and blindness. Types II and III typically show less severe hearing loss, less severe vestibular effects and more residual vision, with Type III occurring rarely
- Neurofibromatosis Type II with progressive hearing loss resulting from auditory nerve tumors
- Other neurodegenerative syndromes may be associated with late onset hearing loss, but are not as common as the syndromes listed above (e.g. Refsum Disease)

**Non-syndromic losses include:**

- Dominant-progressive hearing loss
- Family history of late-occurring hearing loss
- Connexin 26, which may have late-onset hearing loss in rare occurrences. A small number of studies have shown progressive hearing loss with Connexin 26

**What are the main risk factors associated with late-onset loss?**

- Congenital CMV infection
- Meningitis or mumps infections
- Family history of late-onset hearing loss

- Syndromes associated with late-onset hearing loss
- Head trauma, especially with basal or temporal bone fracture
- Chemotherapy, especially when administered in conjunction with radiation

**How can Primary Care Providers monitor for late-onset loss?**

Performing surveillance and screening within the medical home is the best way to monitor infants and young children for late-onset hearing loss. Primary Care Providers are the medical providers who see the child most often and are able to review auditory skill development and developmental milestones at well-child visits. An immediate referral for audiological evaluation is warranted if parents express concerns about a child's hearing responsiveness or speech and language development. For young children and infants under 3 years of age, typical in-office hearing screening methods are not effective and a referral to a pediatric audiologist is recommended. All children with an identified risk factor for late-onset hearing loss should receive a comprehensive audiological assessment as soon as behavioral testing can be completed. Even if that child has passed newborn screening and no parental concerns have been expressed, a comprehensive evaluation can identify subtle or progressive losses which require remediation and monitoring. A combination of electrophysiological and developmentally-appropriate behavioral tests can be used to test hearing at any age and any developmental level.

Early identification of hearing loss leads to better speech, language and learning outcomes for children. Knowledge of the risk factors for late-onset hearing loss and continued vigilance in screening, monitoring and referral are vital. The goal is to insure that the listening and learning needs of all children are met.

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