

# Infant Hearing Screening: Stakeholder Recommendations for Parent-Centered Communication

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## ABSTRACT

**OBJECTIVES.** The purpose of this study was to identify what stakeholders considered best practices for parent-provider communication regarding newborn hearing screening and diagnosis. We used consensus data to develop educational materials for parents.

**METHODS.** We conducted 29 focus groups and 23 individual interviews between October 2003 and May 2004. Participants included (1) English- and Spanish-speaking parents of infants <18 months of age who had experience with hospital-based newborn hearing screening; (2) parents of children with hearing loss; (3) primary care providers who provide prenatal care or care for newborns; and (4) audiologists, audiology technicians, and hospital nurses.

**RESULTS.** Communication to parents about hospital-based newborn hearing screening was limited. Most parents first learned about the screening in the hospital, but all stakeholders thought a more opportune time for education was before the birth. For parents of infants who did not pass the newborn hearing screening, stakeholders recommended direct communication about the urgency of diagnostic testing. They also indicated that primary care providers needed current information regarding hearing screening, diagnostic testing, and early intervention. All stakeholders thought that a brief brochure for parents to take home would be helpful for hospital-based screening and, if necessary, subsequent diagnostic testing. Primary care providers requested basic, to-the-point information.

**CONCLUSIONS.** The most opportune time to begin discussion of newborn hearing screening is before the birth. Providers need up-to-date information on current standards of hearing screening, diagnosis, and intervention. User-friendly patient education materials, such as those we developed, could assist providers in educating parents.

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### Key Words

newborn screening, parent education, health communication, doctor-patient communication

### Abbreviations

AAP—American Academy of Pediatrics  
EHDI—early hearing detection and intervention

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**T**HE JOINT COMMITTEE on Infant Hearing and the American Academy of Pediatrics (AAP) recommend that all infants be screened for hearing loss in the newborn period and that hearing loss, if present, be diagnosed by 3 months of age. If hearing loss is present, then the infant should be enrolled in treatment by 6 months of age.<sup>1,2</sup> Early identification and intervention are critical for successful speech and language development.<sup>3-5</sup> Unfortunately, many infants who do not pass the hospital-based hearing screening do not receive timely appropriate follow-up care.<sup>6</sup> Large numbers are lost to follow-up care after abnormal newborn hearing screening test results. To ensure optimal outcomes for infants, it is particularly important for parents to receive information about hearing screening and to understand the benefits of early diagnosis and intervention.

The AAP recommends that information about newborn hearing screening and the results of screening be given to parents and primary health care providers in a timely sensitive manner.<sup>2</sup> The Joint Committee on Infant Hearing advises early hearing detection and intervention (EHDI) programs to develop family information materials that are accessible and written in English and other appropriate languages and that these be appropriate for parents with low literacy levels.<sup>1</sup> Currently printed parent education materials are available in 47 states, with information available on state EHDI program Web sites for 29 states<sup>7</sup>; however, there are no accepted guidelines specifying what information parents need to know, by whom it should be given, or in what format it is most effective.

The purpose of this study was to identify what stakeholders thought was optimal parent-provider communication regarding the newborn hearing screening and diagnosis process. (We also reported stakeholder recommendations for improved communication about genetic newborn screening.<sup>8</sup>) Specifically, we elicited feedback from stakeholders regarding (1) current parent-provider communication about screening and diagnostic testing, (2) what information should be included in newborn hearing screening education and the methods through which this information should be communicated to parents, and (3) suggestions about information needed by primary care providers. We then used consensus data to develop educational materials for parents.

## METHODS

### Study Design

This study used a qualitative research design that involved conducting 29 focus groups and 23 individual interviews between October 2003 and May 2004. The study methods were reviewed and approved by the Louisiana State University Health Science Center-Shreveport Research Subjects Review Board and the institu-

tional review board of the Health Resources and Services Administration.

### Focus Group Participants

Focus groups and individual interviews were conducted with 51 parents of infants with normal hearing who were <18 months of age and who had received newborn hearing screening (44 English-speaking and 7 Spanish-speaking), 21 parents of children with hearing loss, 68 health care providers of prenatal care or health care for newborns (19 pediatricians, 24 family physicians, 11 obstetricians, 5 nurse practitioners, 5 physician assistants, and 4 nurse midwives), and 24 hearing professionals and persons screening newborn infants (7 audiologists, 6 audiology technicians, and 11 hospital nurses).

Participants in the focus groups and interviews were selected through purposeful sampling. Local collaborators (described elsewhere) recruited parents of infants with normal hearing and primary care providers.<sup>8</sup> Parents of children with hearing loss in New Mexico and Louisiana were recruited by EHDI professionals. In addition, parents from 13 states who attended the 2004 National EHDI Conference were recruited by a senior research associate at the National Center for Hearing Assessment and Management. Local collaborators recruited audiologists in New Mexico and Louisiana. The audiologists in turn recruited their audiology technicians. Hospital nurses were recruited in Ohio by a local collaborator.

### Focus Group Structure

Our methods of interviewing and data collection for these focus groups were described elsewhere.<sup>8</sup> All sessions except for the Spanish focus groups and the telephone interviews were audiotaped. Stipends for participants varied; parents and audiology technicians received \$25, audiologists and nonphysician health care providers received \$50, and physicians received \$100. We also provided focus group participants with a snack or meal.

### Focus Group Content

#### *Development of Moderator's Guide*

The focus group moderator's guide was developed by a team of individuals with expertise in newborn hearing screening, children's health care, patient education, risk communication, and ethics and with previous experience conducting focus groups.<sup>9-13</sup> After examining current pertinent literature,<sup>14-21</sup> the team drafted a focus group moderator's guide with scripted questions. The director of the Newborn Hearing Screening and Intervention Program (in the Integrated Services Branch of the Maternal and Child Health Bureau, Health Resources and Services Administration) and state-level EHDI professionals reviewed the guide.

### *Parents*

Scripted questions focused on awareness of, knowledge about, and communication parents received about newborn hearing screening and diagnostic testing. Group leaders probed for the sources and content of written and oral information that parents received and their concerns about the newborn hearing screening process. Parents were also asked what information they wanted and how they wanted it delivered (eg, when, in what format, and by whom). Parents were shown newborn hearing screening brochures developed previously by various states and were asked to give specific feedback on the content, wording, graphics, layout, and organization.

In focus groups of parents of children with hearing loss, we asked how and when they were informed that their child had a hearing loss, their experiences with hearing screening, how they were informed of the need for follow-up diagnostic tests, the subsequent process of diagnostic testing, and suggestions for how this entire process could be improved. We also asked what they considered the important issues that needed to be addressed regarding hospital-based hearing screening and diagnostic testing.

### *Primary Care Providers*

We asked providers what they knew about the newborn hearing screening information parents received and the process of getting the information to parents. Providers were also asked what they discussed with parents about hospital-based newborn hearing screening and diagnostic testing and what they thought parents wanted and needed to know about the entire process. Providers were also asked about their experience with their state's EHDI program, including the number of their patients who needed diagnostic testing after the hospital-based hearing screening and the number of patients for whom a hearing loss was identified through the newborn screening program.

### *Audiologists, Audiology Technicians, and Hospital Nurses*

Our questions elicited what the audiologists, audiology technicians, and hospital nurses discussed with parents regarding hospital-based newborn hearing screening and diagnostic testing, when these conversations occurred, what types of questions parents asked, and what the professionals thought parents wanted and needed to know. The audiologists and technicians were asked about training in patient communication and education they received and whether scripts were available for them to use when communicating with parents.

### **Data Analysis**

Our methods for data analysis have been described elsewhere.<sup>8</sup> All themes identified by the reviewers were categorized. The themes were then reported for each of

the stakeholders, ie, parents of children with normal hearing, parents of children with hearing loss, audiologists, audiology technicians, hospital nurses, and primary care providers. In cases in which there was variation within groups in response to a theme, these variations are reported. Statements from participants also are provided.

## **RESULTS**

### **Themes**

On the basis of the focus groups and individual interviews, 4 main themes emerged about the newborn hearing screening and diagnostic process, namely, (1) communication about hospital-based newborn hearing screening, (2) communication about diagnostic testing, (3) recommendations for patient education, and (4) recommendations for pediatric care providers.

### **Theme 1. Communication About Hospital-Based Newborn Hearing Screening**

#### *Parents*

Most parents first learned about newborn hearing in the hospital when their child was born, and they remembered signing a form acknowledging that their child's hearing was tested and being told the results; however, most mothers remembered little of the information they received before their child was tested or whether they were told anything at all. "All I was told was that the test would not take very long." "They just brought my daughter back and said she was fine."

Only a few parents reported being told about hearing screening prenatally. Parents with a family history of hearing loss were more likely to have discussed hearing testing with their primary care provider before childbirth.

#### *Audiologists, Audiology Technicians, and Hospital Nurses*

Audiologists, audiology technicians, and hospital nurses reported that the information they gave parents in the hospital depended on (1) whether the infant was in the same room with the mother or in the nursery or NICU, (2) the time available, (3) their perception of the parent's interest, and (4) the protocol established by the hospital. In some systems, they took the infants from the nursery to conduct the screening and therefore had no contact with parents. In other systems, particularly ones in which the infant roomed in with the mother, the technicians always informed parents about the screening. "We introduce ourselves and let the parent know we are taking their child for a hearing screen. We also ask them about risk factors for hearing loss." In other systems, if the infant passed the screening, then the results were given to the mother by a nurse or put in a bag of other materials and information to go home with the mother. Hospital nurses indicated that their commu-

nication with parents focused most commonly on other issues, such as “choosing a pediatrician, bottle versus breastfeeding, and circumcision.” All audiologists, audiology technicians, and nurses reported that parents rarely asked questions about the newborn hearing screening process.

### *Primary Care Providers*

All primary care providers thought that parents received information about newborn hearing screening in the hospital, although they were not clear what parents were told and none of them remembered seeing their state’s newborn hearing screening brochure. None of the providers thought that parents knew very much about hearing screening, and providers reported that parents rarely asked questions about this topic. “It is very unusual for a parent to ask the pediatrician about hearing screening in the hospital unless the infant failed the screen.”

Among prenatal care providers, none of the obstetricians and only a few family physicians reported discussing hearing screening prenatally. One family physician said, “I tell mom her infant will have a physical, a shot of vitamin K, drops in the eyes, a heel stick or metabolic screen, and hearing screening.” Nurse midwives reported that, if parents had questions about any of the tests that happened in the hospital, then they discussed hearing screening with the other tests; otherwise, they did not mention hearing screening. Nurse midwives reported that only a few patients (<5%) asked questions about testing in the hospital.

## **Theme 2. Communication About Diagnostic Testing**

### *Parents*

Parents of children who passed the hearing screening had no experience with diagnostic testing and therefore did not comment on it. Most parents of children with hearing loss remembered being told that their child needed follow-up diagnostic testing but were unclear regarding why they needed it or what it meant. Several mothers of infants who were in the NICU were confused about the infant being tested several times for hearing loss. “They really did not tell us much about why they had to do another test. They said it was part of discharge and they kept retesting and not telling us about anything or about what was going on. In the NICU they are always running tests for something, so there is a lot of confusion as to what your infant is being tested for and why.”

Many parents of children with hearing loss thought there was too much of a delay from the initial screening to the time when diagnostic tests were performed. Some parents said providers often downplayed the need for timely follow-up testing. “It seemed that providers passed it off [that the infant had failed the screen] at the

hospital. They said it was probably fluid in the ear.” Some parents thought it was important for parents to get the message that diagnostic testing could be performed quickly. “Get a referral from your primary care physician. You can do it today. (That’s the first step.)” “You need to provide a sense of urgency without scaring people.”

### *Audiologists, Audiology Technicians, and Hospital Nurses*

When an infant did not pass the hospital-based hearing screening, the audiologist or nurse usually met with the parents personally to explain the possible reasons why the infant did not pass the screening test, to discuss the need for diagnostic testing, and to give parents an information sheet about hearing loss. All hearing professionals considered it important that communication about the need for diagnostic testing be clear but not alarming; however, communication varied, and many audiologists thought that the messages given sometimes were too complex or used jargon that was unfamiliar to parents. For example, in some states audiologists and audiology technicians tell parents that “the infant has been referred for follow-up testing.” The providers who used this term realized that often the meaning of the word “refer” was not clear to parents. In an attempt not to frighten parents, others gave more abstract explanations, such as, “the right ear didn’t show the results we were expecting, so we have to do some follow-up testing,” which they realized might not be understood easily by all parents. Providers’ attitudes seemed mixed regarding use of the word “fail.” Some providers never used it because they thought it was confusing or overly alarming, whereas others thought it was essential to help parents realize the importance of the situation. “Your infant failed the hearing screening. This doesn’t mean that your infant can’t hear, it just means that we need to do more tests.” Providers’ attitudes also were mixed regarding the use of probabilities. Some said, “Three in 1000 infants have a hearing loss, so it is important that you come back for retesting.” Others thought that this made the risk sound so minimal that parents were unlikely to follow through.

### *Primary Care Providers*

If an infant did not pass the screening examination, then the primary care providers we interviewed received a written notice at their office/clinic. In general, primary care providers thought that the proportion of infants with a false-positive hearing examination was large. “I tell parents that about a third of the infants I see have to be retested. You don’t really need to worry about this.” Other providers did not think the information should be presented as critically important. “I tell parents, ‘This is just a screening test. Don’t worry. I’ve seen this a lot in my practice, but it needs to be repeated.’ ” “Your infant probably has normal hearing, but [the test] needs to be done again.” Nurse midwives reported that, when par-

ents asked them questions about diagnostic testing in the hospital, they generally gave them brief information and advised them to talk to their pediatricians. Most pediatricians reported feeling comfortable discussing the results of hearing screening with their patients but thought they lacked adequate information about appropriate resources for additional testing or intervention.

### **Theme 3. Recommendations for Patient Education**

#### *Parents*

All parents thought that the optimal time to discuss newborn hearing screening was before the birth, during the third trimester, rather than during the hospital stay. Parents wanted simple, to-the-point information. Most parents wanted to be informed by their prenatal provider and to be given a pamphlet to take home. "You don't always remember everything your doctor tells you." With respect to the patient education brochures, none of the parents wanted to know a great deal about the hearing screening test unless their child needed follow-up diagnostic tests. For example, no parents were interested prenatally in knowing about the screening or diagnostic testing equipment or how it worked, in seeing an anatomically correct drawing of the ear, or in receiving explanations of the causes and effects of hearing loss. One aspect of many current pamphlets that all parents reported liking was information about the developmental milestones for children's acquisition of speech and language.

Parents of children with and without hearing loss stated that parents needed to know prenatally that their child's hearing would be tested and why it is important. They suggested using phrases such as, "Your infant's hearing will be tested in the hospital." "If we find a problem, there are many things we can do to help the infant." "It will not hurt the infant." "Be sure your infant gets tested." "Hearing will help your infant learn and speak." "Sometimes follow-up testing is needed."

Most parents of children with and without hearing loss thought that details of diagnostic testing should be discussed only if the infant did not pass the hospital-based newborn hearing screening. At that point, parents of children with hearing loss thought it was essential for parents to understand the importance of follow-up diagnostic testing because their child had "moved into another category," which some parents referred to as a "high-risk category." Several parents indicated that parents needed to receive the message about the need for diagnostic testing more than once because they might experience denial at first.

Parents of children with hearing loss thought that a simple brochure describing the need for diagnostic testing would be useful. They thought that the most important point to emphasize was to have the diagnostic testing performed as soon as possible. Some parents thought

the message should be realistic and blunt, "Your infant failed the hearing test. This puts your infant at a high risk for hearing loss." Most parents objected to words such as "fail" and "high risk." Those parents suggested terms such as "did not pass" or "did not respond." Some parents thought that the word "refer" (eg, "your infant has been referred") would be confusing to many parents.

Spanish-speaking mothers wanted written materials in conversational (not medical) English and Spanish. They preferred learning from providers who were bilingual or who used an interpreter.

#### *Audiologists, Audiology Technicians, and Hospital Nurses*

Audiologists, audiology technicians, and hospital nurses also said that information about hospital-based newborn hearing screening should be first given prenatally, verbally and with an accompanying simple, straightforward, attractive brochure. One audiologist suggested giving information about newborn hearing screening together with the information about the Supplemental Nutrition Program for Women, Infants, and Children. Audiologists, audiology technicians, and hospital nurses reported that they thought parents needed to know that a test would be performed and why it was important. None thought there was a need for a videotape in the hospital, because it would be difficult to show at that time.

#### *Primary Care Providers*

Primary care providers recommended a culturally sensitive brochure, in English and Spanish, for parents. They recommended that the content state that screening will occur; it is performed to make sure the infant can hear well; most infants are healthy; the test is safe and does not hurt the infant; sometimes follow-up diagnostic testing is needed; and, if diagnostic testing is necessary, then it should be performed as soon as possible. "Most of these infants are not going to have a problem with hearing, but it's really important we do this early because, if there is a problem, we've given your infant a great opportunity for the best chance at a normal life." Prenatal providers stated they would be willing to include information on hearing screening during prenatal visits, and most pediatricians and family physicians agreed that parents needed to receive this information before arrival at the hospital.

### **Theme 4. Recommendations for Pediatric Care Providers**

#### *Parents*

Parents of children with hearing loss thought that pediatricians and family physicians needed more current and accurate information regarding hearing screening and loss. They wanted providers to understand and to communicate the urgency of early diagnosis, as well as the benefits of early intervention. They also suggested that

nurses and audiology technicians needed training regarding what to say to parents if their infant did not pass the hearing screening. Some recommended that the technicians be given a script.

#### *Audiologists, Audiology Technicians, and Hospital Nurses*

Audiologists thought that pediatric health providers would be helped by up-to-date information about screening false-positive rates and recommendations for the timing of diagnostic testing and intervention. The audiologists also thought that, when pediatric health providers were not well informed about hearing screening or hearing loss, they sometimes undermined efforts to provide timely appropriate audiological services. "Parents often get the message that there is no urgency with diagnostic testing." To ensure that pediatricians in one health care system were up to date, the audiologist conducted an annual inservice workshop for them.

#### *Primary Care Providers*

Pediatricians and family physicians requested basic, to-the-point information and a referral list of qualified health care providers for diagnostic testing. They also requested contact information (toll-free telephone number) for personnel they could call if they had questions.

## DISCUSSION

### Summary of Findings

Every year, ~12 000 infants with permanent hearing loss are born in the United States,<sup>1</sup> costing an estimated 2 billion dollars over their lifetimes.<sup>22</sup> Currently >90% of infants are screened for hearing loss before they leave the hospital.<sup>23</sup> On average, children with hearing loss are still being diagnosed much later (12–25 months) than has been recommended ( $\leq 3$  months).<sup>7</sup> Educating parents about hearing screening and diagnosis and increasing physician involvement are thought by many to im-

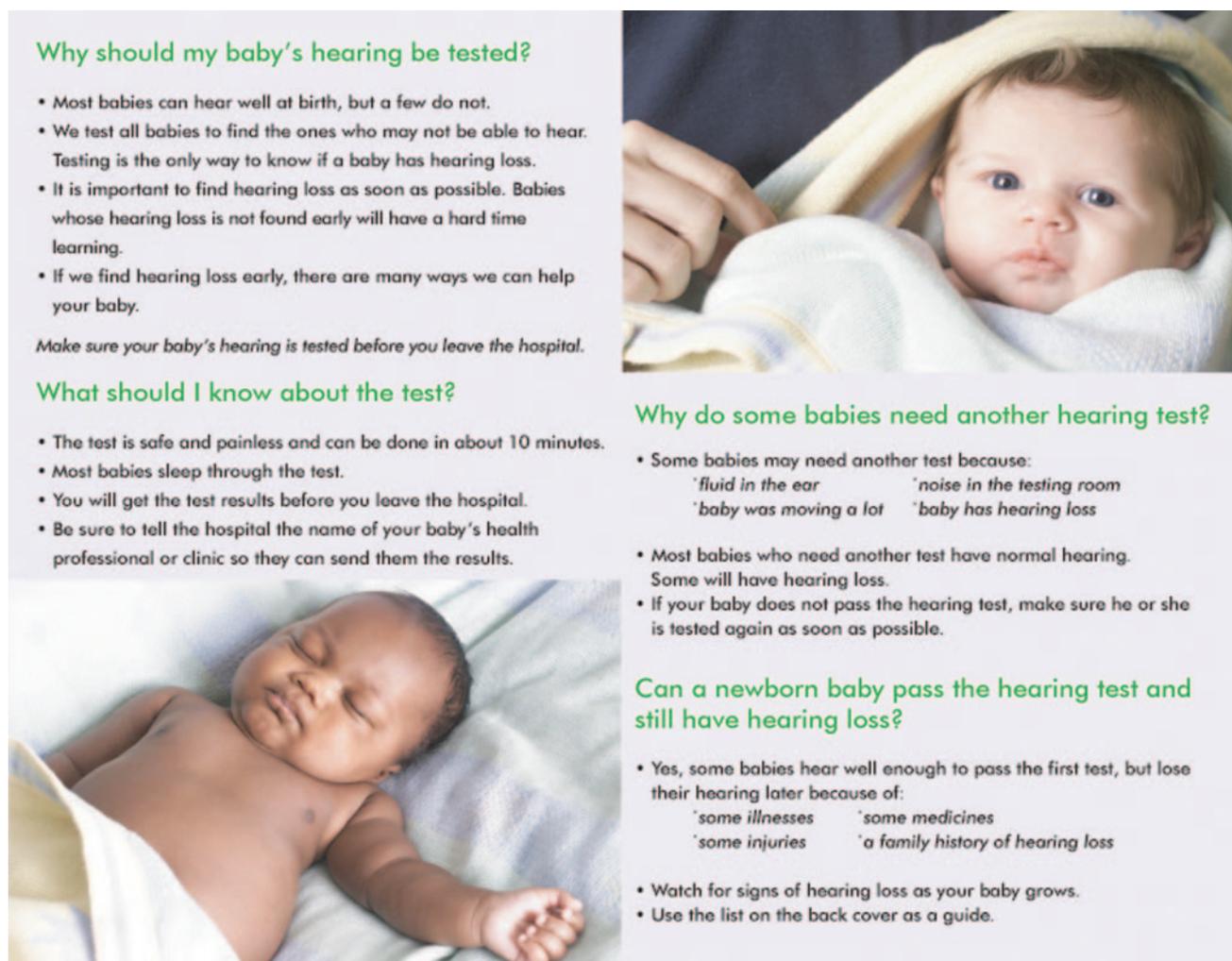


FIGURE 1  
Hearing screening brochure (inside).

prove parent understanding, satisfaction, and follow through with diagnostic testing.<sup>1,2,24</sup>

In this study, we found that parents and clinicians had limited knowledge and awareness of current newborn hearing screening practices. Neither parents nor providers considered education about hearing screening a priority at the time of delivery. Rather, all stakeholders suggested that parents be educated briefly about hearing screening during the third trimester of pregnancy. Prenatal providers reported being willing to give brief screening patient education if the American College of Obstetricians and Gynecologists recommended it.

Parents preferred to receive information orally from a trusted health care provider and to be given a brief, to-the-point brochure to take home. Many Spanish-speaking parents requested brochures in English and Spanish. Although parents and providers were interested in up-to-date information, neither group was interested in receiving lengthy information about initial hearing screening. All stakeholders suggested that par-

ents receive the following information prenatally: all infants should be tested; it is important because hearing will help the infant learn and speak; the test does not hurt the infant; a few infants will need diagnostic testing; if a problem is found, there are many things that can be done to help the infant; and parents need to act quickly if diagnostic testing is necessary.

With regard to communication about diagnostic testing, parents and providers thought that details of diagnostic testing needed to be discussed only with parents whose children did not pass the hospital-based newborn hearing screening. Many parents of children with hearing loss thought that diagnostic testing was delayed unnecessarily and that providers sometimes downplayed the need for timely follow-up testing. They wanted providers to understand and to communicate the urgency of early diagnosis, as well as the benefits of early intervention. This is consistent with the recommendation by the AAP<sup>2</sup> that providers need to communicate screening results in a timely sensitive manner.

**Why does my baby need another hearing test?**

- Some babies may need another test because:
  - fluid in the ear
  - noise in the testing room
  - baby was moving a lot
  - baby has hearing loss
- Most babies who need another test have normal hearing. Some will have hearing loss.

**Why is it important to have another hearing test as soon as possible?**

- Testing is the only way to know if a baby has a hearing loss.
- The earlier a hearing loss is found, the better it is for a baby.
- If your baby has a hearing loss, there are many ways we can help your baby.

**Finding hearing loss early can make a big difference in your baby's life.**

**What will happen during my visit?**

- A hearing specialist (an audiologist) will test your baby and tell you the results or tell you if more tests are needed.
- The test is safe and painless.
- A few babies will need a more complete set of hearing tests, so you may be asked to bring your baby back.
- If your baby needs more testing, get it done as soon as possible.

**Can a newborn baby pass the hearing test and still have hearing loss?**

- Yes, some babies hear well enough to pass the first test, but lose their hearing later because of:
  - some illnesses
  - some medicines
  - some injuries
  - a family history of hearing loss
- Watch for signs of hearing loss as your baby grows.
- Use the list on the back cover as a guide.
- If you have questions about your baby's hearing, talk to your baby's health professional.

**An appointment has been made for your baby's next hearing test:**

\_\_\_\_\_  
Your Baby's Name

\_\_\_\_\_  
Audiologist's Name

\_\_\_\_\_  
Time and Date

\_\_\_\_\_  
Place

\_\_\_\_\_  
Phone Number

*Please call if you need to reschedule.*

FIGURE 2  
Diagnostic testing brochure (inside).

Finally, providers need up-to-date information on screening, diagnosis, and treatment. For example, because of improvements in screening technology and procedures, some physicians' perceptions of the rates of false-positive results with hospital-based hearing screening are no longer accurate. Many physicians we interviewed thought, on the basis of their experience, that between one third and one half of their patients needed diagnostic testing after discharge; however, the average rate of referral at the time of hospital discharge in US hospitals is now <5%.<sup>7,25</sup>

### Limitations

Our findings should be interpreted in light of the study's limitations. Our purposeful sample was not a random population sample. The selection of focus group participants and interviews was determined largely because of the availability of collaborators who could assist in recruiting participants. Although our results cannot be considered representative of the US population or any regional population, they do provide important information about the perceptions of some stakeholders regarding the need to improve communication about newborn hearing screening and diagnosis.

### Patient Education Materials

Using the input of stakeholders, a review of current newborn hearing screening brochures, our previous research, and patient education and communication literature, we developed 4 user-friendly, patient-centered, parent education brochures (in English and Spanish) on hospital-based hearing screening and diagnostic testing. Examples of the English-language brochures are included in Figs 1 and 2.

### Implications

Newborn hearing screening information should be provided to all expectant mothers during the prenatal period. For newborn hearing screening programs to be successful, primary care providers need updated information on current standards of hearing screening, diagnosis, and intervention and need to be involved actively in educating their patients about the benefits of newborn hearing screening and early diagnosis. User-friendly parent education materials in English and Spanish (Figs 1 and 2) could assist providers in educating parents. In addition, primary care providers need a list of qualified referral resources for diagnostic testing and early intervention.

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