

June 2007

An Evaluation of Loss to Follow-Up in State EHDI Programs: Findings from the Virginia EHDI Program

Final Report

Prepared for

**Virginia Department of Health
Early Hearing Intervention and Detection Program**
109 Governor St., 8th Floor
Richmond, VA 23219

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EXECUTIVE SUMMARY

Each year, nearly 12,000 infants are diagnosed with hearing loss (Health Resources and Services Administration, 2002). Failure to diagnosis and begin intervention in a timely fashion can lead to delays and/or permanent impairment to an infant’s speech and language development (Karchmer & Allen, 1999). Recognizing the importance of early hearing detection and intervention, the Joint Committee on Infant Hearing (JCIH, 2000) issued a recommendation for universal infant hearing screening and benchmarks for follow-up known as the “1-3-6” Plan—screening by 1 month, diagnosis by 3 months, and initiation of intervention by 6 months of age.

In 1999, Virginia instituted the Code of Virginia (§[32.1-64.1](#)) and regulation [12 VAC 5-80](#), mandating hearing screening of all infants born at all hospitals with infant nurseries and all hospitals with neonatal intensive care services. The success of infant hearing screening has been unequivocal. An estimated 92% of all infants in the United States (Directors of Speech and Hearing Programs in State Health and Welfare Agencies, 2004) and 97% in Virginia are screened for early hearing loss.

The full promise of early detection, however, cannot be fully realized unless commensurately high rates are achieved for follow-up to rescreening, diagnosis, and early intervention. The Centers for Disease Control and Prevention (CDC) estimates that nearly half of infants who are referred for diagnosis do not receive it by 3 months of age; a third of those infants diagnosed with hearing loss do not initiate intervention by 6 months of age (CDC, 2003).

In an effort to more fully understand the factors that underlie the failure to follow up to evaluation, diagnosis, and intervention in a timely fashion, the CDC Early Hearing Detection and Intervention Program (EHDI) awarded to RTI International a contract to comprehensively evaluate the loss to follow-up in five states: Arkansas, Massachusetts, Michigan, Utah, and Virginia. The evaluation project was planned and conducted collaboratively with CDC technical officers and the state EHDI coordinators. The specific evaluation objectives of the project were:

- To investigate and document factors that contribute to loss to follow-up including:
 - structural barriers: state policies and regulations, organizational systems, availability of screening and follow-up services, availability of equipment, and transportation;
 - financial barriers: health insurance coverage of screening services and follow-up evaluations; and
 - personal barriers: norms, beliefs, attitudes, knowledge, social support systems, maternal age, parity, and ethnicity.

- To provide information that will inform strategies and policies to increase the rates of follow-up:
 - create a program that is more responsive to consumers’ needs, and
 - improve the cultural competency of the program.

The evaluation project involved three data collection activities: (1) focus groups with state EHDI stakeholders (parents, providers, hospital staff, advocates, and state EHDI staff); (2) a Maternal Exit Survey of post-partum women prior to hospital discharge; and (3) a Computer-Assisted Telephone Interview (CATI) survey of women whose infants had been referred for additional rescreening or diagnosis. The use of these three information sources allowed the study to gain a fuller understanding of the challenges of ensuring early hearing screening and intervention in Virginia and the United States.

The purpose of this report is to present the findings of the project’s data collection activities in Virginia. In this chapter we summarize the key highlights of those findings.

Virginia Focus Groups

Focus groups with key EHDI stakeholder groups in Virginia revealed the following major challenges and barriers to follow-up:

- A shortage of audiologists primarily due to lack of or inadequate insurance reimbursement for diagnostic services.
- A lack of a standards for counseling and referring families resulting in uneven quality of these screening procedures.
- No systematic way to inform providers (audiologists and physicians) of the screening results; the onus lies largely with the parent to bring documentation to the visit but they often do not.
- The lack of medical home and/or having a pediatrician identified prior to birth leaves families with fewer tangible links to the follow-up process.
- The designated “medical home” does not in fact coordinate the various specialized care needs of the infant but instead typically operates in isolation from the other providers involved in the follow-up and intervention process.
- Lack of or inadequate private and public health insurance coverage to cover all the costs of follow-up and intervention. In some cases these costs are covered but parents are misinformed about their coverage or are not informed about public programs such as Part C that will cover them.
- The cumbersome, lengthy process of obtaining referrals and approvals from private and public insurers for intervention that can delay the process by weeks and months.
- Inadequate information exchange among professional staff working with families; staff are not always aware of all the programs available to support families.

- Some physicians downplay the importance of the screening results and/or still promote a “wait and see” approach which sends a mixed message to parents who are receiving other information and counseling, encouraging them to take the referrals seriously and address them in a timely fashion.
- A lack of knowledge about hearing loss among extended family and friends can create conflict and stress for families in the midst of the diagnostic or intervention process.
- A lack of or perhaps insufficient linkages to family support services; parents noted a need for more family-to-family networks.
- Cultural barriers related to language and stigma against disability make it difficult for families to understand the hearing loss issue, accept it, and then address it.

Maternal Exit Survey

The Maternal Exit Survey, conducted in four hospitals in Virginia, revealed the following key findings regarding screening practices and maternal knowledge, attitudes, and beliefs about hearing loss and screening results:

- Two thirds of respondents (65%) reported that had received information regarding hearing screening *prior* to hospital admission.
- Nearly three quarters of the respondents (73%) reported that they had received information about hearing screening since being admitted to the hospital.
- Two thirds of the respondents (66%) indicated that a hospital staff person had talked to them about the hearing screening *prior* to the procedure.
- Less than half of respondents (39%) reported receiving the results of their infant’s hearing screening, both in person and in writing.
- A third of the respondents who completed the Spanish version of the survey (33%) reported that they had not received written materials regarding hearing screening in Spanish.
- Over half of respondents who completed the Spanish version of the survey (55%) indicated that no one had explained the results of the hearing screening in Spanish.
- A majority of the respondents (76%) indicated they received all the information they needed regarding the hearing screening, and that the hospital staff had spent enough time explaining the results (75%).
- The majority of the respondents (88%) indicated that they understood the meaning of the hearing screening test result.
- Of those respondents whose infant *did not pass* the hearing screening test:
 - Three quarters believed the hearing screening result to be true (75%).
 - Nearly all indicated they knew what to do next (94%) and thought it was important to retest soon (100%).
 - Nearly three quarters (73%) indicated feeling anxious about the result.

- Over half (56%) indicated that the hospital had made a follow-up appointment.
- A quarter (24%) had not received any information about where to go for follow-up evaluation.

CATI Survey

The Computer Assisted Telephone Interview (CATI) Survey conducted with 190 women whose infants had not passed the initial hearing screening revealed findings regarding screening and follow-up practices, the information provided, maternal knowledge, attitudes and beliefs about hearing loss, the hearing screening, and follow-up re-screening and diagnostic evaluation.

Information about Hearing Screening

- A minority of respondents (12%) remembered receiving information regarding the hearing screening test *prior* to hospital admission.
- Nearly a third of the respondents reported that they did not fully comprehend the materials provided on hearing screening; some understood only some portion of the materials (18%), a few reported that they did not understand the materials all that well (4%), or had not read the materials (6%).
- Among Spanish-speaking mothers, the majority (81%) received hearing screening materials in Spanish but less than half (37%) did not have anyone explain to them the hearing screening results in Spanish.

The Hospital Hearing Screening Experience

- Almost all respondents had received a hearing screening test (95%) and the results (97%) prior to hospital discharge.
- Two thirds of the respondents (65%) remembered receiving both verbal and written confirmation of the results of their infant's hearing tests.
- Almost all respondents indicated that they received all the information they needed regarding the hearing screening test (89%) and a somewhat smaller majority thought that the hospital staff had spent enough time explaining the results (82%).

Beliefs and Attitudes about the Hearing Screening Test Result

- A majority of the respondents indicated that they understood the meaning of the hearing screening test result (89%) and believed it to be true (84%).
- Although nearly all respondents indicated they understood the results, half thought the hearing screening test result meant the infant had "*fluid in his or her ears and it was nothing to worry about*" (47%) or that the infant "*was probably okay but there was a problem with the test*" (48%). A third (29%) did not realize the result meant the child should be retested soon and a quarter (26%) thought the infant had hearing loss.

Follow-Up Procedures

- Almost all the respondents (93%) indicated that they understood what to do next in terms of follow-up and completed their follow-up appointment (96%).

- Just under two-thirds of respondents (61%) had the hospital or doctor's office make the follow-up appointment; another third (31%) received a list of audiologists.
- More than half of respondents indicated that no one had called (55%) or sent them a letter (54%) to remind them about their follow-up appointment.
- Eighty-six percent of respondents made an appointment for a follow-up evaluation by 1 month post-discharge from the hospital.
- Ninety-one percent of the respondents whose infant had not passed the follow-up evaluation had undergone further diagnostic evaluation.

Family Social Support Services

- Of those respondents whose infants had been definitely diagnosed with hearing loss, the majority (83%) had not received any information about family-to-family support networks.

Maternal Anxiety

- Overall, a majority of the respondents (86%) expressed anxiety about the results of the hearing screening result.
- Among those whose infants had been referred to diagnostic evaluation, under half (45%) reported that they were "very anxious" about the effects of a possible hearing loss in their infant.

Conclusions and Recommendations

Based on the findings of this evaluation, we offer some key conclusions and recommendations with implications for EHDI programs and policies.

- A shortage of audiologists could pose an impediment to the timely follow-up of infants referred for additional follow-up. One factor cited for the shortage is inadequate insurance reimbursement. Efforts to examine this issue more closely and identify the appropriate programmatic and policy solutions are warranted.
- Physician knowledge and attitudes about early hearing screening could potentially influence parents in both negative and positive ways with respect to follow-up compliance. Continuing education and promotion of the benefits of early screening, detection, and intervention are needed to reinforce the training of younger physicians and to dispel the outdated notions of an older generation of physicians.
- Extended family and friends' lack of knowledge and understanding of hearing loss, its detection and intervention, can be a source of conflict and misinformation. Education and counseling activities should extend beyond the immediate family to significant others so that they can offer support that is informed, positive, and empowering.
- The majority of women do not remember receiving information about hearing screening and hearing loss during the prenatal period. Hospital stays are typically too short and rushed to provide an effective environment for education and counseling. More effort should be directed to ensuring that *all* pregnant women receive education and counseling on hearing screening.

- Educational materials are not universally understood or even read. Attention should be given to their comprehension and appeal. This study was not able to distinguish between lack of use of informational materials or a lack of recall on the part of respondents. It is possible that the low rates of recall of information about hearing screening summarized above may reflect a sense that materials are not compelling or presented in a way that makes them memorable. The fact that some respondents reported that they did not fully understand materials suggests that it will be useful to more rigorously assess the materials that are presented and to assess the nature of their presentation.
- Although women appear to think in a global sense that they understand the test results and have all the information they need, their misconceptions about the hearing screening test reveal a potential lack of comprehension of the results. This lack of understanding could potentially be addressed through education and counseling in the prenatal period, both written and oral confirmation of the results, and more intensive counseling and education during the hospital stay.
- Spanish materials are not widely disseminated to all who need them and more could be done in this regard. Efforts should be directed at ensuring that all non-English speakers receive the results of the hearing screening in their native language.
- The medical home is an important factor in ensuring access to health care. Families that have no established link to a health care provider for their infant will likely find it more difficult to navigate the follow-up process in a timely manner. Identification of these families prior to discharge so that they can be tracked and supported more intensively may prevent or mitigate loss to follow-up.
- Systematic links to follow-up were not uniformly available to all women. Overall, completion rates to follow-up and diagnosis were quite high; however, additional supports such as scheduling appointments prior to discharge and reminder calls and letters could promote timeliness for those high-risk families who face various barriers to accessing health care.
- The majority of women whose infants did not pass the hearing screening test experience some level of anxiety. Post-test counseling should address parental concerns and worries, but should do so in a way that stresses the importance of follow-up.
- The majority of women who have an infant with a diagnosed hearing loss would like to have another family to connect with but the links to family support networks appear to be largely lacking and need to be improved.

1. INTRODUCTION

Permanent hearing loss affects up to 12,000 infants every year (1–3 per 1,000 births) and is the most frequently occurring birth defect (Health Resources and Services Administration [HRSA], 2002; National Center for Hearing Assessment and Management [NCHAM], 2002). Appropriate early intervention by 6 months of age can significantly improve infants' prognosis for speech and language acquisition and minimize impairments to their cognitive and social development (Karchmer & Allen, 1999; Yoshinaga et al., 1998). Thus, timely screening for hearing loss, follow-up evaluation, and entry into early intervention are critical.

Data obtained from the Centers for Disease Control and Prevention's (CDC's) 2004 survey of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA, 2004) estimate that among the 48 states and territories reporting, 91.7% of all infants are screened for hearing loss, most prior to hospital discharge. In the *Morbidity and Mortality Weekly Report* "Infants Tested for Hearing Loss—United States, 1999–2001" (CDC, 2003), CDC reported that in 21 states and territories that reported screening data during that period, the number of infants who were screened increased by approximately 35% and the number of infants receiving an evaluation increased by an estimated 9%. Among the 10 states and territories that reported audiologic evaluation referrals, the rates of referral decreased from 4% in 1999 to 2% in 2001. The decline in referral rates was attributed to improved screening methods and technologies that resulted in fewer false positives requiring further evaluation (CDC, 2003).

The CDC report also indicated that the number of infants completing follow-up testing and initiating early intervention services needed to be increased. In 2001, nearly half of the infants referred to audiologic evaluation did not receive one and approximately one third of infants identified with hearing loss were not reported as enrolled in an intervention service (CDC, 2003). Similar estimates were reported in the 2004 DSHPSHWA survey, indicating little improvement in the number of infants completing follow-up in the intervening years.

The benefits of early detection can only be fully realized if infants with hearing loss are linked to intervention services in a timely and appropriate manner. Despite nearly universal screening of all infants, loss to follow-up for additional evaluation or intervention remains a formidable obstacle to achieving the full promise of early detection (White, 1997). There may be many reasons for this including poor data tracking, parental attitudes and beliefs, medical personnel, geography, and socioeconomic factors (Joint Committee on Infant Hearing [JCIH], 2000; White, 1997, 2001).

1.1 National Efforts to Enhance the Screening and Detection of Infant Hearing Loss

There is considerable federal support for implementation and evaluation of universal infant screening programs. HRSA funds 50 states and jurisdictions for program implementation while CDC provides funding for data surveillance and monitoring, namely through the Early Hearing Detection and Intervention (EHDI) program. The EHDI program is designed to screen and track infants with possible or confirmed hearing loss, thereby promoting infants' entry into an intervention program and fostering the adoption of communication skills among children with hearing impairments. Primarily, the EHDI programs are managed at the state level and supported by state, federal, and private institutions. The program's mission is for every state and territory to develop an EHDI program that will identify infant hearing loss and encourage hearing loss intervention as early as possible.

The components of the EHDI programs are known as the "1-3-6" plan. This plan promotes the following:

- screen every infant by 1 month of age,
- conduct a follow-up evaluation by 3 months of age if the infant does not pass the initial screen, and
- begin intervention by 6 months of age if the infant receives a confirmed diagnosis of hearing loss.

In addition, the EHDI program strives to promote a medical home for every infant in need of one, a culturally sensitive family-to-family support, and an effective system of tracking and follow-up (JCIH, 2000; Strickland, 2002).

1.2 Virginia's Efforts to Enhance the Screening and Detection of Infant Hearing Loss

Screening and Referral to Follow-Up Evaluation. The Code of Virginia (§[32.1-64.1](#)) and Virginia regulation [12 VAC 5-80](#), promulgated in 1999, require that all hospitals with infant nurseries and all hospitals with neonatal intensive care services screen the hearing of all infants and report the status and/or results of that screening to parents prior to discharge. These hospitals must also report the status and/or results of that screening to the Virginia Department of Health (VDH) and the infant's primary care provider within 2 weeks.

If the infant does not pass the initial screening the hospital must refer the infant for diagnostic evaluation (VDH, 2002b). The specific protocols that guide the referral process are contained in VDH's "Protocols for Diagnostic Audiological Assessment" (<http://www.vahealth.org/hearing/Audiologicprotocolfinal904.pdf>).

Diagnostic Evaluation. All persons who provide audiological services must report the status and/or results of diagnostic evaluation of all infants referred for such services to VDH

within 2 weeks of the evaluation. They must also give parents information about hearing loss, including choices about learning communication, and to refer them to local early intervention services (VDH, 2002a).

Tracking and Surveillance Systems. All hospitals use a web-based reporting system called VISITS—Virginia Infant Screening and Infant Tracking System—to report screening results on individual infants to VDH (NCHAM, 2001). The information obtained from hospitals and audiologists is maintained and tracked in the VISITS database. This system tracks the follow-up status of infants who have not passed the initial screening and are referred for further diagnostic evaluation, and infants who pass the initial screening but are otherwise deemed “at risk for emergent hearing loss” (e.g., family history of deafness, prematurity) (VDH, 2002b). It also tracks infants who have missed their appointments and those transferred out of state.

VDH sends a letter to parents of identified infants and their medical providers (if that name is provided by the hospital) detailing specific recommendations for follow-up. In addition, VDH sends letters to parents of all infants who are diagnosed with hearing loss informing them of the services and resources available for early intervention services and resources.

Education and Training. VDH conducts a variety of educational and training activities to support screening and surveillance, including statewide workshops on infant hearing screening, equipment, and requirements, and regional training sessions for hospital staff on electronic reporting system (NCHAM, 2001).

VDH is also engaged in a number of education activities aimed at parents and the general public, such as distributing brochures for parents on infant hearing screening and follow-up (English and Spanish), developing a parent resource guide, conducting public-information campaigns, and presenting at state and national professional organization meetings.

1.3 Purpose of this Evaluation Project

The benefits of the early hearing detection and intervention system cannot be realized unless the “1-3-6” plan is fully implemented and achieved. Although a number of studies based on surveys have identified important factors and barriers to screening and intervention, it is still unclear, for example, which follow-up strategies are most successful or why, despite a hospital’s best tracking and follow-up efforts, parents still do not bring their infants in for screening, diagnosis, or intervention. To date, no study has examined in-depth the barriers and factors contributing to loss or delay to follow-up. Such an examination is warranted if states are to improve follow-up rates.

In 2002, CDC awarded to RTI International a contract to comprehensively evaluate loss to follow-up in five state EHDI programs: Arkansas, Massachusetts, Michigan, Utah, and Virginia. The evaluation project was planned and conducted with ongoing support and

collaboration of CDC partners and the state EHDI coordinators in each of the aforementioned states. The specific evaluation objectives of the project were:

- To investigate and document factors that contribute to loss to follow-up including:
 - structural barriers: state policies and regulations, organizational systems, availability of screening and follow-up services, availability of equipment, and transportation;
 - financial barriers: health insurance coverage of screening services and follow-up evaluations; and
 - personal barriers: norms, beliefs, attitudes, knowledge, social support systems, maternal age, parity, and ethnicity.
- To provide information that will inform strategies and policies to increase the rate of follow-up:
 - create a program that is more responsive to consumers’ needs, and
 - improve the cultural competency of the program.

To achieve these objectives, the evaluation implemented a study design that involved:

- focus groups with key EHDI stakeholders—parents, physicians, audiologists, hearing loss advocates, hospital screening staff and state EHDI program managers, and early intervention professionals (Part C program staff);
- a self-administered survey of mothers prior to hospital discharge (referred to hereafter as the “Maternal Exit Survey”); and
- a computer-assisted interview survey of mothers whose infants did not pass the initial screening (referred to hereafter as the “CATI survey”).

1.4 Purpose and Organization of this Report

In this report, we present the findings of the data collection activities carried out in Virginia. The findings of the entire project including the other four states can be found in the forthcoming *Assessment of State Early Hearing Detection, and Intervention Programs (EHDI): A Program Operations Evaluation Protocol: Final Report*. Chapter 2 presents the findings of the focus groups; chapter 3 presents the findings of the Maternal Exit Survey; and chapter 4 presents the findings of the CATI survey. Each chapter describes the data collection methods and results, and includes a brief discussion of the findings. Detailed tables of the survey data are included in the appendices.

2. FOCUS GROUPS AND KEY INFORMANT INTERVIEWS

The purpose of the focus groups was to identify and explore the relevant factors associated with loss to follow-up and to use that information to inform the development of Maternal Exit and Computer-Assisted Telephone Interview (CATI) survey instruments. RTI concentrated its discussions primarily on factors related to state policies and procedures, financial burdens, and personal burdens. In this respect, the focus groups and key informant interviews served as formative research that shaped subsequent data collection activities. Nonetheless, these qualitative data deserve to be examined in their own light as they add context and a richness of detail that complements the survey data.

Focus groups were conducted November 10 and 11, 2003, in Richmond and Newport, Virginia. Stakeholders represented in focus groups and key informant interviews included audiologists, hearing advocates, physicians, and parents.

2.1 Methods

Recruitment of Stakeholders. Initially in planning the focus groups/interviews and identifying the appropriate stakeholders to include in them, the RTI team held a series of meetings with the staff of the Virginia Department of Health Early Hearing Detection and Intervention (VDH EHDI) Program. Once RTI and VDH had identified all the relevant professional and agency stakeholders, RTI contacted each one by mail, e-mail, and telephone. Once they had agreed to participate, stakeholders signed and returned an informed consent form to RTI.

To abide by HIPAA privacy rules, RTI could not directly contact parents to participate in the focus groups. Instead, VDH EHDI sent recruitment letters to parents, and those who were interested in learning more about the project sent a letter of interest and a signed informed consent form to RTI. Only at that point did RTI contact parents to confirm receipt of their informed consent and verify their eligibility using screeners that the Centers for Disease Control and Prevention (CDC) and RTI developed collaboratively. The eligibility criteria included parents whose children who had not been refused screening for religious or other reasons and parents of children who were 5 years old or younger (to minimize recall bias).

Initially, the study design called for conducting focus groups of parents distinguished by their screening experiences such that the groups would represent parents whose infants had and had not met the "1-3-6" benchmarks. However, due to significant challenges in the recruitment of parents, it was not possible to separate groups by screening experiences.

In total, RTI conducted 3 focus groups and 2 key informant interviews involving 17 stakeholders. **Table 2-1** illustrates the number of groups and interviews conducted as part of the Virginia site visit.

Table 2-1. Number of Focus Groups/Interviews and Number of Participants

	Number of Focus Groups	Number of Interviews	Number of Participants
Advocates	1		8
Audiologists	1		4
Parents	1	1	4
Physicians		1	1
Hospital Screening Staff		1	1
Total	3	3	18

Interview Procedures. The focus groups and interviews were conducted in person, during site visits to each state that took place over a 2-month period. The focus groups met for approximately 2 hours at a facility identified by VDH EHDI staff. Key informant and one-on-one interviews lasted for approximately 1 hour, typically in the same facility used for the focus groups or in the participant’s office (for professionals). A moderator led the focus groups or the interviews using a semi-structured discussion guide developed by RTI and reviewed and approved by CDC. A member of the research team took notes on a laptop and monitored the audio taping of the discussion. The audio taping was done for each focus group and each interview in order to produce transcriptions of each session.

The moderator and note taker informally debriefed following each focus group or interview to capture their immediate thoughts and impressions. The moderator and note taker also debriefed with the state EHDI Program Director at the end of the site visit to provide her with general feedback on the activities conducted.

2.2 Analysis

Stakeholders’ responses were recorded on audiocassette and transcribed. Transcriptions were entered into N-Vivo—a qualitative data analysis software program—coded and analyzed. The coding structure was based on the conceptual framework for the project which focused on structural, financial, and personal factors that impact follow-up (or loss to follow-up) within EHDI programs. The coding structure also took into account the research team’s observations of the emerging themes from the groups and interviews. N-Vivo allowed comparisons of responses to questions or concepts across cases and identification of themes or patterns across topics. When necessary, the coding structure was amended in an iterative fashion so salient themes could be introduced and less prominent themes placed outside the coding structure.

2.3 Results

2.3.1 Structural Factors

Availability and Accessibility of Services. Although the implementation of the EHDI program in Virginia involved “some learning curves,” there appeared to be agreement that “...the hospitals have done a superb job” of implementing infant screening. One issue identified, however, was the limited number of hospital screeners. In some hospitals, if the screener is not present due to illness or vacation infants go unscreened prior to discharge. Some parents interviewed described how they were given instructions to follow up on their own for hearing screening but that the location for screening “was full.”

Meanwhile, although the physicians with whom we spoke thought there were services readily available, others—most notably audiologists—disagreed. This disagreement may be due to the fact that the physician stakeholders were based at an academic medical center with an ample supply of relevant services. “The number of providers is getting smaller...because they’re not able to get reimbursed.”

One advocate who was also a parent of a hearing-impaired infant described her own experience, “...we learned [about] this wonderful approach in Pennsylvania but there were no providers in Richmond [Virginia]...I was crushed...How in the world can there not be an auditory/verbal provider in this area?!”

Beyond screening, intervention is an area in which there are many challenges. Negotiating the system to finance hearing aids was a tremendous hassle. When asked how long it takes from the time of identifying an infant who could benefit from amplification to actually getting hearing aids was “...6 months to a year. Because there’s...the reimbursement game...” Many described instances in which parents were falsely informed that hearing aids and batteries were not covered by insurance or other third-party payors.

Addressing intervention more broadly, one advocate explained, “There are still major school systems in Virginia who offer no choice [about intervention approaches]. They might say they do, [but] Total Communication is not the only choice and if that’s not what you choose you’re left out cold.”

Medical Home. One factor that may impede the timely entry into follow-up is the lack of a medical home. After discharge, the physician with whom we spoke explained “We’re not seeing a lot in follow-up and I’m thinking...one reason is because they have not established a pediatrician before [discharge].” Although mothers of infants are asked to identify a pediatrician, if they have not already identified a pediatrician they will likely list the name of the attending physician in the hospital—and never actually follow up with that physician for care. However, “...if they are [on] Medicaid and then they have to choose a Medicaid HMO and then they have to choose a pediatrician, so they have to go through hoops.”

The concept of the medical home as the coordinator of care for a child with special health care needs was not evidenced in practice according to the feedback of the informants. Various providers (audiologists, ENT, EI staff) caring for a child were operating largely in isolation from one another and communication among and between them sporadic and informal. Audiologists commented that physicians needed to take on the coordination role because they had the most contact with the family and were in the best position to manage the hearing loss in the context of the child’s whole health and development.

Screening, Diagnostic, and Intervention Practices. The audiologists were of the opinion that the hospital screening aspect of the EHDI system in Virginia was running smoothly, and they had not observed any problems either with the training of the screeners or the use/maintenance of the equipment. The parents, on the other hand, raised a number of issues. None had received any information about the hearing screening during their pregnancy or prior to the screening. They first learned of the screening when they were told by the screener that their infant had “failed” and needed to be retested. The post-screen counseling they received was less than adequate as it downplayed the “do not pass” result and the screeners themselves were described as not especially knowledgeable or helpful. One parent with whom we spoke did not return to have her infant re-screened until she received a letter from the state EHDI when he was 6 months old. She delayed the follow-up because the screeners had not impressed upon her the importance of returning for a re-screen within the month.

I didn’t really think too much of the screening system because then people told me that like a lot of the screenings come back negative and then you go back for the ABR.—Parent

The mixed assessment of the screening process among the various informants reflected the lack of a standardized screening protocol among the hospitals. Some provided the results both in verbal and written forms, others just one or the other. No doubt also some hospital screeners provided detailed information about the follow-up process and others not as much.

Every hospital, I mean, we receive referrals from like 23 different hospitals. Every one has a different procedure in terms of how that child ends up getting to us.
—Audiologist

And this diversity of screening protocols to some extent may have been a contributor to the loss to follow-up because the major juncture at which parents were lost to follow-up according to the audiologists was between the time of discharge and the re-screen. Once the family was past the re-screen process, there was less of a problem tracking them. At that point there would be some professional to help them coordinate their care (the audiologist and then eventually an early intervention coordinator).

The 6-month reminder letter sent by the state EHDI program to parents who had not completed re-screen was viewed as having mixed impact on follow-up. While some

audiologists saw few parents coming back as a result of the letters, others thought the letters had been motivating to some of the parents they had seen.

One factor that audiologists agreed contributed to the delay in follow-up was a requirement that the hospital provide parents a “choice” of facilities to which they might go to receive re-screening. The audiologists thought it would be much better to encourage the parents to go back to the birthing hospital (assuming it was convenient for them) so they could be much more easily tracked and their appointment status monitored.

Another major contributor to delay in follow-up was managed care, including the Medicaid HMOs, because the paperwork involved in obtaining a referral for a re-screen, diagnostic evaluation, or intervention often took weeks if not months. Likewise, the “reimbursement game” that parents had to play with their insurers often added months to follow-up. For one of the parents with whom we spoke, it took nearly a year from the time her infant was diagnosed to obtain her HMO’s “ok” to receive intervention.

...the HMOs have not worked to facilitate better care or quicker care in this instance. It’s not happening.
—Audiologist

Once into intervention, the parents expressed a high degree of satisfaction with their early intervention services. However, informants pointed out that although there are EI centers accessible throughout the state, they varied tremendously in their range and quality of services. The most convenient EI center might not necessarily have the resources or competence to address hearing loss.

...it is hard in today’s world to give the time to sit down and to actually be informed enough on our part to know all of the different intervention services and to know the communication methods and all that.
—Audiologist

Information Exchange. The informants noted that they did not have the information they needed to help families get through the follow-up process in a smooth and timely fashion. For example, there was no standard form or means by which to communicate the results of the screening from the hospital to the audiologist and physician. Some had triplicate forms that were sent to the parents, the physicians, and the audiologists; others left it to the family to convey the results to their providers. The audiologists and physician informants agreed that it would be very helpful to them to receive the results of the screening

directly from the hospital so they would not have to receive it second-hand from the parents with no documentation of what had transpired.

Moreover, the state tracking database maintained by the state was not accessible to providers and informants viewed this as an important source of verifying the status of the families referred to them. They agreed that the care of these families was a “shared venture” but they did not have all the means at their disposal to work with the other EHDI stakeholders (the physicians, state EHDI staff, EI coordinators) to ensure that these families would not fall through the cracks of the system.

A major barrier to information exchange was related to HIPAA regulations. Prior to HIPAA's enactment, audiologists could more readily share relevant information with the infant's pediatrician or any other relevant service providers—including Part C programs—as necessary. Now, HIPAA requires parental consent for exchange of information. While this was not an insurmountable barrier, it was one which was mentioned by many stakeholders with whom we spoke.

Audiologists also expressed frustration at their own networking limitations. One explained that she only recently came to learn of a state program, Care Connection, which was established to meet the need she had just identified. One may posit, however, that if this well-connected audiologist only just learned of the program there are likely to be other less-connected audiologists who do not know of the resources available from this program.

State Policies, Practices, and Procedures. Although stakeholders viewed the EHDI legislation in Virginia as a great benefit to their efforts they conceded that the law had “no teeth.” They described a fairly widespread lack of understanding among insurers regarding what the legislation mandated them to cover. Furthermore, the self-insured plans were exempt from these coverage mandates because of federal ERISA legislation (Employee Retirement Income Security Act). A number of stakeholders also noted that the limits of state budgets to finance EHDI and related programs (e.g., intervention) were hindering the promise of the legislation.

Financial Factors. Financial issues were seen as a significant barrier for follow-up to those in the EHDI program. As one audiologist stated plainly, “...the biggest barrier to follow-up is lack of reimbursement.” Another elaborated, “We’re running out of [audiology] providers that are willing to provide care because of insurance refusal to pay.”

...it's heartbreaking to me to think that just because somebody's low income, that knocks them out of choice.—Audiologist

These views were echoed by the advocates. They commented that financial issues play the most significant role in intervention. In some communities there is a shortage of audiologists who can offer a range of intervention approaches. And parents of infants with hearing loss explained, “My insurance pretty well limits me to where I can go.”

While negotiating the health system to finance hearing aids was described as cumbersome, some parents were able to successfully manage it eventually. As one parent commented, “The only thing I have to pay for is hearing aid batteries.” Another followed up, “We get our batteries through early intervention [Part C of IDEA]. Have them write it into your IFSP [Individual Family Service Plan].”

2.3.2 Individual-Level Factors

Physician Knowledge, Beliefs, and Attitudes. The knowledge of all stakeholders and the exchange of accurate and appropriate information regarding follow-up through the EHDI

program is critical to ensuring appropriate follow-up. Many with whom we spoke described the importance of understanding the significance of identification and appropriate follow-up for infants with hearing loss.

Audiologists described many instances in which physicians provided parents with inaccurate or inappropriate information. One audiologist explained: “What has happened so many times is ...the infant supposedly passed the infant screening, no problem. Mom’s recognizing something. The physician says, ‘Give him time. Give him time. You’re comparing him to an older infant’ or something. Maybe he’s just a littler slower in development.’ And the infant is profoundly deaf and here’s 6 months where the infant received nothing.”

There’re actually professionals out there who are telling families, ‘oh, just one ear’s got a hearing loss. Don’t bother getting a hearing aid. They’re expensive. Don’t worry with it. It’ll be okay.’—Audiologist

Related to this issue is the observation that parents often receive conflicting information. “...you’ll get the infant that maybe doesn’t pass on one side and the physician says, ‘Oh, don’t worry about it.’ And then the family gets a letter from the state saying, ‘You need to follow up.’”

Of particular concern to many audiologists were the many physicians who encourage parents not to be concerned about positive screening results: “...there’s still an awful lot of the old school, ‘If they’re not talking by 4, we’ll deal with it then.’” But, there was some agreement that this problem is declining as the number of more recently trained physicians rises. “Pediatricians are starting to kind of get the hand of it...We get a lot less, ‘Don’t worry he’ll grow out of it.’”

Parent and Family Knowledge, Beliefs, and Attitudes. The parental education was described by informants as “a huge component” of the EHDI process and they identified both some weaknesses and needed enhancements to address them. The parents did not find the brochure provided at the hospital as especially helpful at the time as it focused solely on hearing and development but gave no information about the screening itself. They also thought the amount of information they received at subsequent phases of the follow-up as “overwhelming” and a terrific ordeal to read through and find what they needed.

Informants suggested providing more information during the prenatal visits and the hospital tour. The mediums in which the information was communicated needed to be diversified as well beyond just paper pamphlets and brochures. The parents were especially enthusiastic about the videos that had received from their EI coordinators.

A factor that informants raised as a barrier to education and following through on referrals to evaluation and intervention was parental denial. Informants had observed that the denial was especially prevalent among families whose infants had mild to moderate hearing loss because the problem was less obvious and more easily dismissed.

Meanwhile, even in instances in which health care professionals may agree with a diagnosis and appropriate intervention, friends and family may offer opinions or advice that create conflict. This is particularly true in instances in which family or friends may question a diagnosis of hearing loss. One parent described the following situation: "I don't know how many times my dad is like, 'He doesn't have a hearing loss...he's not wearing his [hearing] aids but he heard me.' I'm like, 'Okay, low tones. He can hear *you*. He can't hear me. I matter.'"

Because I talk loud enough for my son to hear me...without his hearing aids everybody's like, 'He heard you!'...Everybody thinks he's not deaf. I'm like, 'Well, you guys don't go to the doctors. You don't see the tests. You don't sit around and listen to everything they say, so you don't know.'
—Parent

Audiologists reported that they were more concerned about following up with children of hearing families than those born to deaf parents integrated into the deaf community/culture. As one audiologist described, "...deaf culture is a whole different issue because they have different needs and different priorities in terms of what intervention is...if an infant's deaf, they're incorporated into the deaf community. They get language. So we're not as concerned if they're born into a deaf family. They already have the culture."

However, deaf culture and the controversy surrounding cochlear implants was a subject about which advocates had a great deal to say. They explained that many in the deaf community do not view deafness as a disability that needs to be treated with hearing aids.

Family Support Networks. Despite the audiologists' reports that they work to link parents of children with hearing loss to other families with similar situations, parents with whom we spoke reported that they would like more parent-to-parent support networks. Among those with whom we spoke, one appeared to be particularly isolated. One mother mentioned that she participated in an online (Yahoo) support group for families of children with hearing loss. Others described activities sponsored by their Part C program.

Cultural and Other Barriers. Subpopulations that appear to be of particular risk for lack of follow-up are children in non-English-speaking families. In the experience of the audiologists, some ethnic cultures such as Asians seemed to have an especially strong stigma against disabilities which made it difficult to accept and address the hearing loss in their child. This in addition to language barriers made them an especially difficult population to serve.

Other individual-level barriers included poverty and other health care needs. The former face any number of transportation, economic and life stressors which make attending to a child's health need difficult. Those who have special health care needs are also at special risk for

Issues are just magnified when you look at our clients who have come from different languages and different cultures and who have no insurance.—Audiologist

loss to follow-up: because "...[if] the infant is multiply handicapped...the hearing loss always goes on the back burner."

2.4 Discussion

Focus groups in Virginia identified various structural, financial, and personal factors which could contribute to loss of follow-up in the EHDI program. These factors reflect the interrelated nature of programs such as EHDI. Parents whose children do not pass their infant hearing screen are faced with a system which has an increasing degree of complexity as a family proceeds through the process.

Our findings suggest that at the time these interviews were conducted, the shortage of professional audiologists and intervention options was a key challenge for the VDH EHDI program. Furthermore, it appears that these shortages and limitations are fueled in large part by the lack or inadequacy of health insurance reimbursement for these services.

Physician knowledge and attitudes about early hearing screening also appear to be out of step with the prevailing recommendations. There are still perceptions that a "wait and see" approach is appropriate and that there is a lack of understanding of the value of early intervention. While these focus groups could not ascertain the extent of these views among physicians, it is still a barrier to be aware of and address, even if these beliefs are held by a minority of physicians.

Family beliefs and attitudes also are a barrier for parents of infants with hearing loss. Family and friends may not fully appreciate the nuanced nature of hearing loss and question the diagnosis altogether. There are also issues particular to deaf culture that may impact the kind of intervention parents will select for their infants.

Finally, the medical home appears to be an important component of linking parents to follow-up evaluation and intervention. Within the VDH EHDI system, the pediatrician or other primary is notified of the infant's hearing screening results and is expected to assist the family in complying with the recommendations for follow-up. Families that have no established health care provider for their infant will not have that critical resource to help them navigate the follow-up process.

Limitations. This chapter presents the individual perspectives of multiple stakeholders regarding issues that impact the VDH EHDI program. Because these qualitative data are gathered from a selective, nonrandom pool of participants, the findings are not generalizable to all EHDI programs, professionals serving the hearing loss population, or parents of children who have hearing loss. However, these findings provide a solid understanding of the experiences and challenges that affect the EHDI program.

Other noteworthy limitations to note are recruitment challenges. RTI staff experienced significant problems recruiting parents primarily because: (1) the relatively low incidence of

infant hearing loss yielded a small pool of eligible parents, (2) only outdated or incorrect contact information was available, and (3) identified parents were geographically dispersed and it was not possible to identify a location convenient to all to meet. For these reasons, the focus groups were not able to capture the full range of experiences parents encountered in having their infant screened, evaluated, and treated for hearing loss.

Physicians were another stakeholder group RTI encountered significant recruitment challenges with, due to their unpredictable work schedules, long hours, and the lack of one central location to convene a group.

3. MATERNAL EXIT SURVEY

The Maternal Exit Survey was conducted in four hospitals in Virginia from May to September 2006. The purpose of the Maternal Exit Survey was to assess the mother's understanding of her infant's hearing screening result and the recommended next steps for following up with additional rescreening or evaluation if her infant had not passed the initial screening. In addition, the Maternal Exit Survey captured information about the mother's attitudes toward screening and follow-up along with basic demographic information.

RTI's Institutional Review Board (IRB) (Federalwide Assurance Number: 3331) reviewed and approved the study protocol. In addition, the participating hospitals' IRBs either reviewed and approved the protocol or deferred to RTI as the IRB of record.

3.1 Methods

Selection of Hospitals. In order to have some diversity in the patient population, RTI provided the states with some guidelines for selecting hospitals, including type of residential area and size of hospital. After introducing the study to the hospitals they had identified, the states provided RTI with the contact information for each. RTI was then responsible for making further contact with the hospitals to solicit cooperation to participate in the study. RTI worked with the hospital staff to ensure that the necessary IRB approvals were obtained. The four hospitals that agreed to participate included three hospitals in metropolitan areas and one rural hospital with approximately 125 to 300 births per month.

After the necessary approvals were obtained, RTI provided the hospital staff with enrollment packets that included the Exit Survey and an EHDI picture frame magnet, a nominal gift for those who completed the survey. The Maternal Exit Survey was provided in both English and Spanish, depending on the hospital's patient population (a copy of the survey instrument is provided in Appendix A). Each survey form was labeled with a unique study identification number. RTI provided training manuals to the hospital staff responsible for performing the data collection. RTI then trained the staff during 30- to 60-minute sessions which were generally conducted by teleconference.

Sample Selection. The sample from the four participating hospitals was drawn from a census of all women giving birth to a live infant during a specified period of time until approximately 100 surveys had been completed.

Data Collection. The Maternal Exit Survey was distributed to all women who gave birth to a live infant during the data collection period, regardless of the status of their infant's hearing screening. The data collection period was determined by the length of time it took to enroll 100 patients. At the larger hospitals this took only a couple of weeks, while at smaller hospitals it took as long as 3 months. The data collection procedures were designed to fit seamlessly into the normal operations of the hospital so that the study would be easy

to implement. RTI worked with hospital staff to develop an approach that would allow them to distribute the survey after the mother had received the results of the infant’s hearing screening but before she was discharged. This was critical to ensuring that the mothers were able to answer as many of the questions as possible.

Data collection was extended an additional 2 weeks in an attempt to get additional information from mothers whose babies had been referred for further screening. After the first 100 patients had been enrolled, the hospitals distributed the surveys only to those mothers whose infants had failed the hearing screening and were being referred for additional screening.

Mothers placed their completed surveys in an envelope and sealed it, allowing a degree of confidentiality when returning forms to hospital staff. Hospital staff maintained a study log where they linked the study identifying number with the mother’s name. The link between identifying number and the mother remained at the hospital; RTI was only provided the identification number. After finishing data collection, hospital staff sent completed forms to RTI’s Data Capture office where forms were edited, keyed, and stored.

As shown in **Table 3-1**, a total of 707 eligible women gave birth during the data collection period and of these 364 completed the survey. A total of 54 women declined the survey, resulting in a total effective response rate of 90%. For various reasons which we could not ascertain completely, not all eligible women were offered the survey at Hospital D as directed by the study protocol. We suspect in some cases the women were discharged before a survey could be administered. A change-over in key nursing staff during the data collection period and a lack of coverage for the survey over the weekend we believe also resulted in some women being missed.

Table 3-1. Total Response Rate

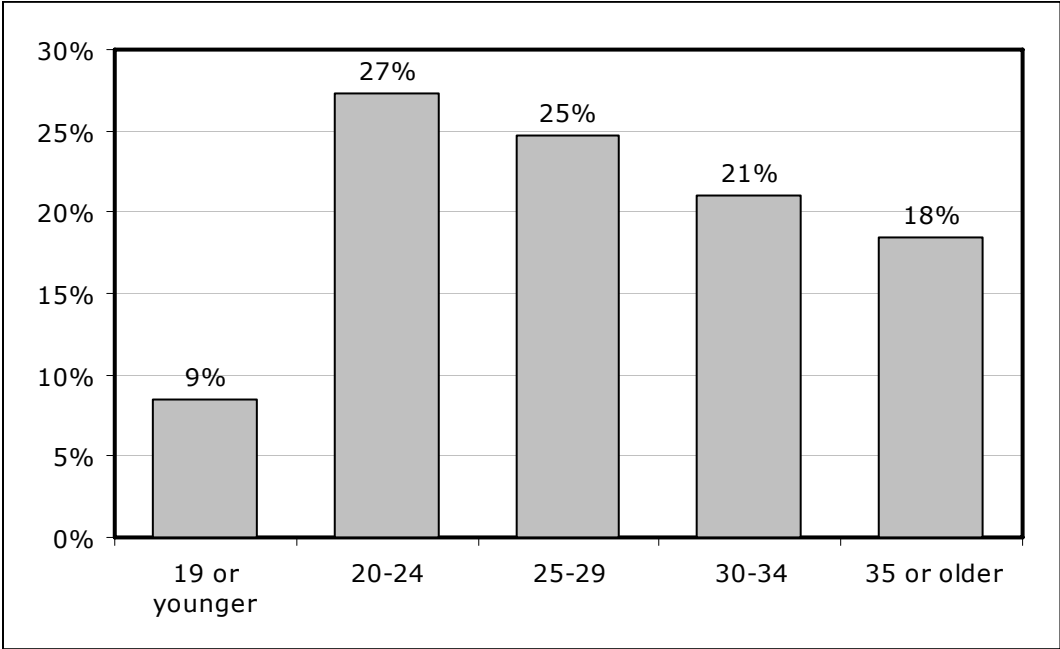
Hospital	Total number of women with a live birth	Total number of Respondents	Total Number Declined/Refused	Total Effective Response Rate ^a
A	127	103	11	90%
B	119	105	4	96%
C	245	103	10	91%
D	216	53	15	78%
Total	707	364	40	90%

^a Total number completed/Total number completed + Total number declined/refused

3.2 Results

3.2.1 Sociodemographics of the Respondents

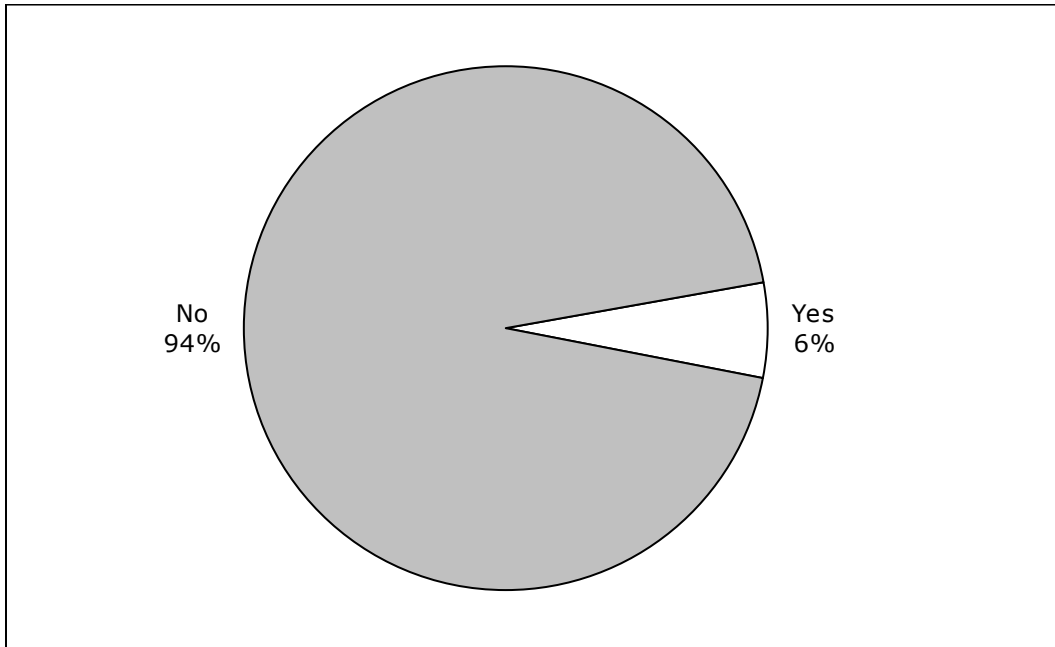
Figure 3-1. Age of Respondent



Respondents indicated their age category.

- One fifth of respondents (21%) identified themselves in their early thirties (30 to 34).
- Just under one fifth of respondents (18%) replied that they fell into the 35 or older age bracket.
- Over half of survey respondents (52%) identified that they were in their twenties (20 to 29).
- Nine percent of respondents identified their age as 19 or younger.

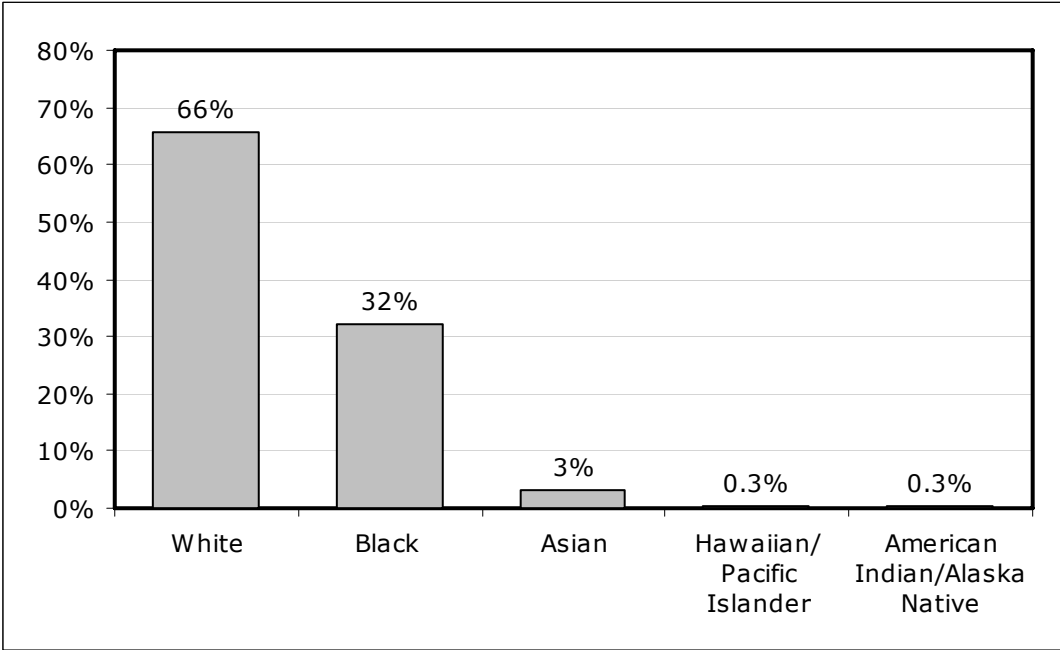
Figure 3-2. Ethnic Self-Identification



Respondents indicated whether they identified themselves as Hispanic or Latino.

- Almost all respondents (94%) identified themselves as not Hispanic or Latino.
- Six percent of respondents identified themselves as Hispanic or Latino.

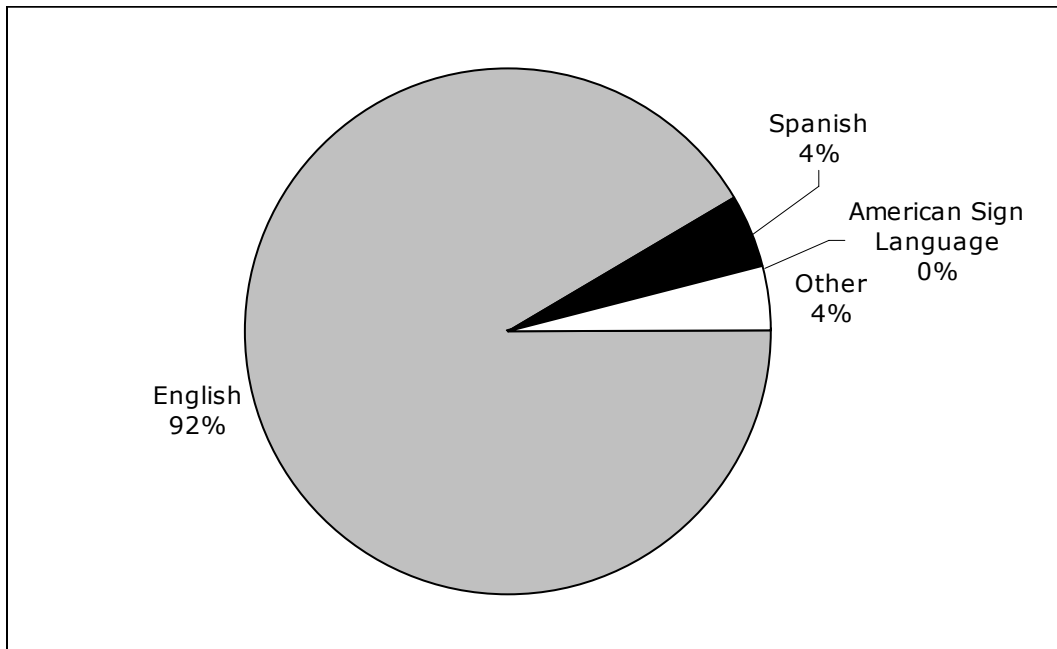
Figure 3-3. Racial Self-Identification



Respondents indicated the race they felt best described them. (Percentages do not necessarily add up to 100 because more than one race could be selected.)

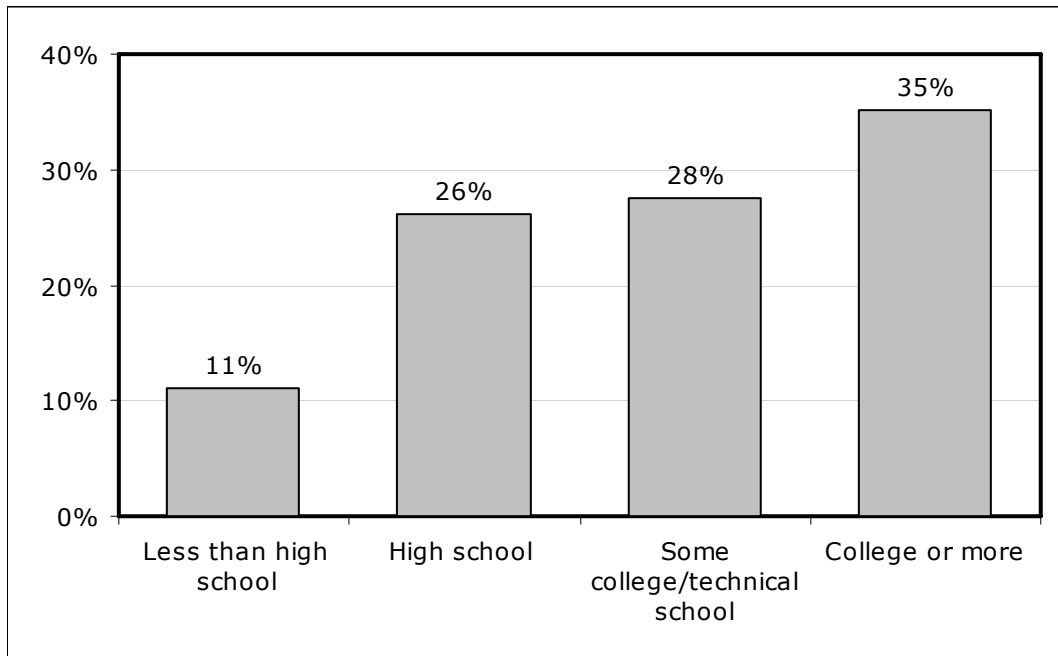
- Two thirds of respondents (66%) identified themselves as White/Caucasian (Hispanic included).
- Almost one third of respondents (32%) identified themselves as African American/Black.
- Combined, just under 4% of survey respondents identified themselves as Asian (3%), Native Hawaiian/Other Pacific Islander (0.3%), and American Indian/Alaska Native (0.3%).

Figure 3-4. Household Language



Respondents indicated what language was most frequently spoken at their residence.

- Almost all respondents (92%) identified English as the primary spoken language in their home.
- Four percent of respondents listed Spanish as the language most frequently used in their household.
- Only 4% of households listed a language other than Spanish or English as the primary language in their residence.

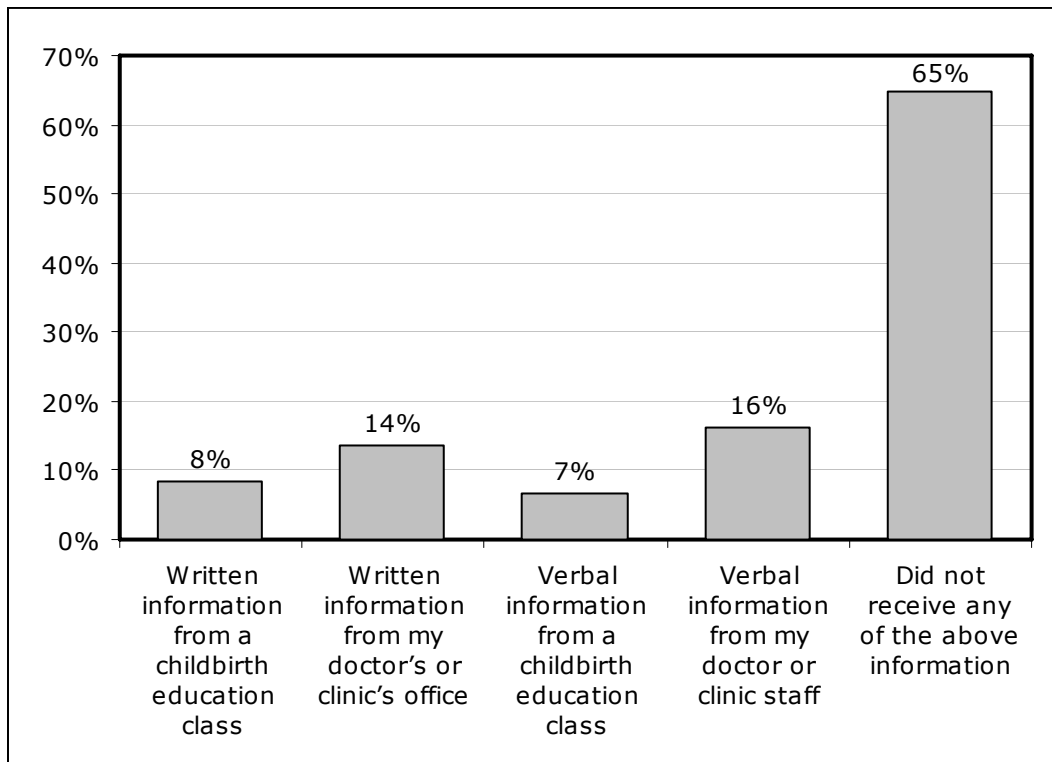
Figure 3-5. Level of Education

Respondents indicated the highest level of education they had achieved.

- Just over one third of respondents (35%) indicated that they had at least graduated from college.
- Twenty-eight percent of respondents had achieved some college or technical school education but had not completed a college degree.
- Just over a quarter of all respondents (26%) indicated they had graduated high school.
- Eleven percent of respondents had achieved less than a high school education, or had not graduated from high school.

3.2.2 Information about Early Hearing Screening

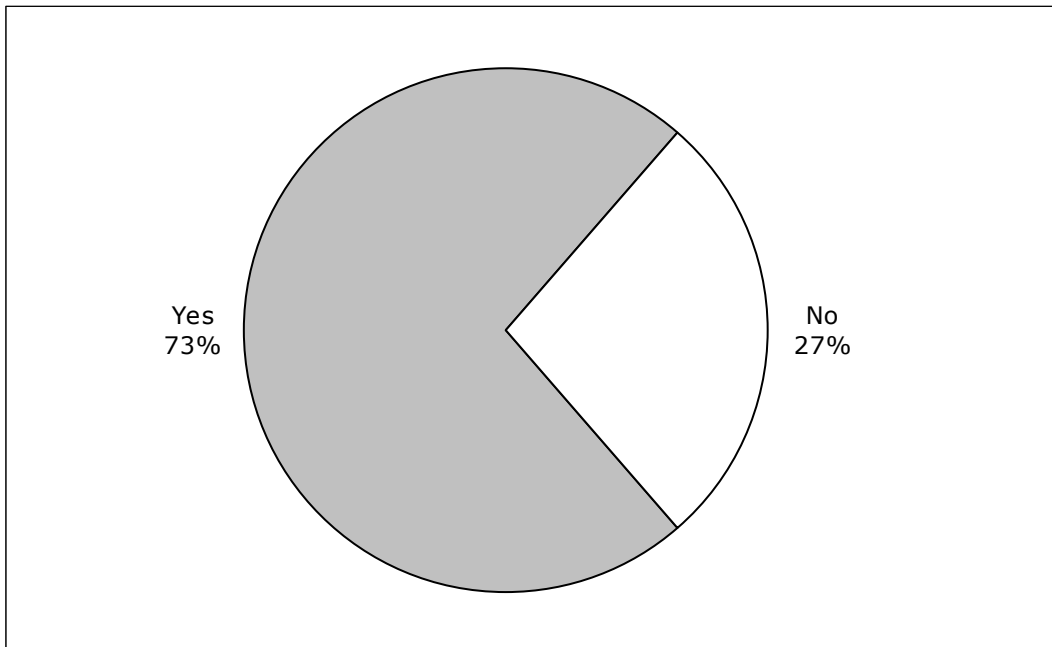
Figure 3-6. Availability of EHDI Information Prior to Hospital Admission



The survey asked respondents whether they had received information about hearing screening prior to admission into the hospital. (Percentages do not necessarily add up to 100 because more than one race could be selected.)

- Just under two thirds of respondents (65%) indicated they had not received any information from the identified sources.
- About a third of those surveyed had received written (14%) and/or verbal (16%) information from their doctor or clinic staff.
- Fifteen percent of those surveyed indicated that they had received verbal information (7%) and/or written information (8%) from a childbirth education class.

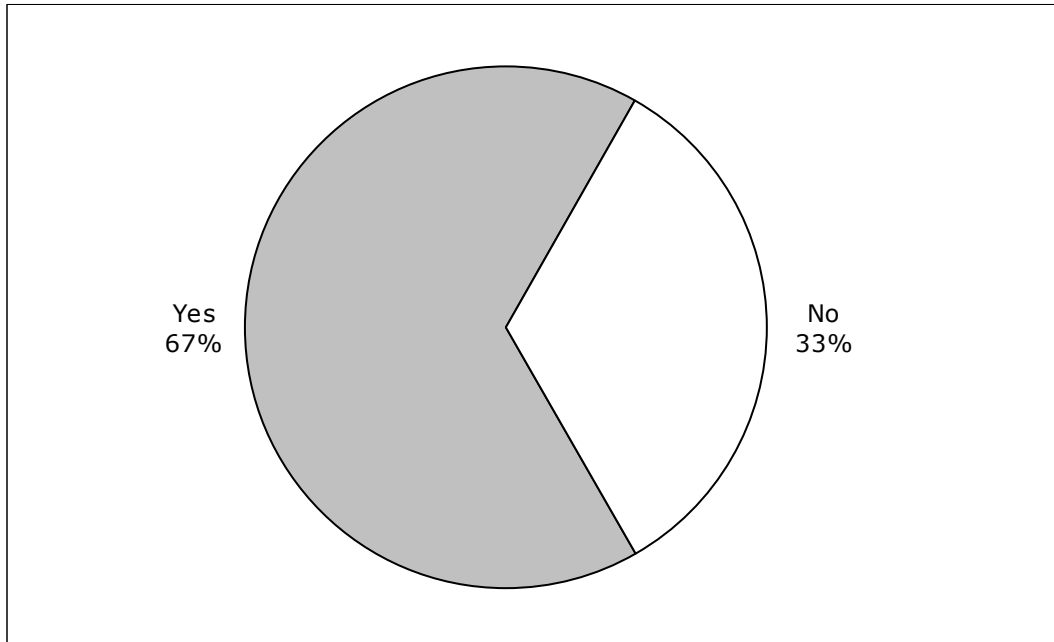
Figure 3-7. Availability of Information at the Hospital



The survey asked respondents whether they had received written information about hearing screening since being admitted into the hospital for delivery.

- Just under three quarters of respondents (73%) received written information about infant testing since being admitted to the hospital.
- Over one quarter of those surveyed (27%) reported not remembering receiving written information about infant hearing testing after admittance into the hospital.

Figure 3-8. (Spanish version only) Provision of Spanish-Language Materials

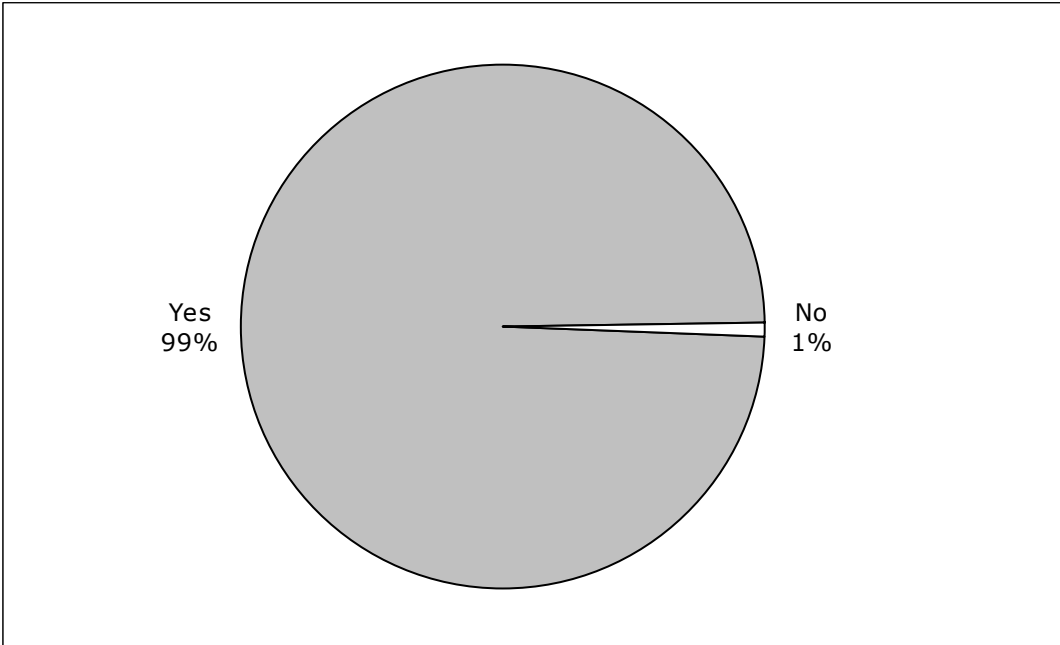


The Spanish version of the survey asked respondents whether they had received written information about hearing screening in Spanish.

- Just over three quarters of respondents (67%) indicated that they had received written information in Spanish.
- A third of those surveyed (33%) reported that they had not received written information in Spanish.

3.2.3 Hearing Screening Experience

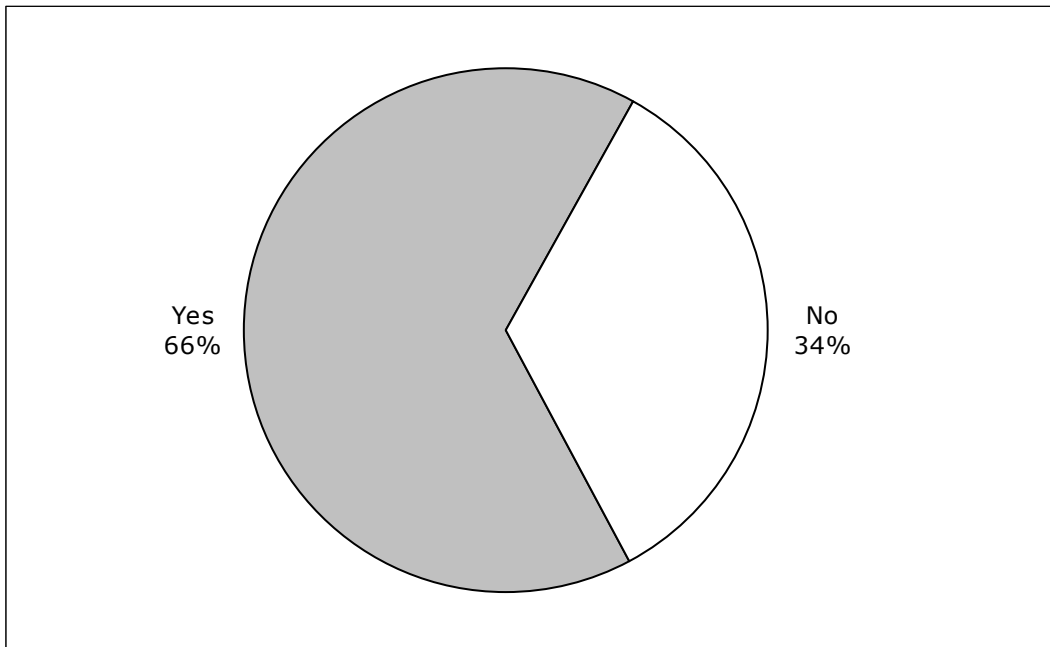
Figure 3-9. Infant Hearing Screening Status



Respondents indicated whether their infant had received a hearing screening.

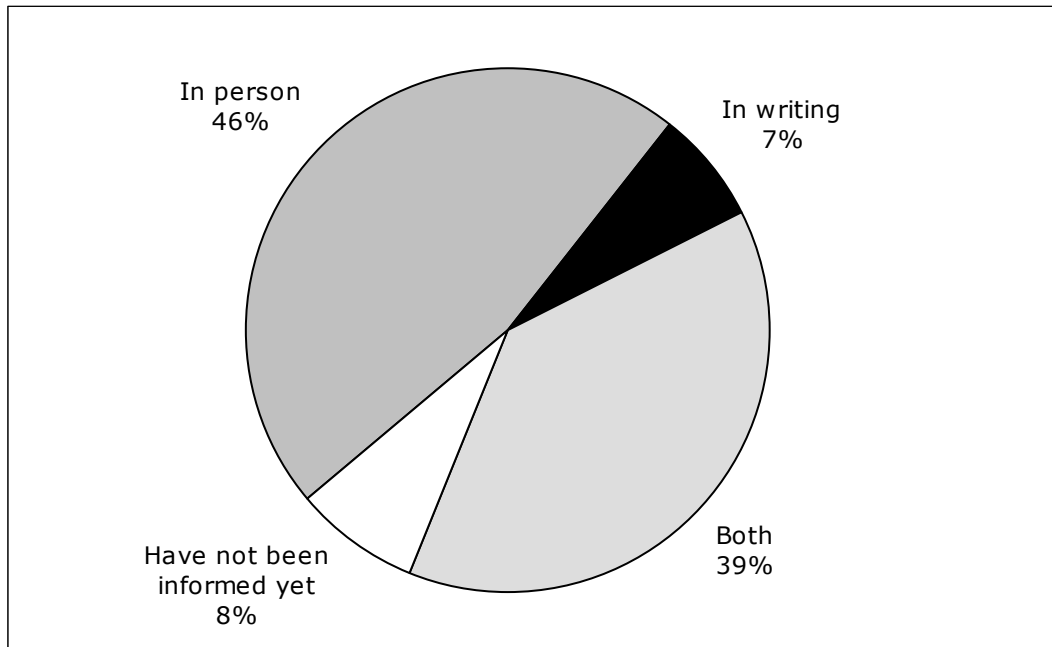
- Almost all respondents (99%) indicated that their infant had received a hearing screening.

Figure 3-10. Counseling Prior to the Hearing Screening



Respondents were asked to indicate whether the hospital staff had talked to them about the hearing screening prior to the procedure.

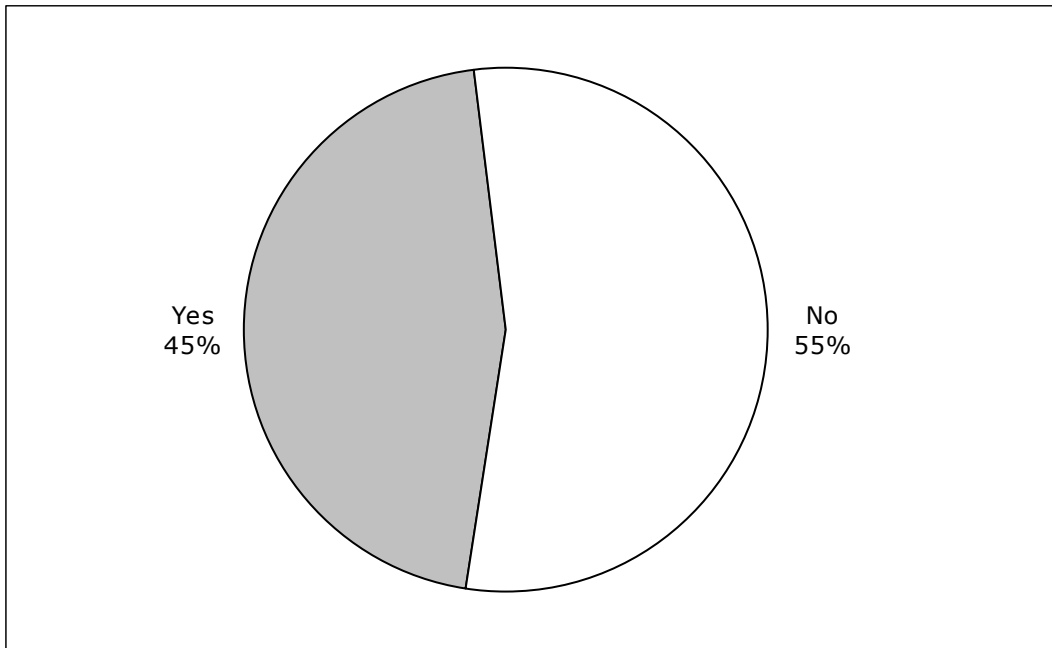
- Two thirds of respondents (66%) indicated that the hospital staff had talked to them prior to their infant’s screening.
- Over one third of those surveyed (34%) said no hospital staff had talked to them prior to their infant’s screening.

Figure 3-11. How the Screening Results were Communicated

The survey asked respondents to indicate how they had received results of the hearing screening test.

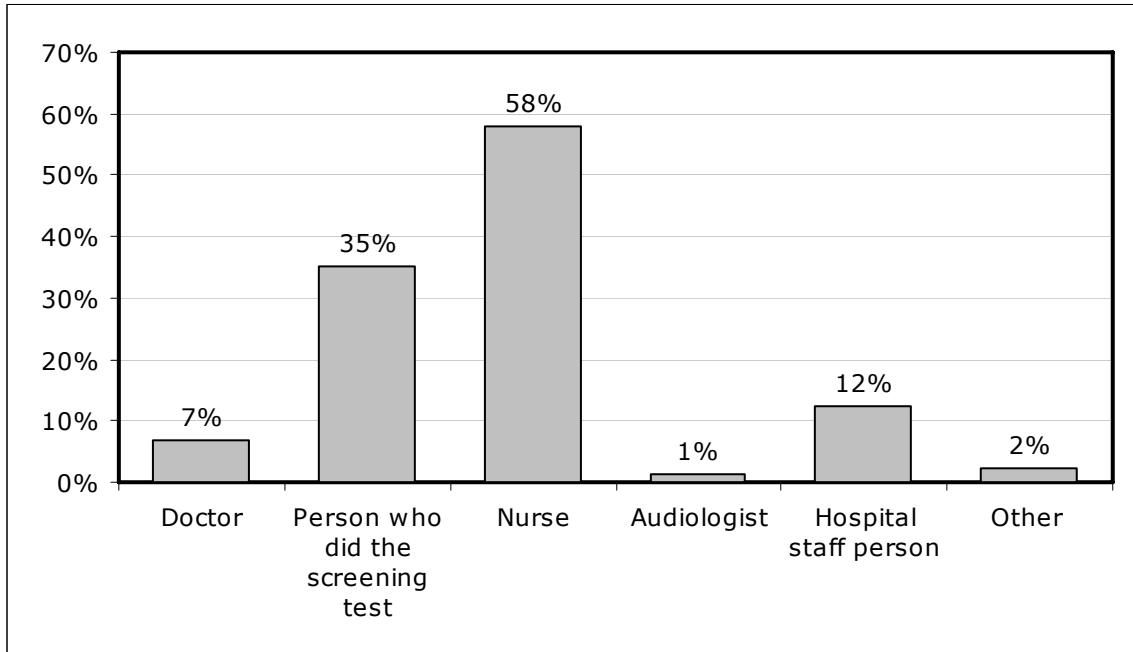
- Almost half of respondents (46%) reported that they had received the results in person.
- Over one third of those surveyed (39%) reported that they had received results of their infant's hearing both in person and in writing.
- Eight percent of respondents indicated that they had not received the results from the test yet.

Figure 3-12. (Spanish version only) Explanation of Hearing Screening Results in Spanish



Respondents who completed the Spanish version of the survey were asked whether someone had explained the results of the hearing screening in Spanish.

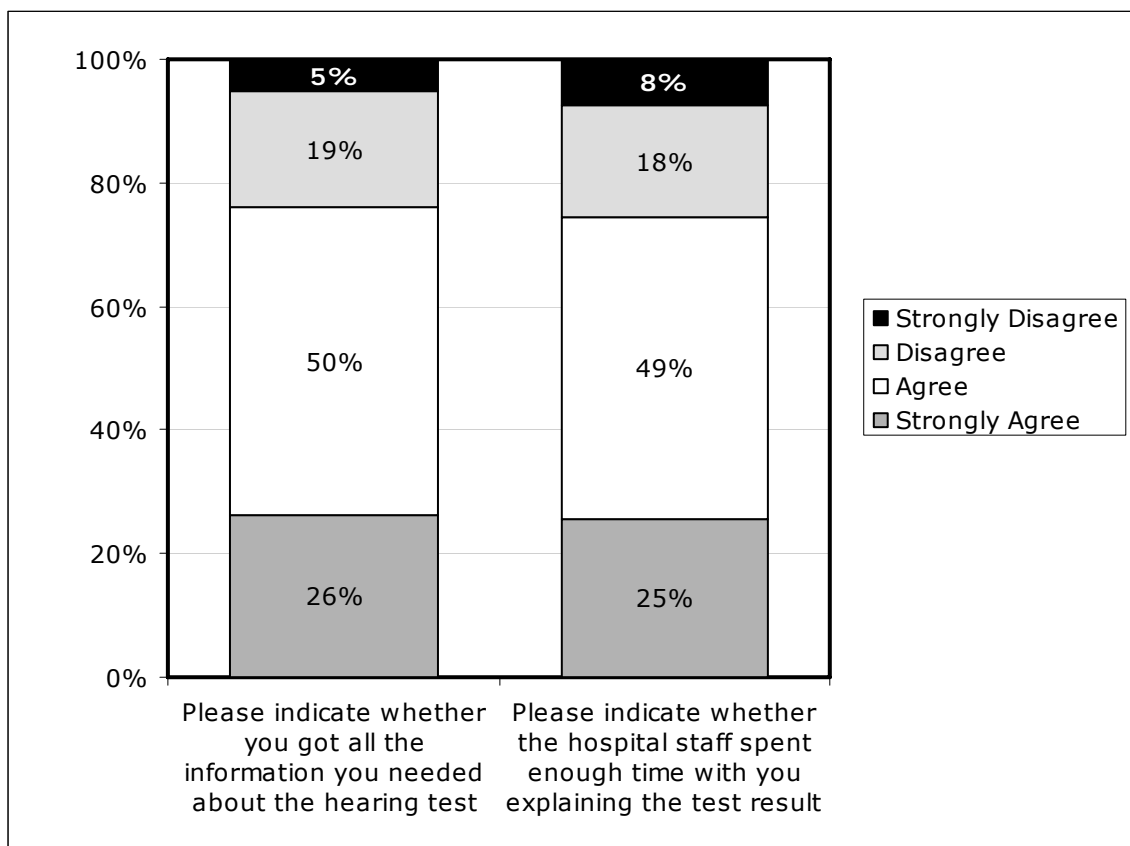
- About half of the respondents (45%) indicated that someone had explained the results in Spanish.
- Over half (55%) indicated no one had explained the results in Spanish.

Figure 3-13. Who Communicated the Screening Results

The survey asked respondents to identify who had informed them of the results for their infant hearing test. (Total may be over 100% because respondents could choose more than one category.)

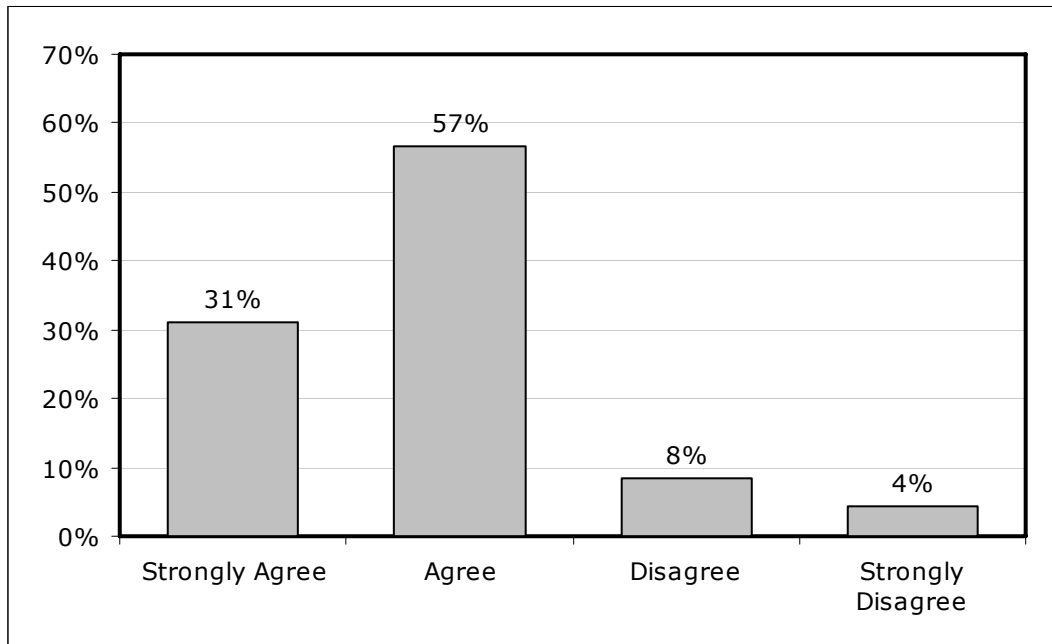
- Over half of respondents (58%) indicated that a nurse had informed them of their infant's results.
- One third of those surveyed (35%) indicated that the test administrator had disclosed the results.
- Twelve percent of respondents indicated that a hospital staff person (title not known) had delivered the results.
- One tenth of the respondents reported that a doctor (7%), audiologist (1%), or other person (2%) had informed them of the results.

Figure 3-14. Assessments of the Overall Hearing Screening Experience



Respondents indicated their agreement with statements concerning the information they received:

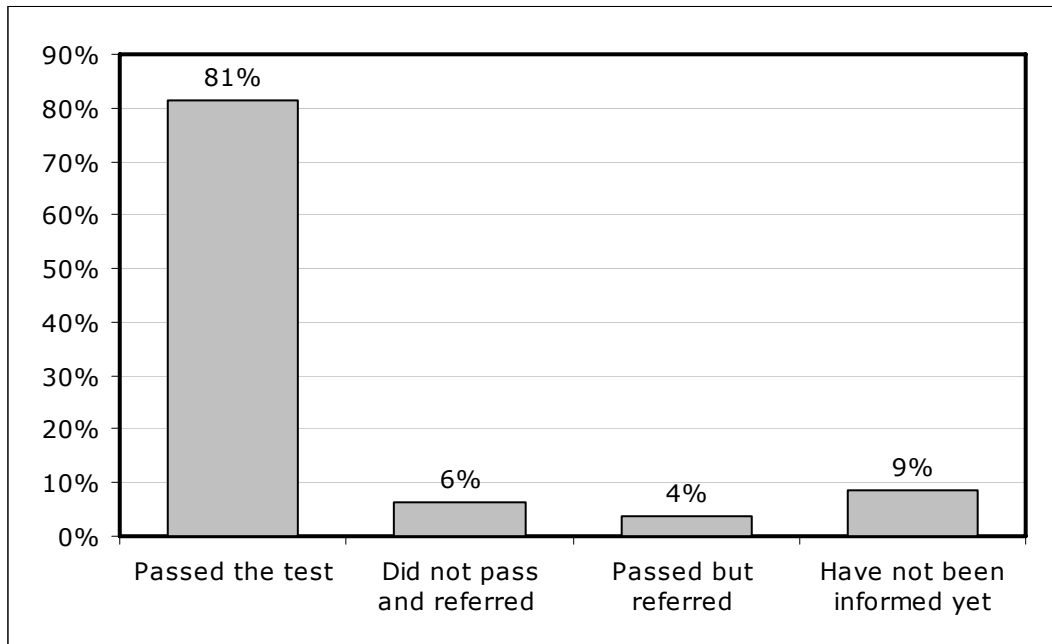
- Three quarters of the respondents strongly agreed (26%) or agreed (50%) with the statement *“You got all the information you needed about the hearing test.”*
- Just under one quarter of respondents strongly disagreed (5%) or disagreed (19%) with the statement *“You got all the information you needed about the hearing test.”*
- Three quarters of the respondents strongly agreed (25%) or agreed (49%) with the statement *“Hospital staff spend enough time with you explaining the test result.”*
- Just over one quarter of respondents strongly disagreed (8%) or disagreed (18%) with the statement *“Hospital staff spend enough time with you explaining the test result.”*

Figure 3-15. Comprehension of the Hearing Screening Result

Respondents indicated their agreement with statements concerning their comprehension of the screening results.

- The majority of the respondents indicated that they strongly agreed (31%) or agreed (57%) with the statement "You understand the meaning of the test result."
- Thirteen percent of respondents disagreed (8%) or strongly disagreed (4%) with this statement.

Figure 3-16. Infant Hearing Screening Results

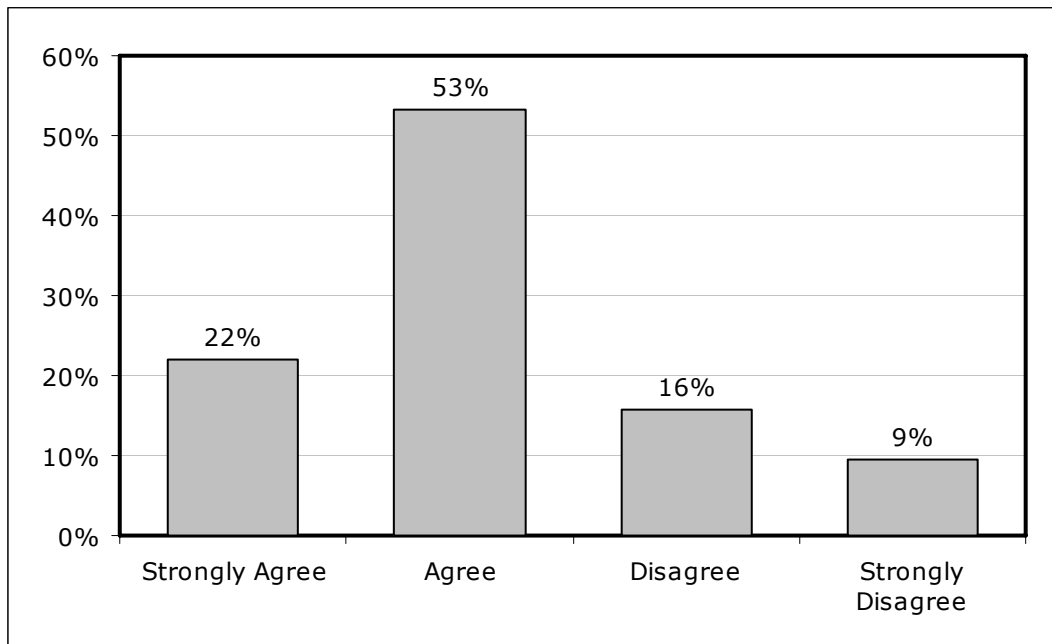


Respondents were asked to disclose the results of their infant’s hearing screening.

- Most of the respondents (81%) indicated that their infant had passed their hearing screening.
- Four percent of survey respondents indicated that their infant had passed the hearing screening test but had been referred for additional testing.
- Six percent of respondents indicated that their infant had not passed and had been referred for additional testing.
- Under one tenth of those surveyed (9%) had not been informed of their infant’s test results.

3.2.4 Beliefs and Attitudes about the Hearing Screening Test Result

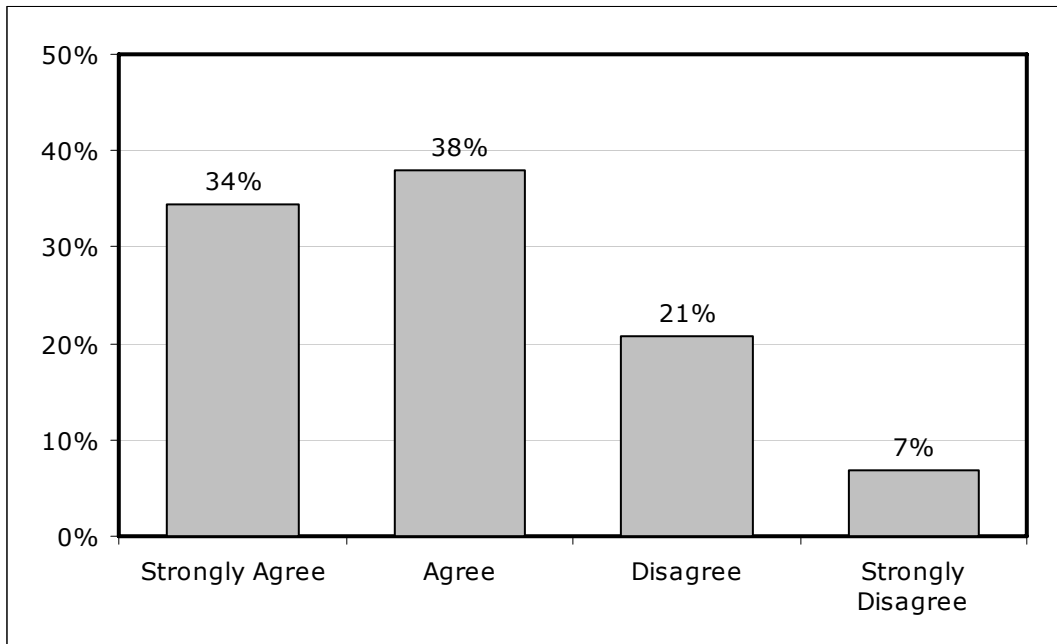
Figure 3-17. Belief in the Hearing Screening Test



The survey asked respondents whose infant had been referred for further testing (n=32) to indicate their agreement with statements related to the hearing screening test.

- Three quarters of respondents strongly agreed (22%) or agreed (53%) with the statement “*You believe the test result.*”
- One quarter strongly disagreed (9%) or disagreed (16%) with this statement.

Figure 3-18. Anxiety about the Hearing Screening Result

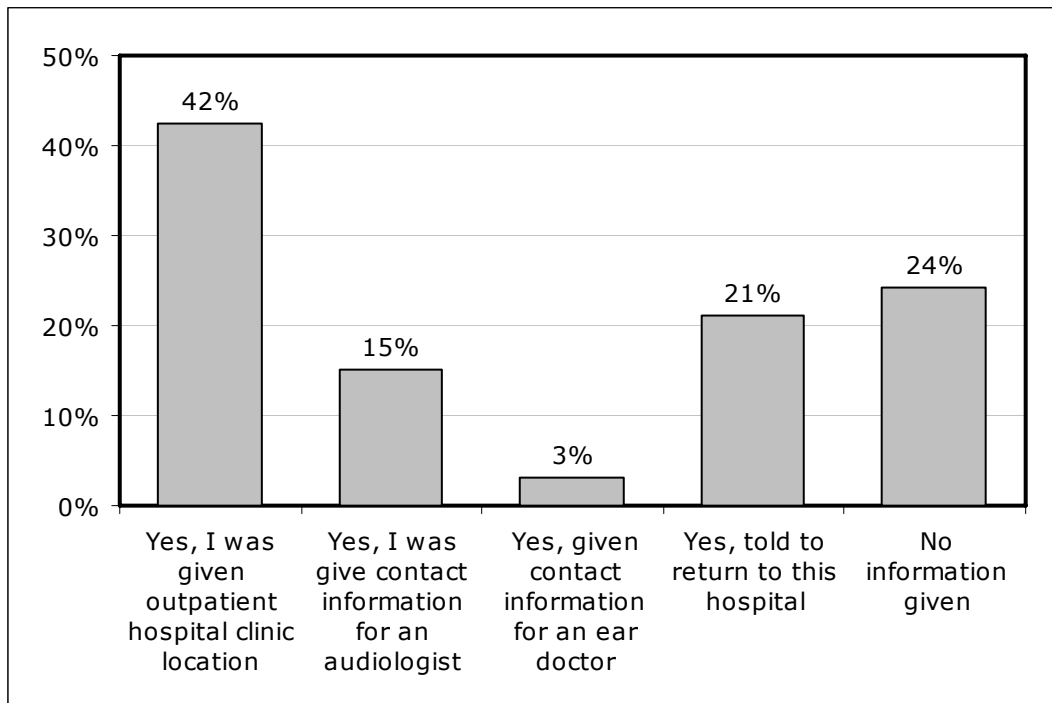


The survey asked respondents whose infant had been referred for additional evaluation to indicate their agreement with statements concerning their anxiety about the hearing screening results.

- Almost three quarters of respondents indicated that they strongly agreed (34%) or agreed (38%) with the statement “*You are feeling anxious about the hearing test result.*”
- Nearly a quarter of the respondents strongly disagreed (7%) or disagreed (21%) with this statement.

3.2.5 Follow-Up Procedures

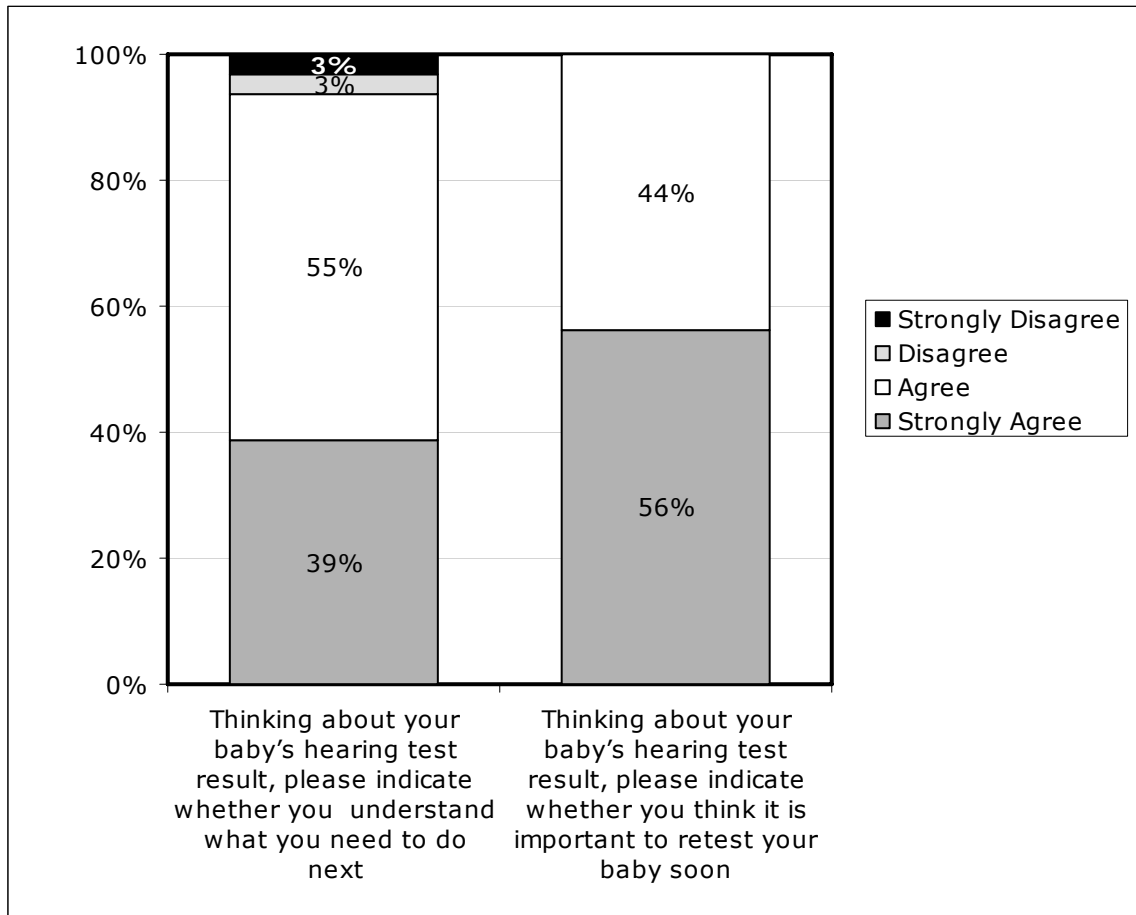
Figure 3-19. Information about Follow-Up Procedures



The survey asked respondents whose infant had been referred for additional evaluation to indicate whether they received information about where to go to receive follow-up evaluation.

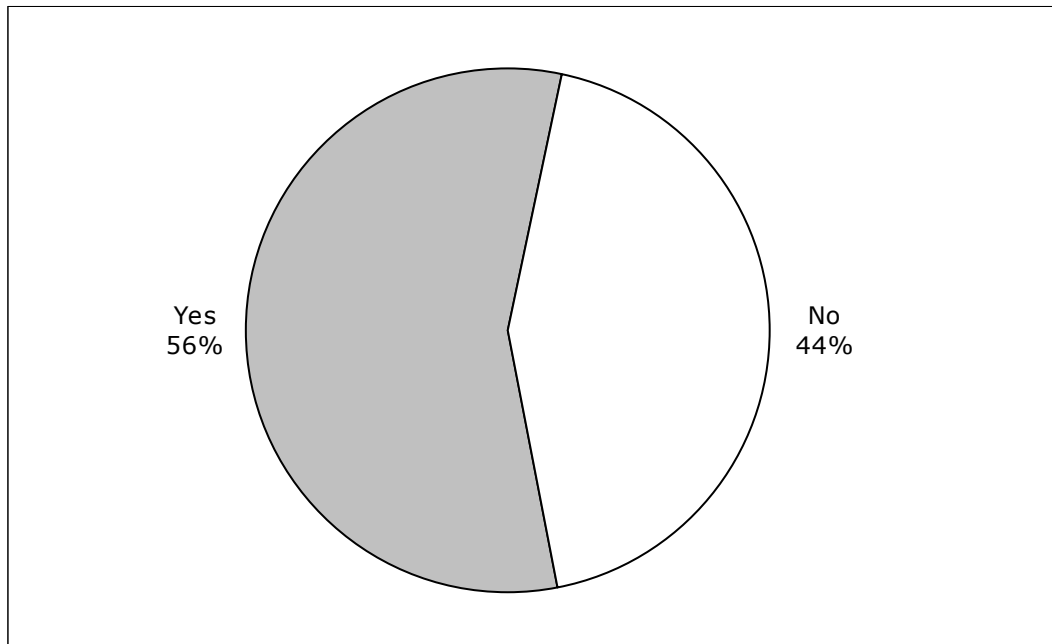
- Almost half of respondents (42%) indicated that they were given information and the location of an outpatient hospital clinic to contact for follow-up testing.
- Just under one quarter of respondents (21%) indicated that they had been told to return to the hospital for follow-up testing.
- Twenty-four percent of those surveyed indicated that they had not received any information about where to go for follow-up infant hearing tests.
- Just under a fifth of those surveyed reported that they were given information about an audiologist (15%) or an ear doctor (3%).

Figure 3-20. Comprehension of Follow-Up Procedures



The survey asked respondents whose infant been referred for additional evaluation to indicate their agreement with statements concerning their understanding of what follow-up procedures they needed to do next.

- Almost all of those surveyed strongly agreed (39%) or agreed (55%) with the statement "You understand what to do next."
- All of those surveyed strongly agreed (56%) or agreed (44%) with the statement "It is important to retest your infant soon."

Figure 3-21. Hospital Scheduling an Appointment for Follow-Up Evaluation

Respondents indicated whether the hospital had scheduled the follow-up hearing evaluation.

- Fifty-six percent of those surveyed indicated that the hospital had made the follow-up appointment.
- Less than half of respondents (44%) indicated that the hospital had not made a follow-up appointment.

3.3 Discussion

Findings from the Maternal Exit Survey of four hospitals in Virginia have implications for the enhancement of the VDH EHDI Program. We highlight the most important ones here.

First, the dissemination of information about infant hearing screening, detection, and intervention *before* birth could be enhanced. Two thirds of the respondents had not received any information from a birth education class or doctor's office during their pregnancy.

After admission to the hospital, the majority of the respondents (73%) received written information about hearing screening but more than one third (34%) had not received any information from hospital staff *prior* to their infant's testing. While ideally women should receive the information prior to testing, it may not be practical to do so given the short duration of hospital stays.

Efforts to provide information and test results in Spanish could be improved. One third of Spanish-speaking respondents (33%) had not received any information or materials

regarding the hearing screening in Spanish and over half (55%) reported that no one had explained the results in Spanish.

The degree of understanding and acceptance of the screening results appears to be uniformly high. The majority of the respondents indicated that they understood the meaning of their infant's hearing screening results (88%). Three quarters of the respondents reported that they had received all the information they needed (76%) and that the hospital staff had spent enough time explaining the results (74%).

Among the respondents whose infant had *not* passed the hearing screening, one quarter (25%) indicated that they disagreed to some extent with the result. However, all of them indicated it was important to have their infant retested soon. This indicates that while there may be some doubt as to the validity of the initial screening result, respondents understood the importance of confirming the result with additional follow-up.

Interestingly, while an overwhelming majority of these same respondents reported that they understood what to do next (94%), tangible links to follow-up appear to be somewhat lacking and could potentially be improved. Nearly a quarter of the respondents (24%) had not received any information about where to go for follow-up evaluation and 44% indicated that the hospital had *not* made a follow-up appointment for them. Depending on the types of audiological services available at the hospital, it may not be standard protocol to make follow-up appointments, but clearly this is a juncture at which parents could be lost to follow-up.

Finally, most of the respondents whose infants had not passed the hearing screening (72%) were understandably anxious. This suggests that perhaps more could be done as part of the post-test counseling to address parental concerns and worries, but in a manner that does not mitigate the importance of follow-up or give the impression that the initial screening is prone to error and should be disregarded.

Study Limitations. A limitation of this study is that the convenience sampling of the hospitals does not allow the findings to be generalized to the larger population of women in Virginia giving birth in hospitals or other certified birthing facilities. At the facility level these data can be generalized to the hospital's patient population because the sample was essentially a census, although a few eligible women refused or were not offered the opportunity to complete the survey prior to discharge.

Another point to keep in mind when interpreting the items related to follow-up is that the responses would vary depending on when the survey was administered. A respondent may have indicated that she had not received any information about what to do next or not had an appointment made. However, this does not mean this information was not given to the respondent at some point after the survey was administered and before she was discharged.

4. CATI SURVEY FINDINGS

The CATI survey captured information regarding the hearing screening at the hospital, the follow-up experience; knowledge, attitudes, and beliefs about infant screening and early hearing loss; and the basic demographics of a sample of women whose infants had not passed the hospital screening test. It was our aim with this component of the study to gain an in-depth understanding of the factors and barriers that impact a parent's capacity to carry out follow-up activities and to do so in a timely fashion.

4.1 Methods

Sample Selection. The RTI study design considered all women delivering a live infant in 2005 whose infant *did not pass* the hearing screening test at the hospital to be eligible for the CATI survey. Excluded from the CATI survey were women who met one or more of the following criteria:

- The infant had never received an initial hearing screening (e.g., missed infants).
- The infant passed the initial hearing screening at the hospital.
- The mother refused the initial hearing screening.
- The infant had died.

The VDH EHDI Program randomly selected a sample of 414 women from a total of 2,953 eligible women in its database using a protocol devised by RTI. RTI computed this sample size based on the expected response rates in Virginia and the other four states, taking into account factors that would depress response rates such as outdated or incorrect contact information and lack of land-line phones.

Recruitment of Participants. VDH EHDI sent each eligible woman selected for the sample a recruitment letter to inform them of the study and solicit their participation. Potential respondents were allowed 2 weeks to call the state contact if they did not want to be in the study. All potential respondents were informed in the letter that they would receive a \$10 gift card if they participated in the interview.

The VDH EHDI Program sent to RTI under strict security protections for electronic data an Excel spreadsheet of the eligible women minus any of those who had declined to participate (n= 2). On receipt of the contact information from the state, RTI sent the name and address information to batch tracing vendors and conducted a National Change of Address search to update and verify its accuracy.

Data Collection. Prior to starting data collection, six telephone interviewers participated in an 8-hour training session during which they learned about the study and procedures for

administering the CATI instrument. These included Spanish-speaking interviewers who could conduct interviews in Spanish if needed.

The telephone interviewers began contacting potential respondents in May 2005 and made up to 20 attempts until contact was made by phone. All data collection was completed by July 2006.

Once contact with potential respondents was made, the interviewer proceeded to explain the study, solicit their participation, and explain their rights as a study subject via an informed verbal consent. If the potential respondent agreed to participate and gave verbal consent, the interviewer then conducted a short eligibility screening to ensure that the respondent was indeed eligible. In rare cases, the information in the state database was not current or accurate so the screening status needed to be verified. Those who were deemed ineligible were only asked a series of demographic questions. Those deemed eligible proceeded with the interview in whole or in part depending on their infant’s screening and follow-up status. A copy of the interview survey instrument is included in Appendix B. It includes the verbal informed consent script.

Of the initial 414 women sampled for the CATI survey, a total of 190 completed the interview. The total response rate was 46%, due in large part to incorrect or outdated contact information. Over half of the potential respondents in the initial sample (56%) were not traceable at the time of the survey. When an interviewer was able to make contact with a respondent, however, the majority (86%) completed the survey.

Table 4-1. CATI Survey Response Rates

Total Sample	Total Located	% Located	Total Completed	Total Refusals	% Refusals	Total Ineligibles	Total Response Rate ^a	Effective Response Rate ^b
414	233	56%	190	26	11%	8	46%	82%

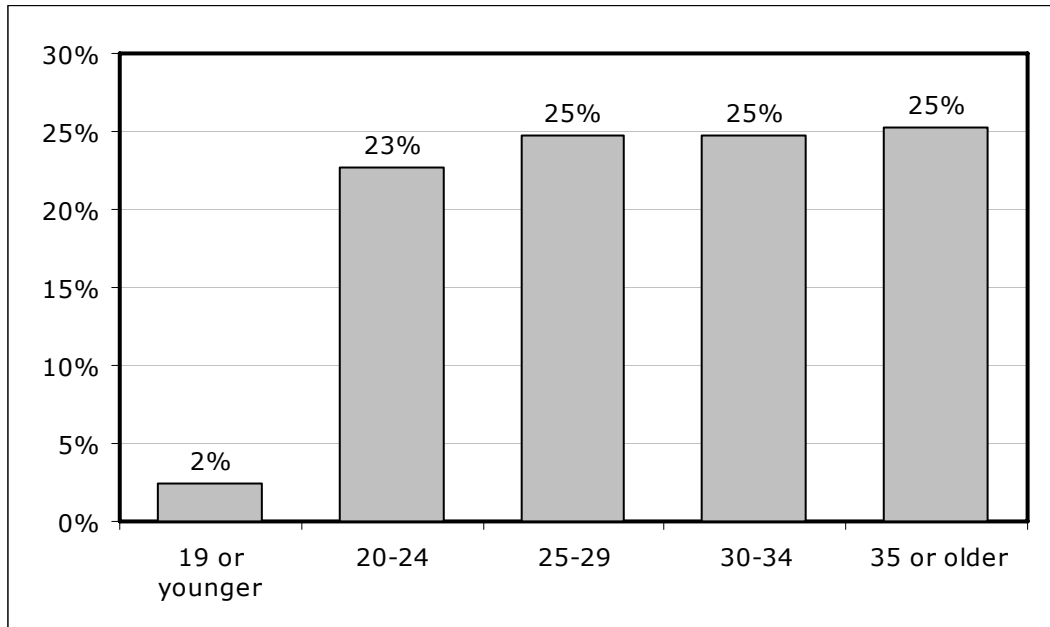
^a Total Completed/Total Sample

^b Total Completed/Total Located

4.2 Results

4.2.1 Sociodemographics of the Respondents

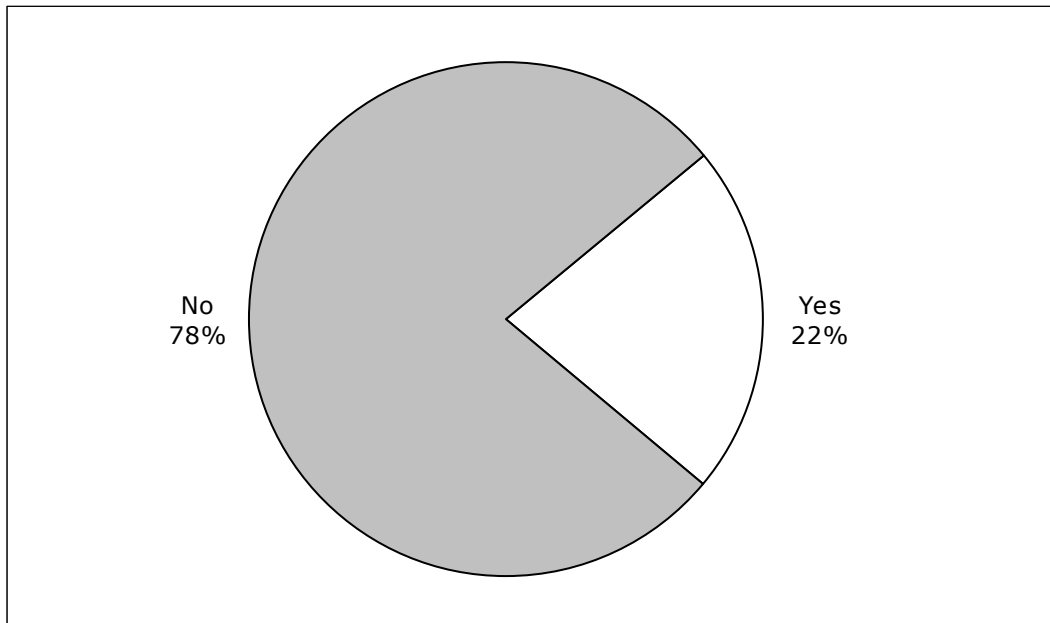
Figure 4-1. Age of the Respondents



The survey asked respondents to indicate their age category.

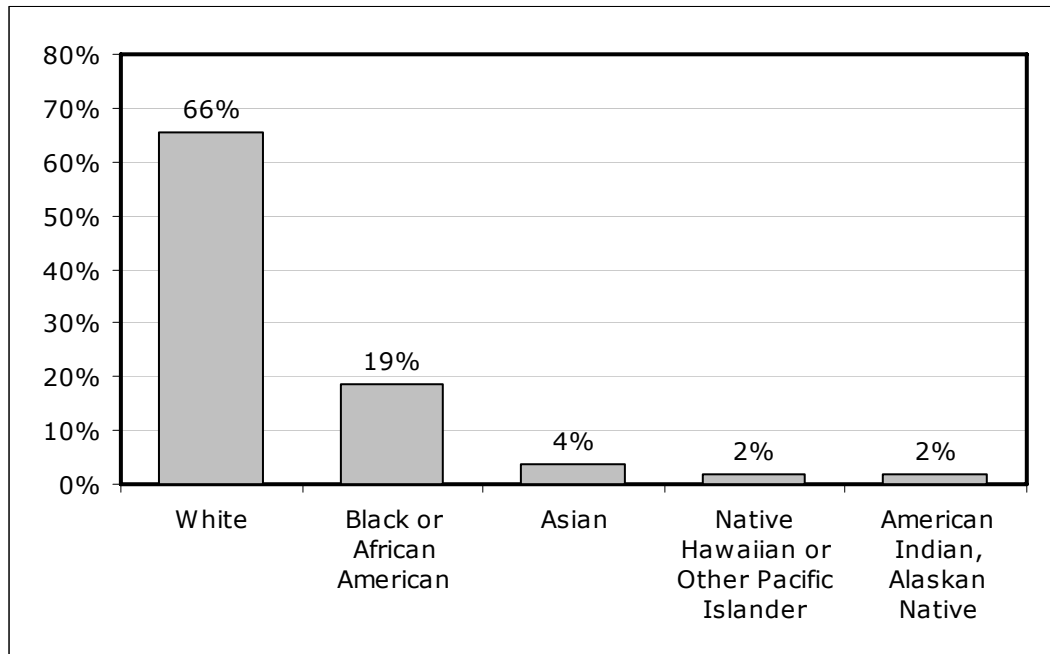
- Half of survey respondents (50%) identified that they were 30 years old or older.
- One quarter of all respondents (25%) identified themselves in their mid- to late twenties (25 to 29).
- Just over one fifth of respondents (23%) replied that they fell into the 20 to 24 age bracket.
- Only 2% of respondents identified their age as 19 or younger.

Figure 4-2. Ethnic Self-Identification



Respondents were asked if they identified themselves as Hispanic or Latino.

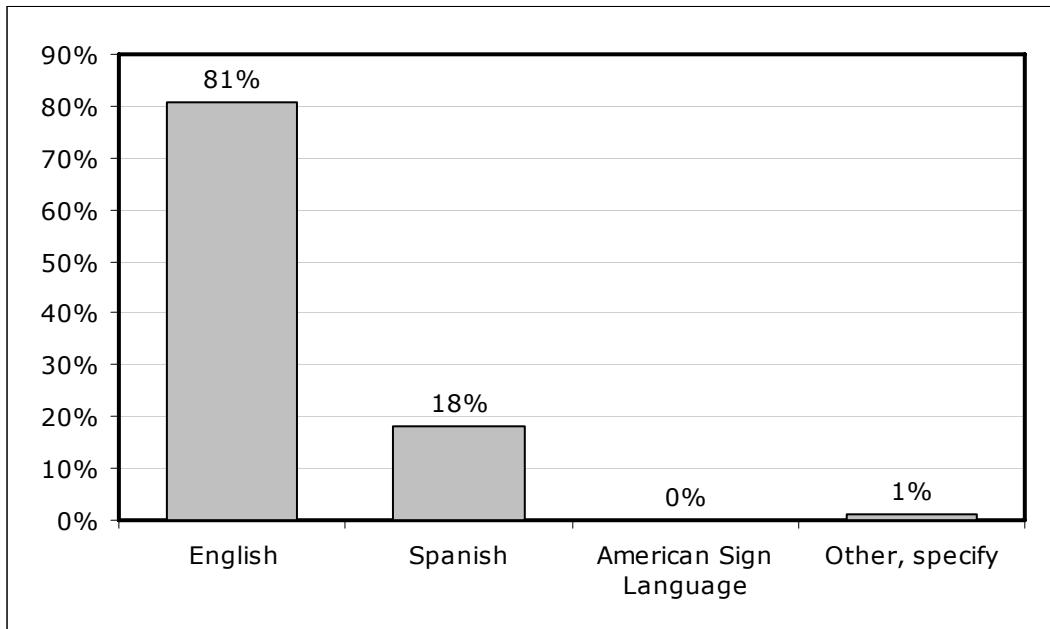
- Over three quarters of all respondents (78%) identified themselves as not Hispanic or Latino.
- Twenty-two percent of respondents identified themselves as Hispanic or Latino.

Figure 4-3. Racial Self Identification

Respondents identified the race they felt best described them. (Percentages do not necessarily add up to 100 because more than one category could be selected.)

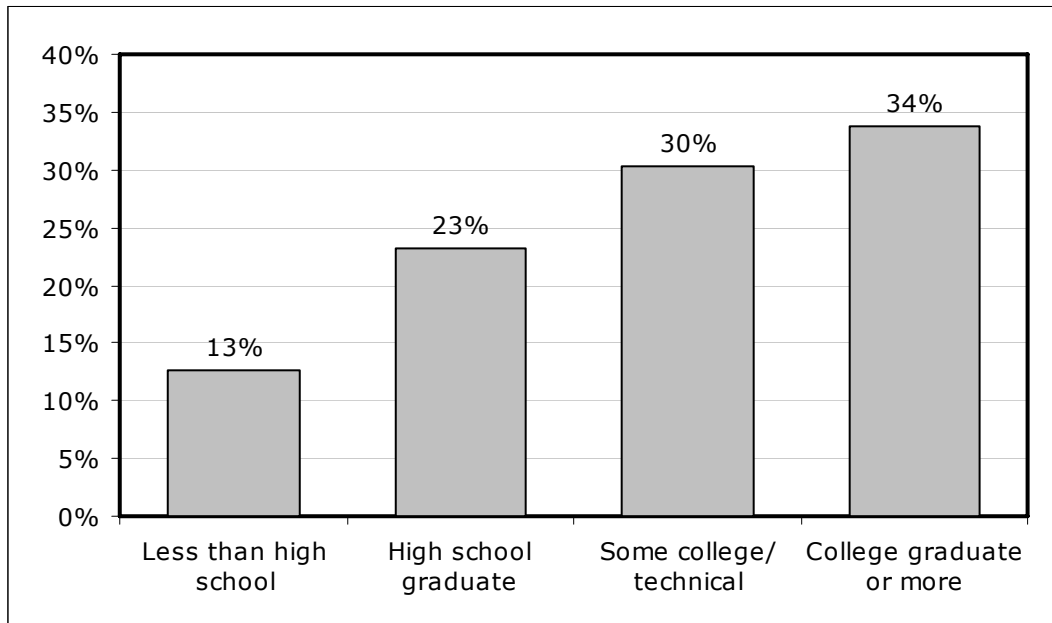
- Two thirds of respondents (66%) identified themselves as White/Caucasian (Hispanic included).
- Just under one fifth of respondents (19%) identified themselves as African American/Black.
- Combined, just under one tenth of survey respondents identified themselves as Asian (4%), Native Hawaiian/Other Pacific Islander (2%), and American Indian/Alaska Native (2%).

Figure 4-4. Household Language



Respondents indicated what language was most frequently spoken at their residence.

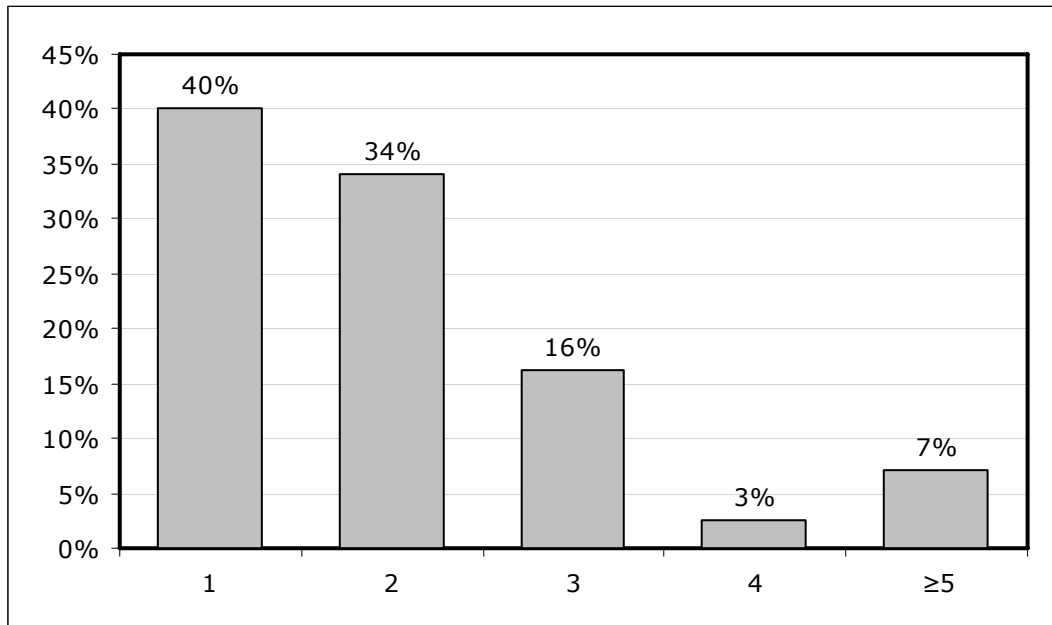
- The majority of the respondents (81%) identified English as the primary spoken language in their home.
- Eighteen percent of respondents listed Spanish as the language most frequently used in their household.
- Only 1% of households listed a language other than Spanish or English as the primary language in their residence.

Figure 4-5. Level of Education

Respondents indicated the highest level of education they had achieved.

- Just over one third of respondents (34%) indicated that they had graduated from college or received some level of post-graduate training or degree.
- Thirty percent of respondents had achieved some college or technical school education but had not completed a college degree.
- Almost a quarter of all respondents (23%) indicated they had graduated from high school.
- Thirteen percent of respondents had achieved less than a high school education or had not graduated from high school.

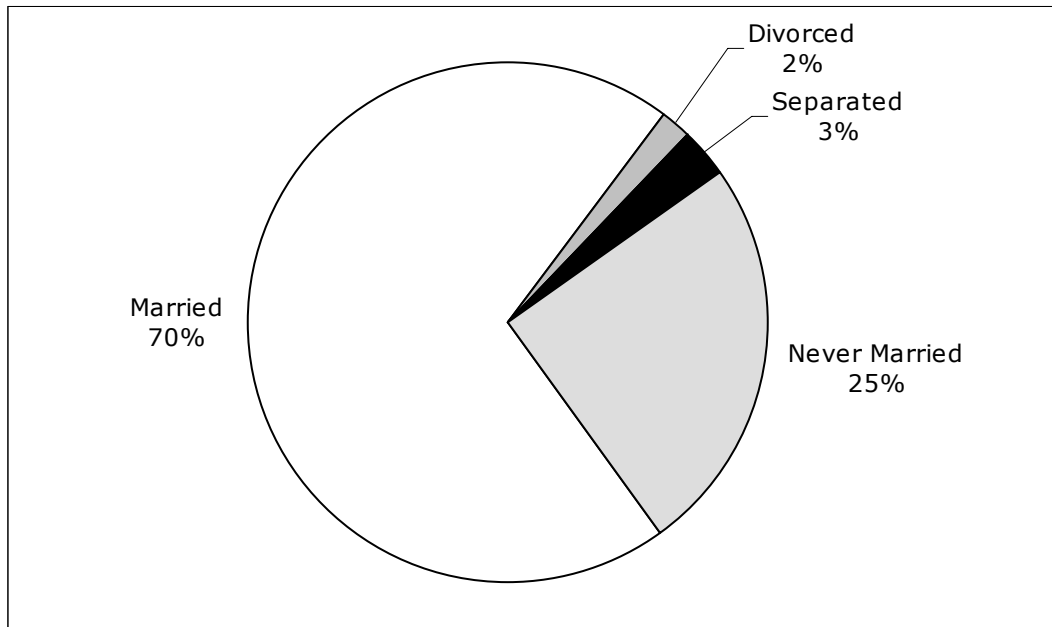
Figure 4-6. Number of Children



Respondents indicated how many children were in their immediate family.

- Forty percent of people surveyed had one infant currently in their family.
- Just over a third of all respondents (34%) had two children in their family.
- Combined, one quarter of all participants surveyed indicated that they had more than two children in their family—three (16%), four (3%), or five or more children (7%).

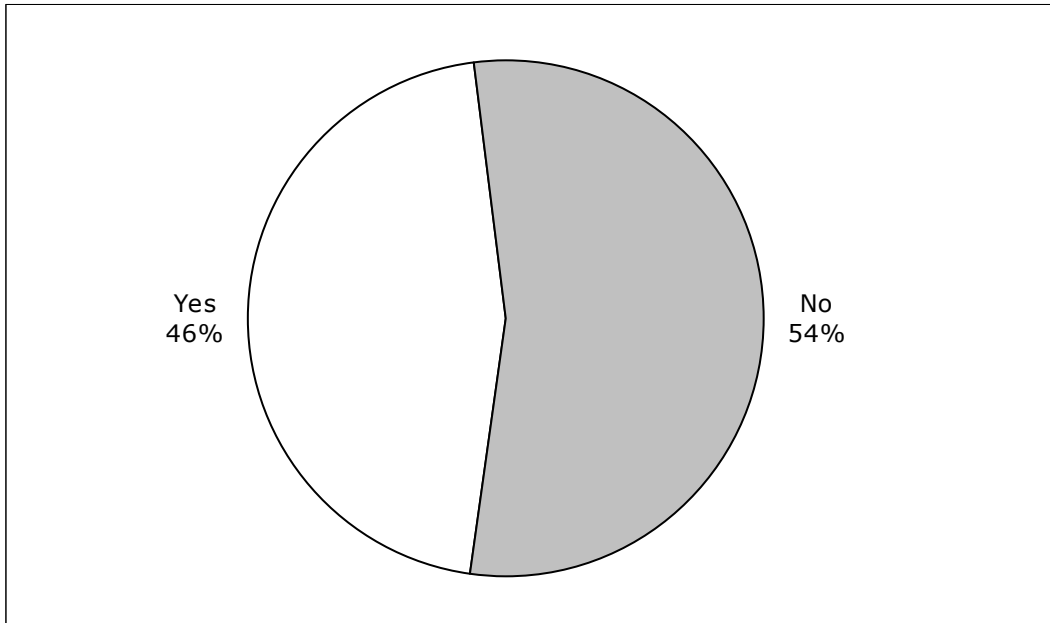
Figure 4-7. Marital Status of Respondents



Respondents indicated their current marital status.

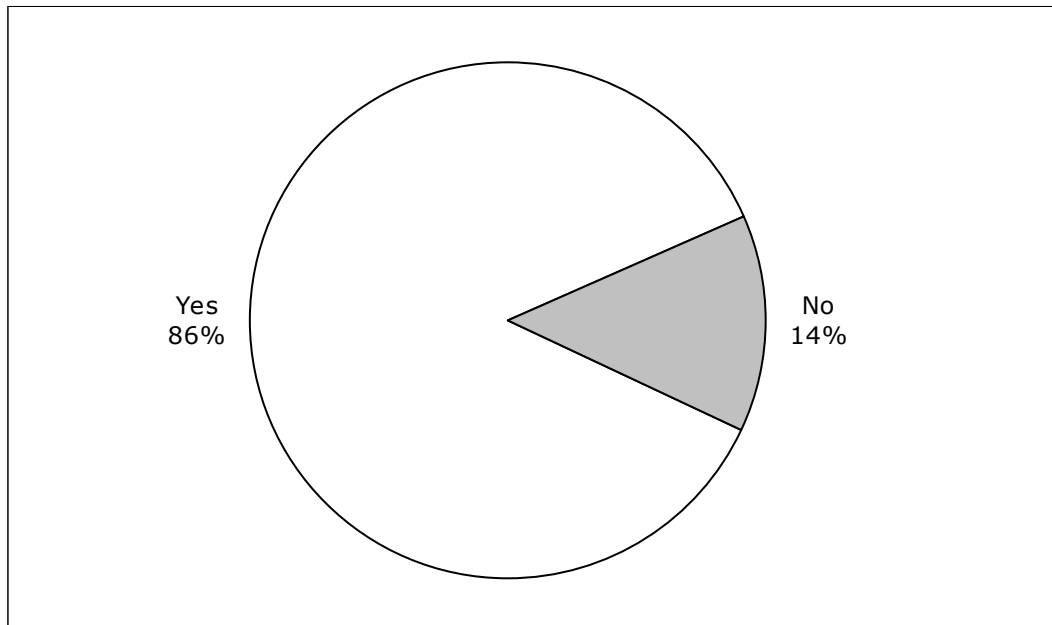
- Over two thirds of all respondents (70%) indicated that they were currently married.
- One quarter of all surveyed (25%) responded that they were single and had never been married.
- Combined, 5% of those surveyed indicated they were separated (3%) or divorced (2%).

Figure 4-8. Living Arrangements



The survey asked respondents who had never been married to indicate whether they lived with a companion or partner.

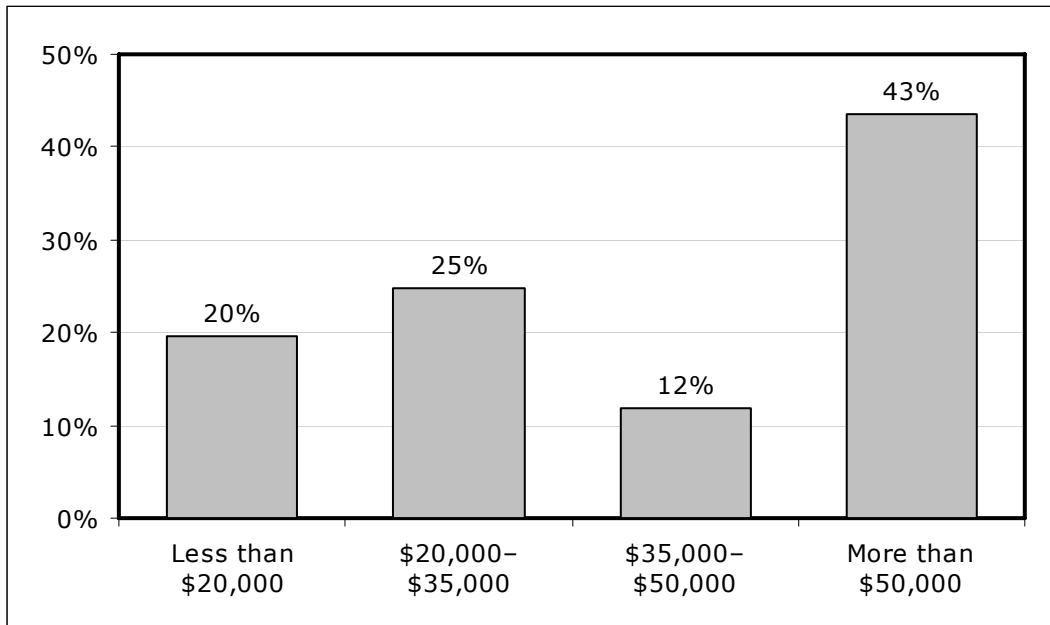
- Over half of respondents (54%) indicated that they lived alone or had no companion or partner in their home.
- Just under half (46%) identified that they currently lived with a companion or partner.

Figure 4-9. Social Support

Respondents indicated whether they had friends and family available to help them take care of their infant.

- The majority of those surveyed (86%) responded that there were family and friends available to help take care of their infant.
- Fourteen percent of respondents indicated that there were no friends or family available to help them take care of their infant.

Figure 4-10. Household Income

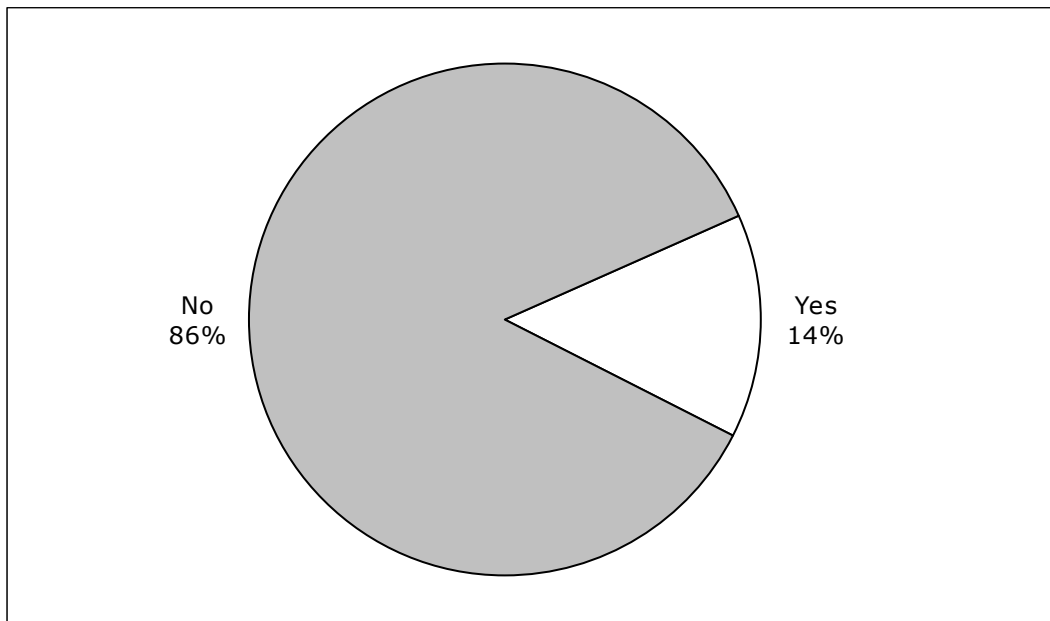


Respondents indicated their total household income (from all sources) for the year 2005.

- Under half (43%) of the respondents indicated that their income was above \$50,000.
- Over half of all respondents (55%) indicated that their income for the year 2005 had been over \$35,000.
- Almost half of all respondents (45%) indicated that their income was below \$35,000.

4.2.2 Health Status and Health Resources

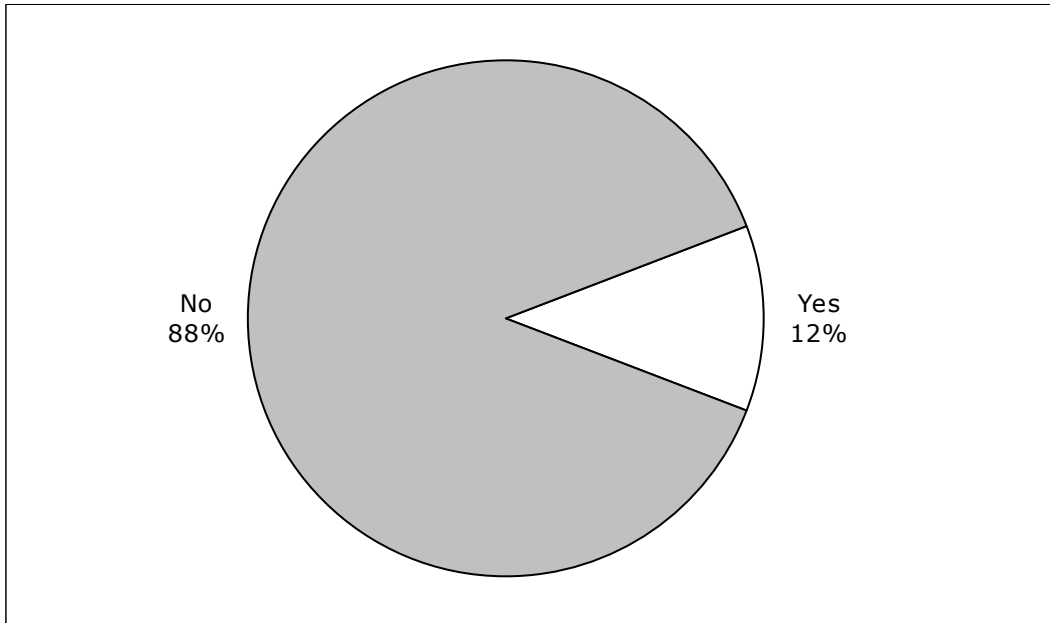
Figure 4-11. Infant's NICU History



Respondents indicated whether their infant had ever been admitted to a NICU or any other special unit in a medical facility.

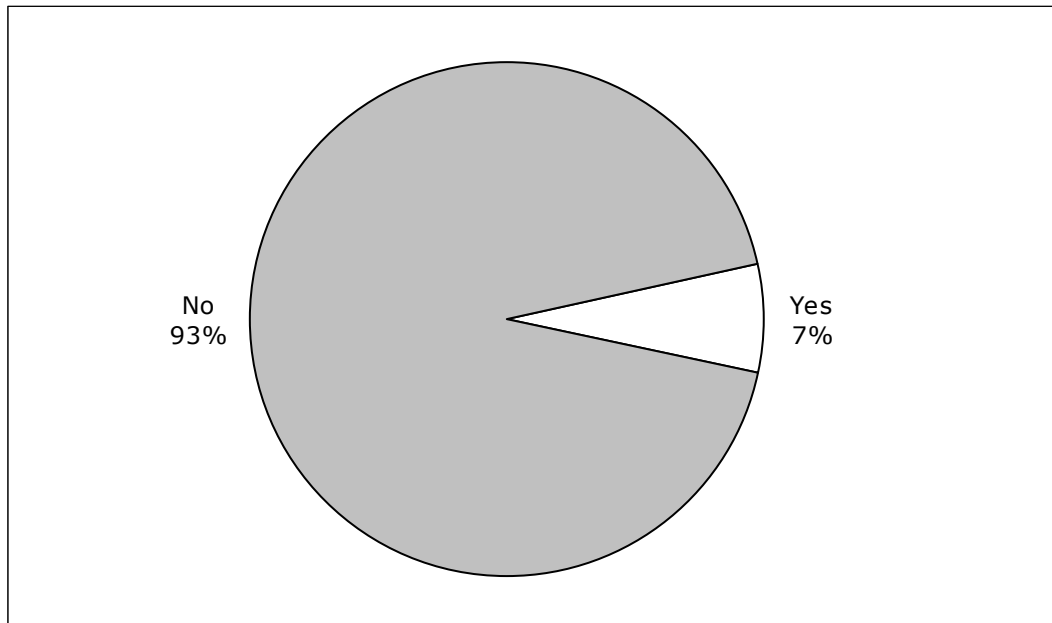
- The majority of respondents (86%) indicated that their infant had not been admitted to the NICU or any other special unit in a medical facility.
- Fourteen percent of respondents indicated that their infant had been admitted into the NICU or a special unit within a medical facility.

Figure 4-12. Infant's Chronic Health History



Respondents indicated whether their infant was currently suffering from a chronic medical condition that required ongoing medical care.

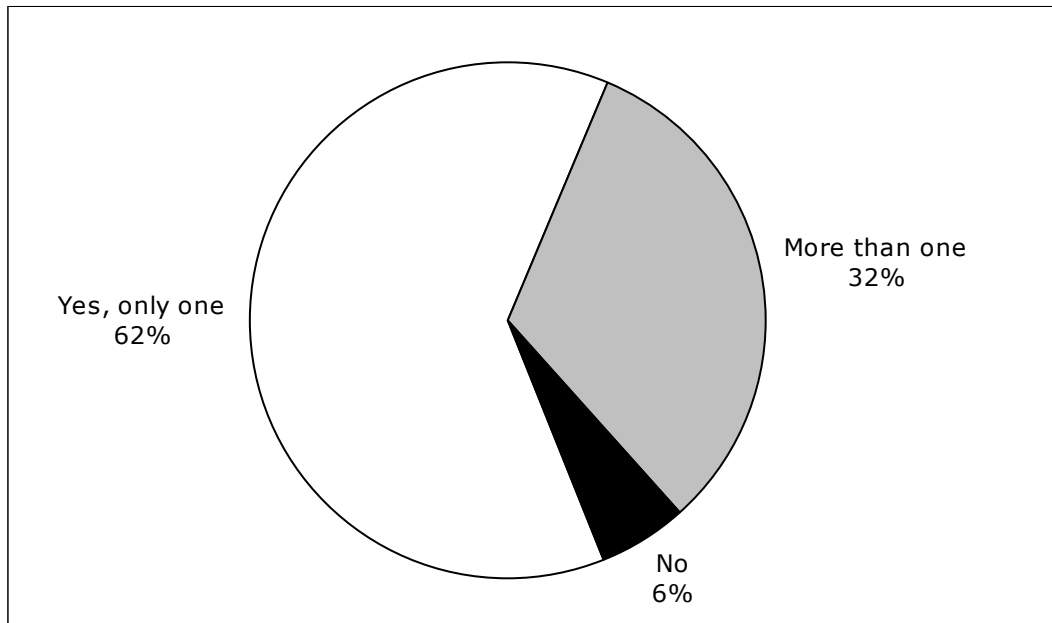
- Eighty-eight percent of those surveyed indicated that their infant did not currently have an ongoing chronic medical condition.
- Just over one tenth of respondents (12%) indicated that their infant currently had a chronic health condition that required ongoing medical attention and treatment.

Figure 4-13. Family Medical History of Hearing Loss

Respondents were asked if there was anyone in their family who had experienced hearing loss or gone deaf before the age of 12.

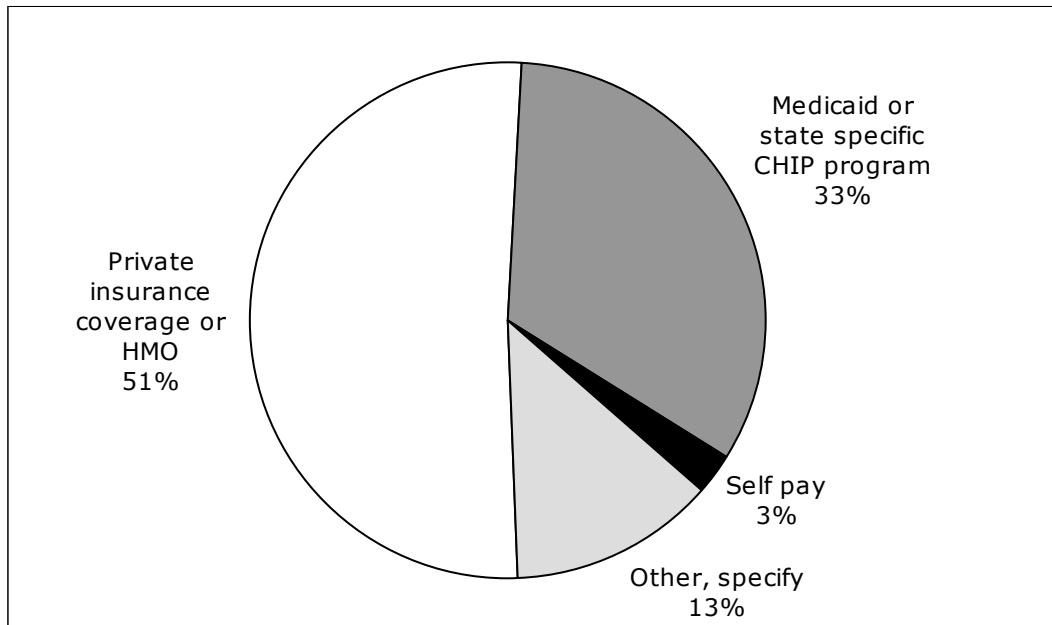
- Almost all respondents (93%) indicated that no one in the family had suffered hearing loss or gone deaf before the age of 12.
- Seven percent of respondents identified that at least one family member had been “hard of hearing” or had experienced complete hearing loss by age 12.

Figure 4-14. Access to a Medical Home



Respondents indicated whether they had a person they thought of as a personal doctor or health care provider for their infant.

- Nearly two thirds of the respondents (62%) replied that they had one person they identified as the personal doctor/health care provider for their infant.
- Just under a third of respondents (32%) named more than one doctor/health care provider as the personal doctor and primary health care provider for their infant.
- Under one tenth of survey respondents (6%) had no one they identified as the personal doctor or health care provider for their infant.

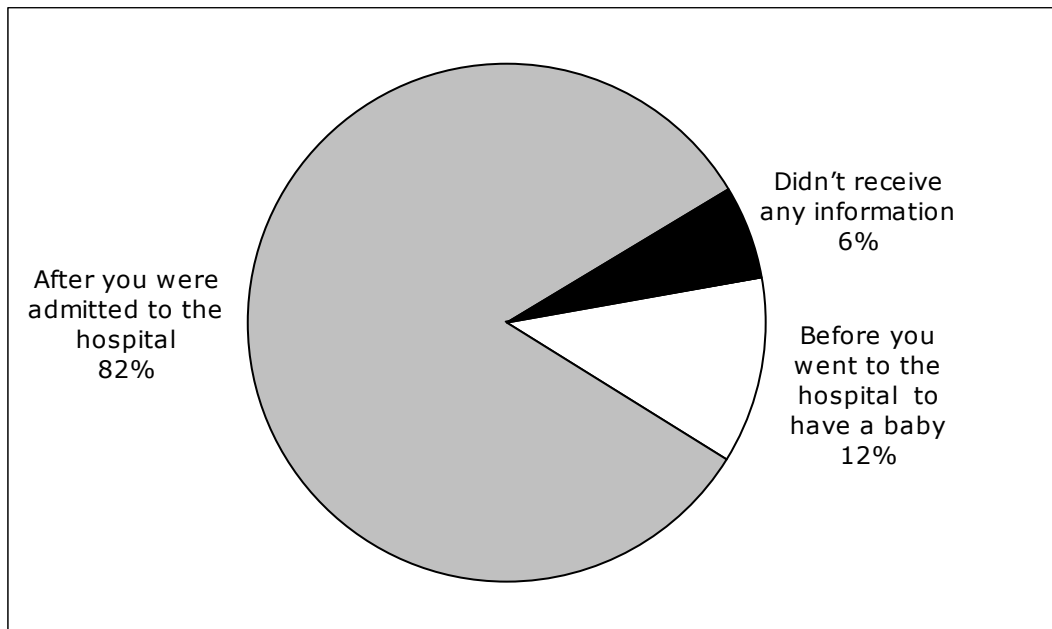
Figure 4-15. Health Insurance Coverage

Survey respondents identified the main source of coverage for their infant's medical needs. Respondents were asked to specifically name other sources that were not explicitly included in the survey.

- Just over half of all respondents (51%) relied on private insurance or HMO coverage to cover their infant's medical expenses.
- One third of respondents (33%) participated in Medicaid or SCHIP (State Children's Health Insurance Program), and used these programs to cover their infant's medical expenses.
- Three percent of respondents indicated that their medical expenses were paid directly "out of pocket," without reliance from any program or funding source.
- Just over one tenth of all surveyed (13%) responded that they used "other" programs/ funding sources to pay for their infant's medical expenses.

4.2.3 Information about Early Hearing Screening

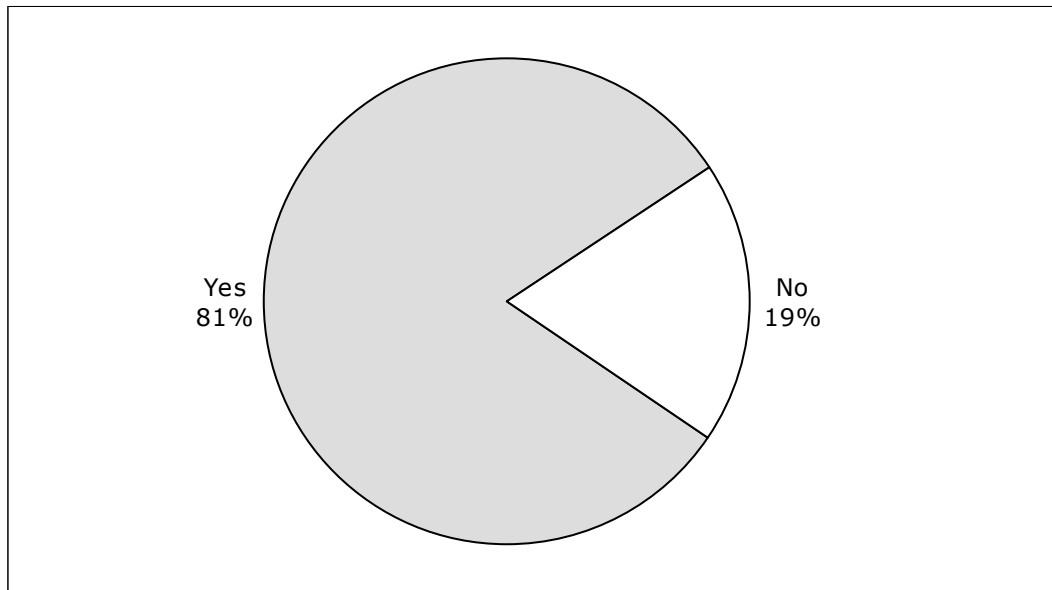
Figure 4-16. Availability of Hearing Screening Information



The survey asked respondents whether they had received information about infant hearing testing prior to giving birth, or once admitted into the hospital for delivery.

- Eighty-two percent of respondents indicated that they had received information once they had been admitted into the hospital.
- Only a minority of those surveyed (12%) responded that they had received information regarding infant hearing screenings *prior* to being admitted into the hospital.
- Six percent of all respondents indicated that they had received no information about infant hearing tests at any point during their pregnancy or throughout their stay at the hospital.

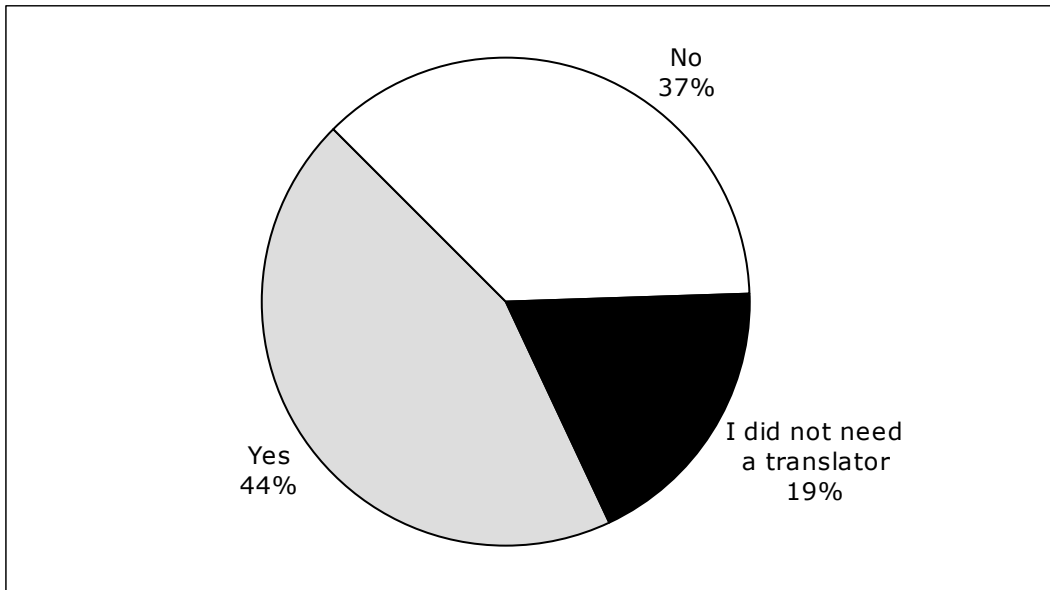
Figure 4-17. (Spanish version only) Provision of Spanish-Language Materials



Respondent who completed the Spanish version of the survey were asked to indicate whether written information about hearing screening in Spanish had been provided.

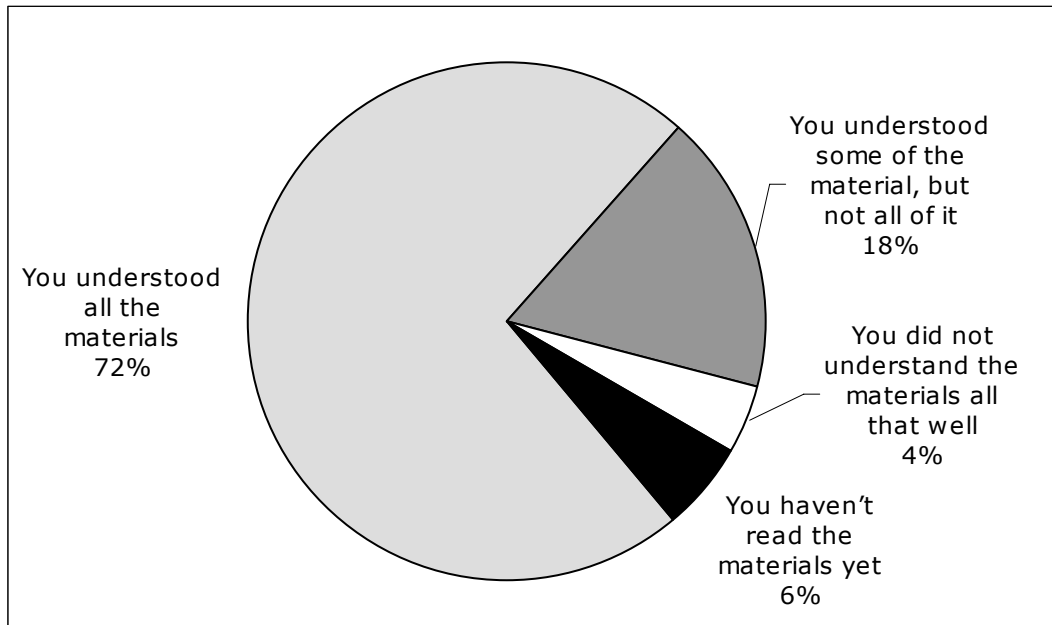
- The majority of the respondents (81%) indicated that they had received materials in Spanish.
- A fifth of those surveyed (19%) responded that they had not received materials in Spanish.

Figure 4-18. (Spanish version only) Explanation of Hearing Screening Results in Spanish



Spanish-speaking respondents were asked to indicate whether someone had explained their infant’s hearing screening results in Spanish.

- Less than half of the respondents (44%) indicated that someone had explained the results in Spanish.
- Over one third of those surveyed (37%) responded that no one had explained the results in Spanish.

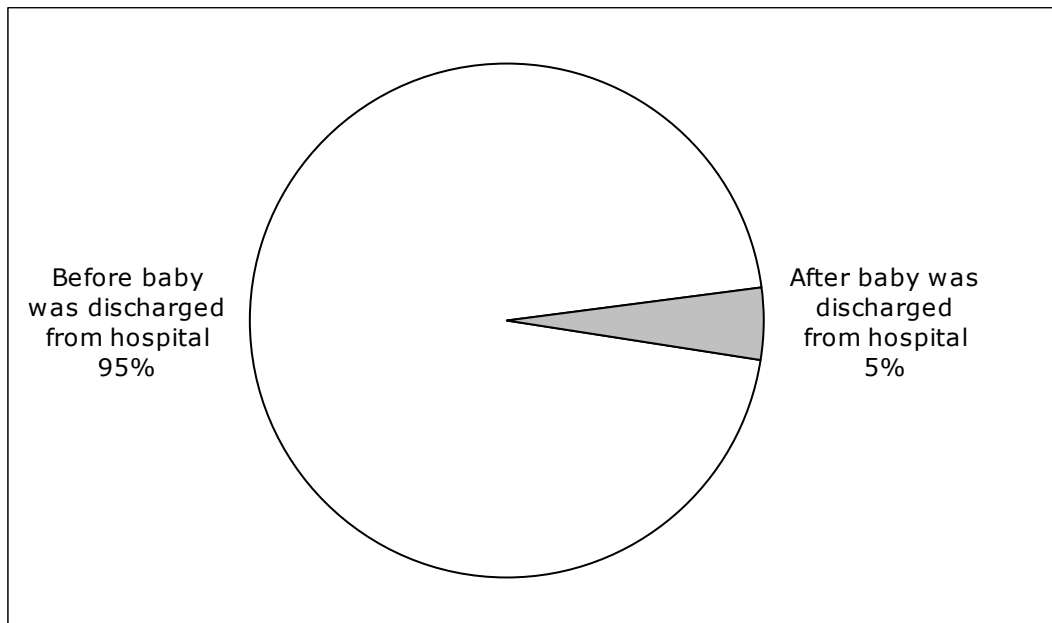
Figure 4-19. Comprehension of Information Provided

Respondents who had received information indicated how well they had understood all the information that had been presented to them about hearing screening.

- Almost three quarters of all respondents who had received information (72%) indicated that they had completely understood all information.
- Almost one fifth of all respondents (18%) indicated that they understood some but not all of the material they had received.
- Combined, 10% of respondents indicated that they had not understood the materials all that well (4%), or had not read the materials (6%).

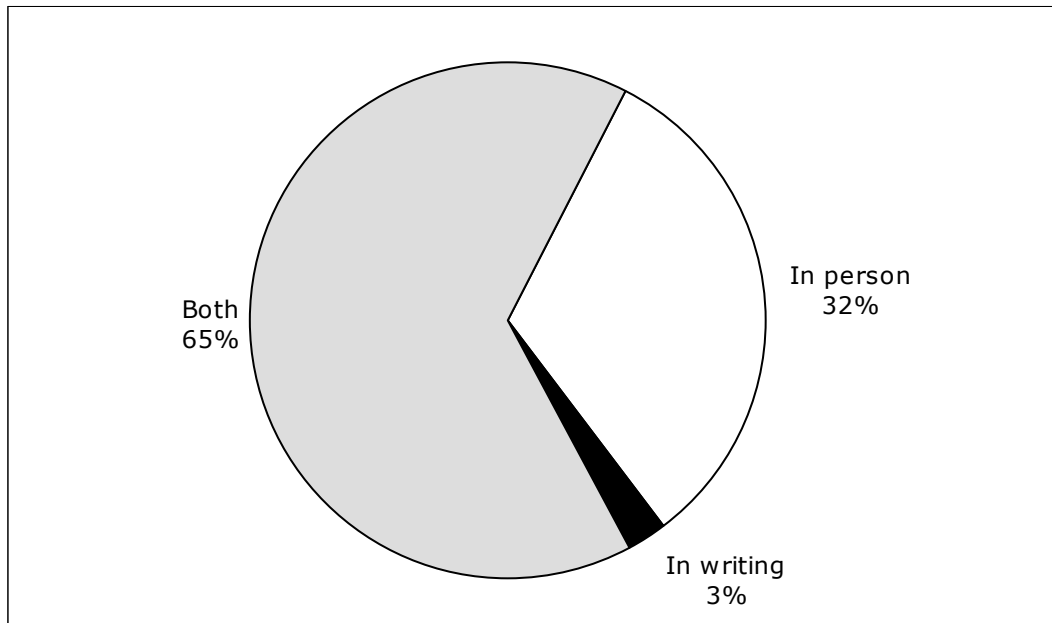
4.2.4 The Hospital Hearing Screening Experience

Figure 4-20. Infant Hearing Screening Status



Respondents indicated whether their infant had received a hearing screening before being discharged from the hospital.

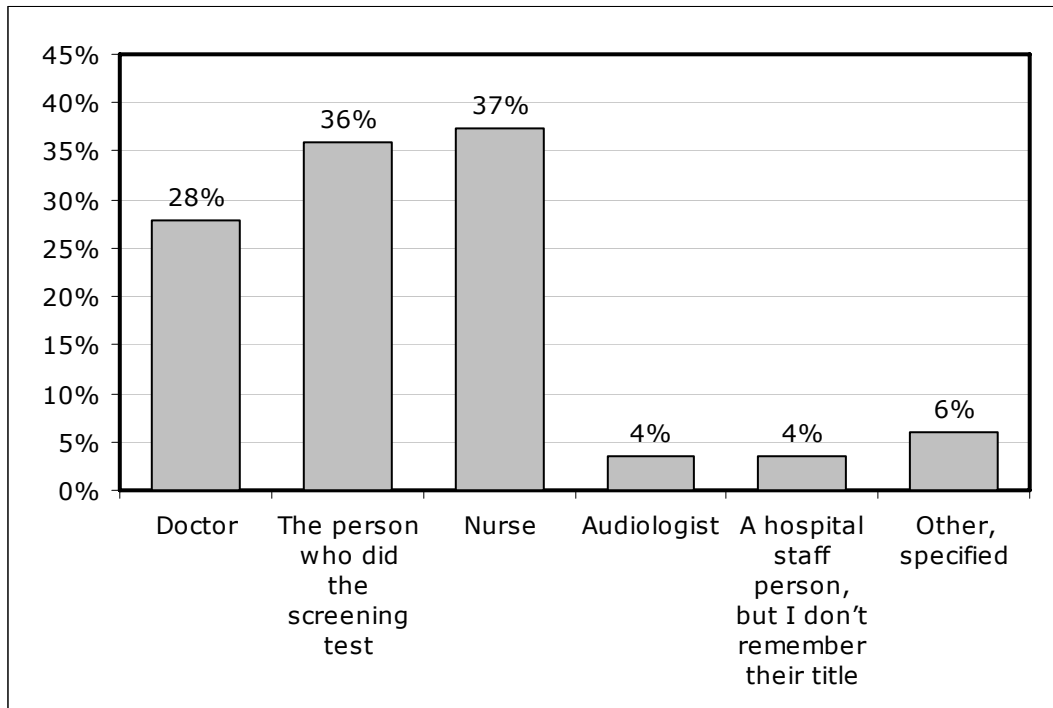
- Almost all respondents (95%) indicated that their infant had received a hearing screening before discharge from the hospital.
- Five percent of respondents said their infant had not received a hearing screening before being discharged from the hospital.

Figure 4-21. How the Hearing Screening Results were Communicated

Respondents indicated how the notice of their infant’s hearing screening results had been received—verbally, in writing, or both.

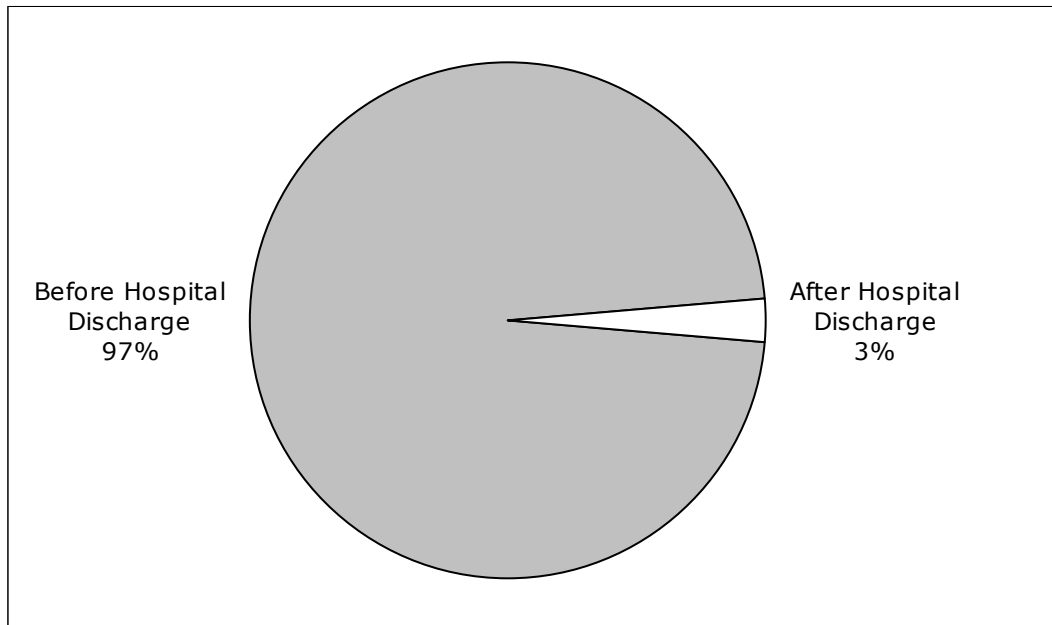
- Just under one third of respondents (32%) said that they had received only oral confirmation of their infant’s test results.
- Three percent of those surveyed indicated that they had received only written notice of the results of their infant’s hearing test.
- Two thirds of respondents (65%) received both verbal and written confirmation of the results of their infant’s hearing tests.

Figure 4-22. Who Communicated the Hearing Screening Results



Respondents indicated who had informed them of the results for their infant hearing screening. (Survey respondents were asked to check “all that apply,” so the total may be over 100%.)

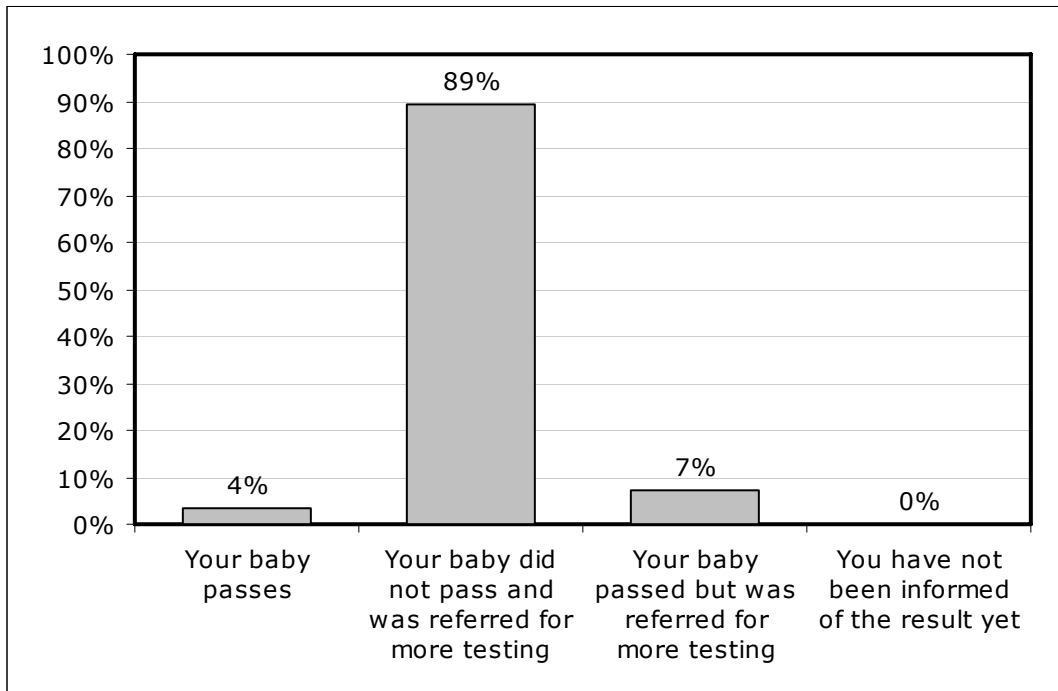
- Nearly two thirds of respondents indicated that either a nurse (37%), or the individual administrating the test (36%) had informed them of their infant’s results.
- Over one quarter of all surveyed (28%) indicated that a doctor had disclosed the results of their infant’s hearing tests.
- Eight percent of respondents indicated that either an audiologist (4%) or a hospital staff person (4%) had delivered the results of their infant’s hearing test.

Figure 4-23. When the Screening Results were Communicated

Respondents whose infants had received a hearing screening were asked to indicate whether they had received results of the hearing screening before discharge from the hospital.

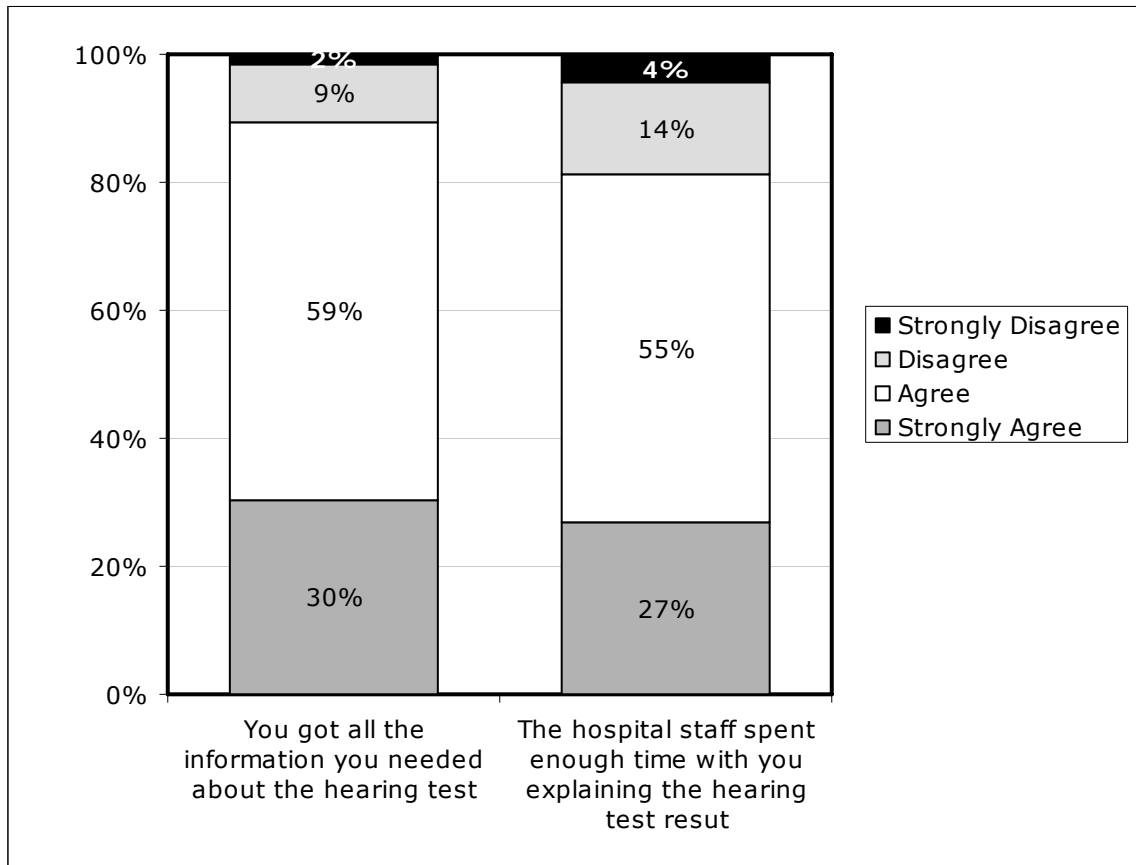
- Almost all respondents (97%) indicated that they had received the results before discharge.
- Three percent of respondents indicated that had received the results after they were discharged from the hospital.

Figure 4-24. Infant Hearing Screening Results



The survey asked respondents to disclose the results of their infant’s hearing screening.

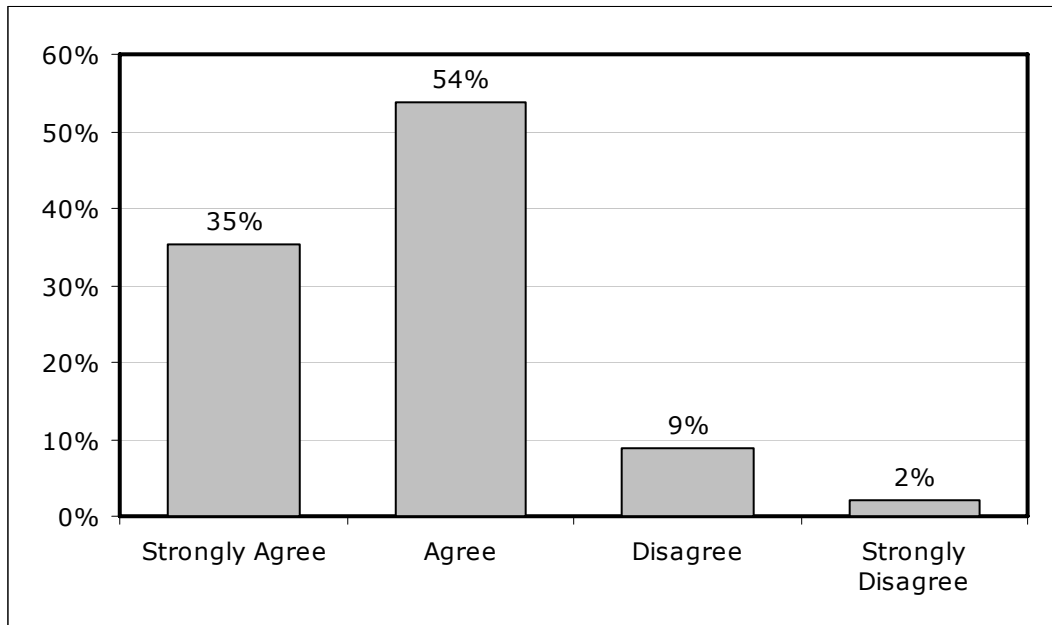
- Most of the respondents (89%) indicated that their infants had *not* passed the hearing screening.
- Seven percent of survey respondents indicated that their infant had passed the hearing screening but had been referred for additional testing.
- Four percent of respondents indicated that their infants had passed the hearing screening. (We speculate that these parents may have confused the difference between the initial and subsequent hearing screening and re-screening results or the child’s screening status had changed from the time the initial list from the MI-EHDI Program was received by RTI.)

Figure 4-25. Assessments of the Overall Hearing Screening Experience

Respondents were asked to indicate their agreement with statements regarding their hearing screening experience.

- Almost all of respondent strongly agreed (30%) or agreed (59%) with the statement *"You got all the information you needed about the hearing test."*
- Eleven percent of respondents strongly disagreed (2%) or disagreed (9%) with the statement *"You got all the information you needed about the hearing test."*
- Just over three quarters of the respondents strongly agreed (27%) or agreed (55%) with the statement *"The hospital staff spent enough time with you explaining the test results."*
- Under one fifth of respondents strongly disagreed (4%) or disagreed (14%) with the statement *"The hospital staff spent enough time with you explaining the test results."*

Figure 4-26. Comprehension of Hearing Screening Test Results

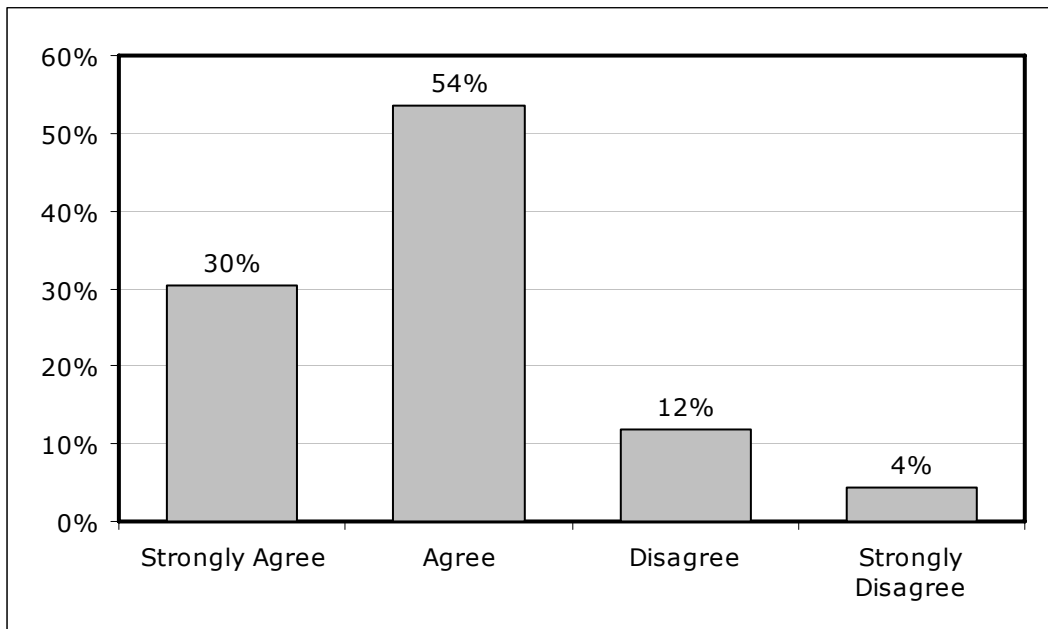


Respondents were asked to indicate their agreement with a statement concerning their comprehension of the hearing screening results.

- The majority of respondent strongly agreed (35%) or agreed (54%) with the statement *“You understood what the hearing results meant.”*
- Just over one tenth of respondents either disagreed (9%) or strongly disagreed (2%) with this statement.

4.2.5 Belief and Attitudes about the Hearing Screening Results

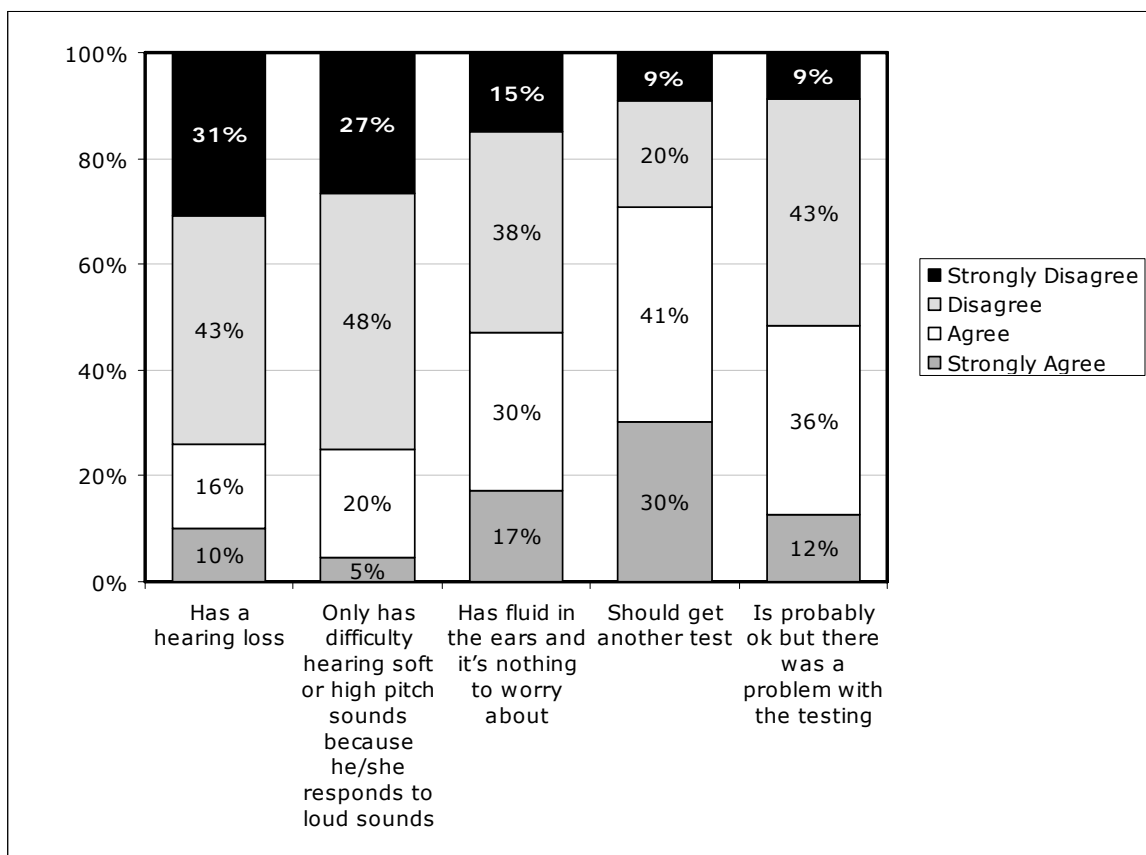
Figure 4-27. Belief in the Hearing Screening Results



Respondents were asked to indicate their agreement with a statement concerning their belief in the hearing screening results.

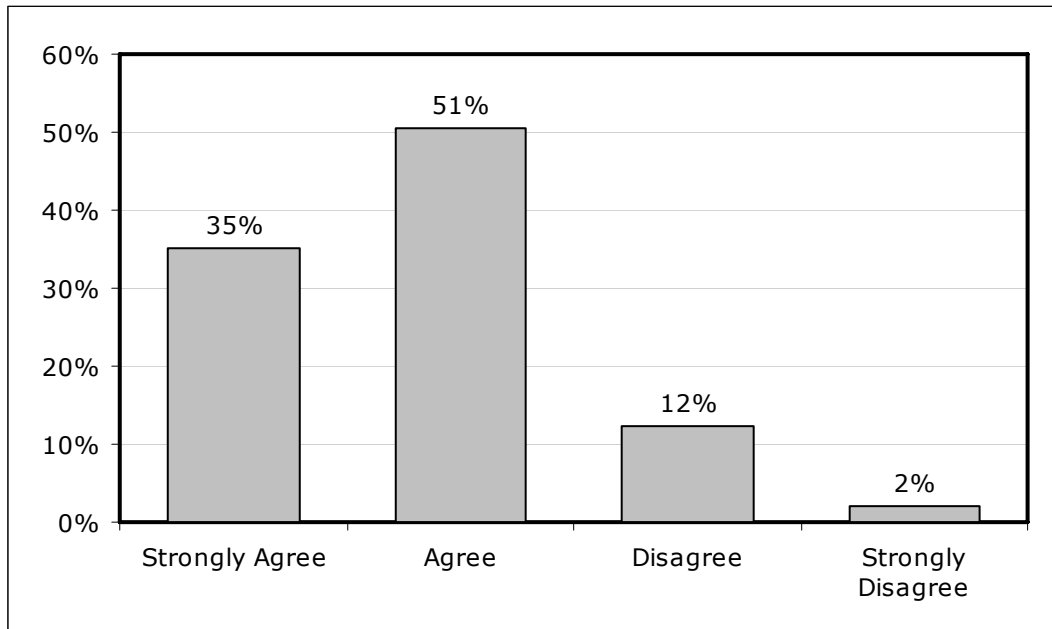
- The majority of the respondents either strongly agreed (30%) or agreed (54%) with the statement *"You believed the test results."*
- Twelve percent of those surveyed disagreed with the statement, while 4% strongly disagreed with the statement.

Figure 4-28. Beliefs about What the Hearing Screening Result Means



Respondents indicated their agreement with a number of statements regarding what the hearing screening result means or implies.

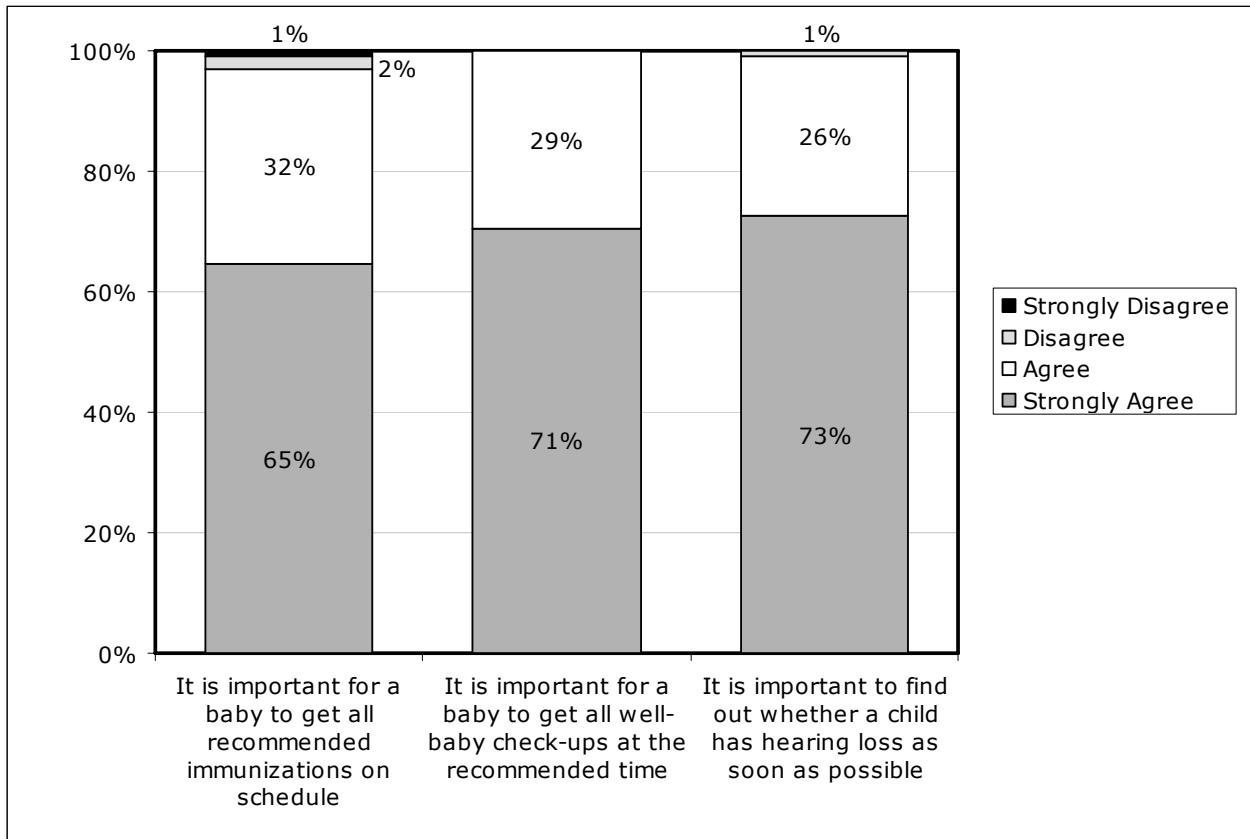
- Almost three quarters of all respondents strongly disagreed (31%) or disagreed (43%) with the statement *“Your infant has hearing loss.”* Nearly a quarter of the respondents strongly agreed (10%) or agreed (16%) with this statement.
- Three quarters of respondents strongly disagreed (27%) or disagreed (48%) with the statement *“Your infant only has difficulty hearing soft or high pitch sounds because he/she responds to loud sounds.”* A quarter of the respondents strongly agreed (5%) or agreed with this statement (20%).
- Nearly half of respondents strongly agreed (17%) or agreed (30%) with the statement *“Your infant has fluid in the ears and it’s nothing to worry about.”* Just over half strongly disagreed (15%) or disagreed (38%) with this statement.
- Almost three quarters of all respondents indicated that they strongly agreed (30%) or agreed (41%) with the statement *“Your infant should get another test.”* A third of the respondents strongly disagreed (9%) or disagreed (20%) with this statement.
- Respondents were split almost evenly on their agreement/disagreement with the statement *“Your infant is probably okay but there was a problem with the testing.”*

Figure 4-29. Anxiety about the Hearing Screening Result

Respondents were asked to indicate their agreement with a statement concerning their anxiety regarding the hearing screening result.

- A majority of respondents strongly agreed (35%) or agreed (51%) with the statement *"You were anxious about the hearing test result."*
- Fourteen percent disagreed (12%) or strongly disagreed (2%) with this statement.

Figure 4-30. Beliefs about Infant Care

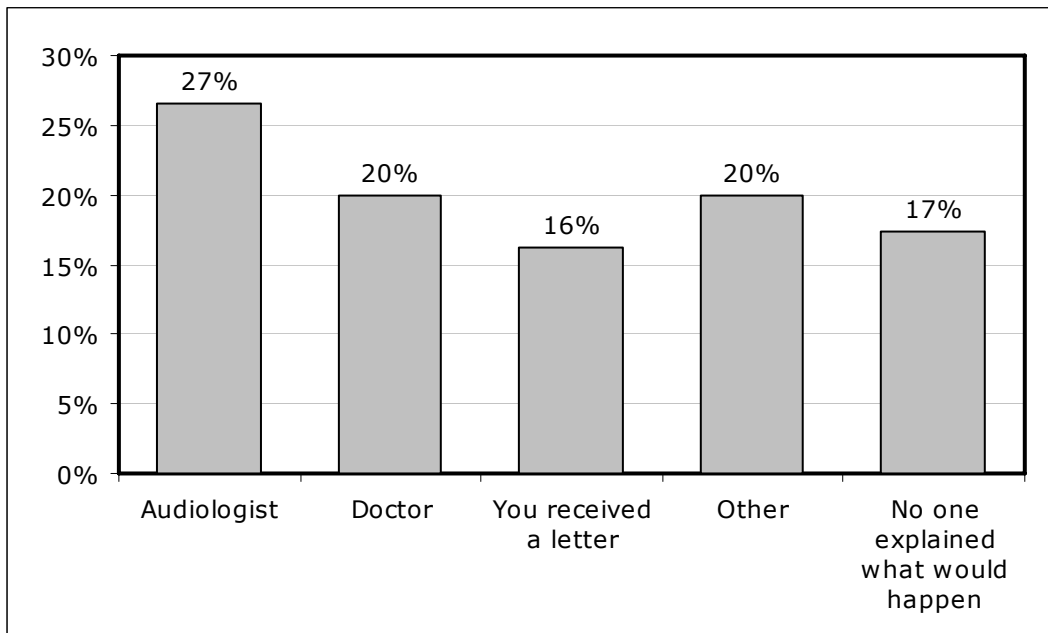


Respondents were asked to indicate their agreement with statements concerning infant care.

- Almost all respondents (97%) strongly agreed or agreed with the statement *“It is important for an infant to get all recommended immunizations on schedule.”*
- All respondents (100%) said that they strongly agreed or agreed with the statement *“It is important for an infant to get all well-infant check-ups at the recommended time.”*
- Almost all respondents (99%) strongly agreed or agreed with the statement *“It is important to find out whether an infant has hearing loss as soon as possible.”*

4.2.6 Follow-Up Procedures

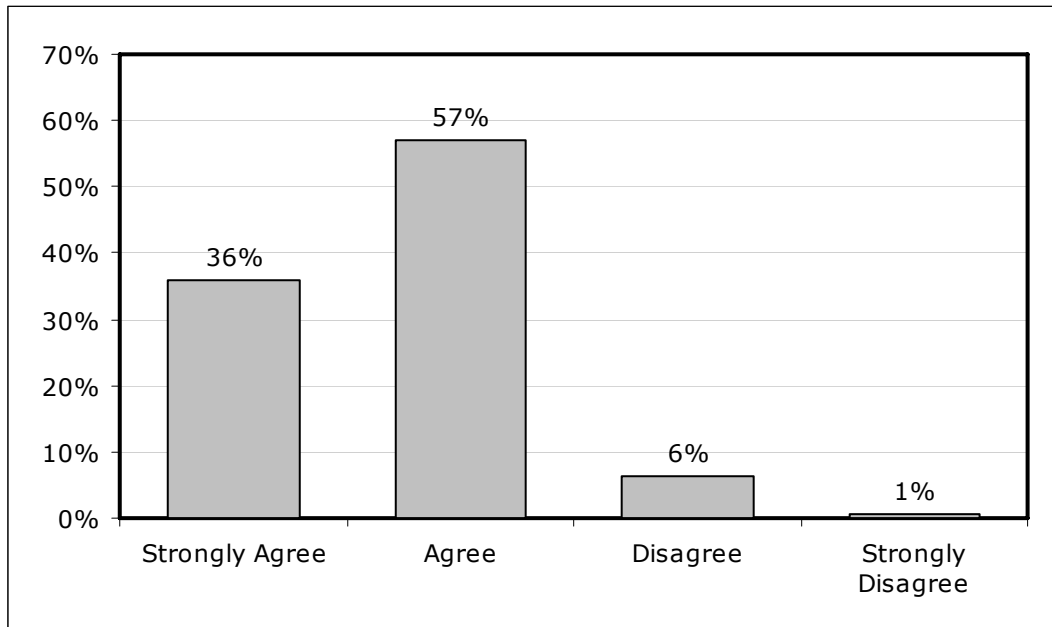
Figure 4-31. Who Communicated Information about Follow-Up Procedures



Respondents indicated who had notified them about the procedures of follow-up evaluation.

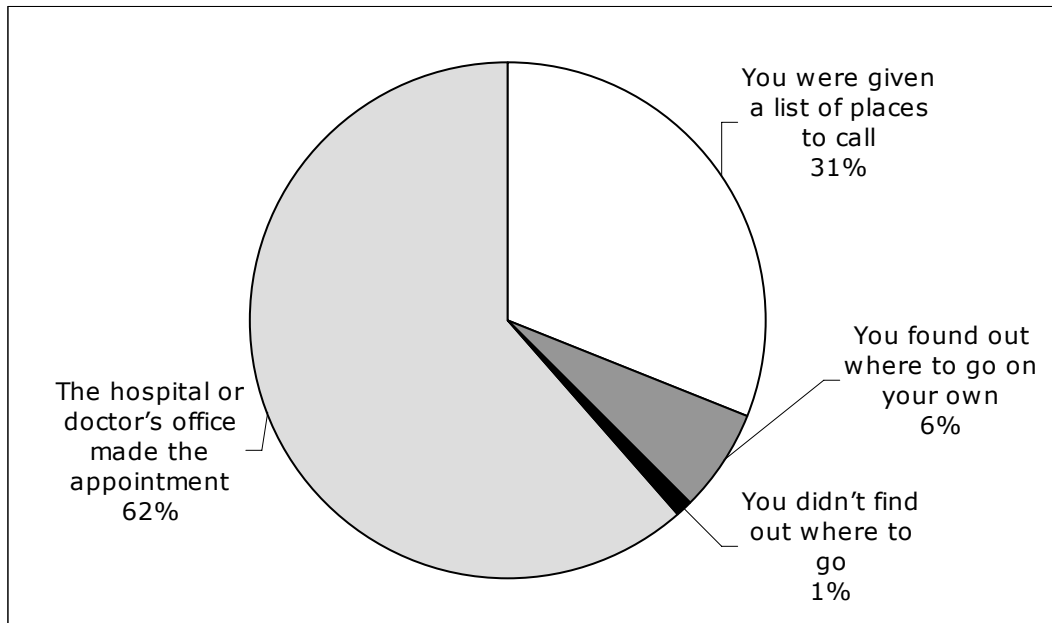
- Almost half of respondents identified an audiologist (27%) or a doctor (20%).
- Sixteen percent of respondents received follow-up information via a letter.
- A fifth of the respondents identified another unnamed source (20%).
- Seventeen percent of respondents indicated that no one had explained the follow-up procedures to them.

Figure 4-32. Comprehension of Follow-Up Procedures



Respondents were asked to indicate their agreement with a statement concerning their understanding of follow-up procedures.

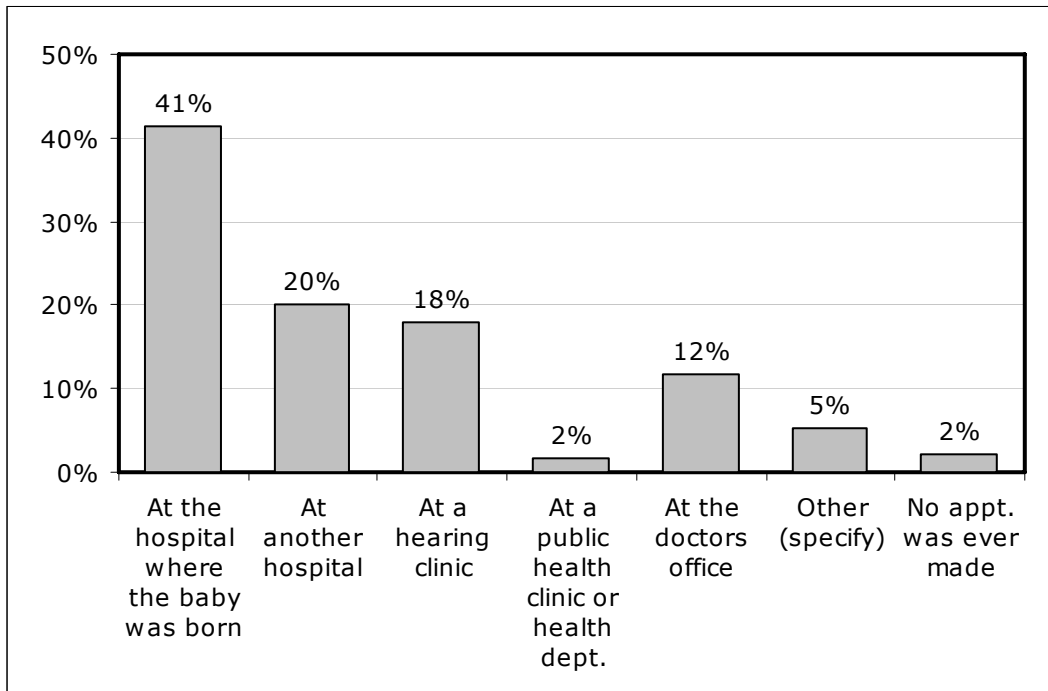
- Almost all respondents strongly agreed (36%) or agreed (57%) with the statement *“You understand what to do next.”*
- Seven percent of the respondents disagreed (6%) or strongly disagreed (1%) with this statement.

Figure 4-33. Scheduling an Appointment for Follow-up Evaluation

Respondents indicated how they received information about where to go to receive follow-up evaluation.

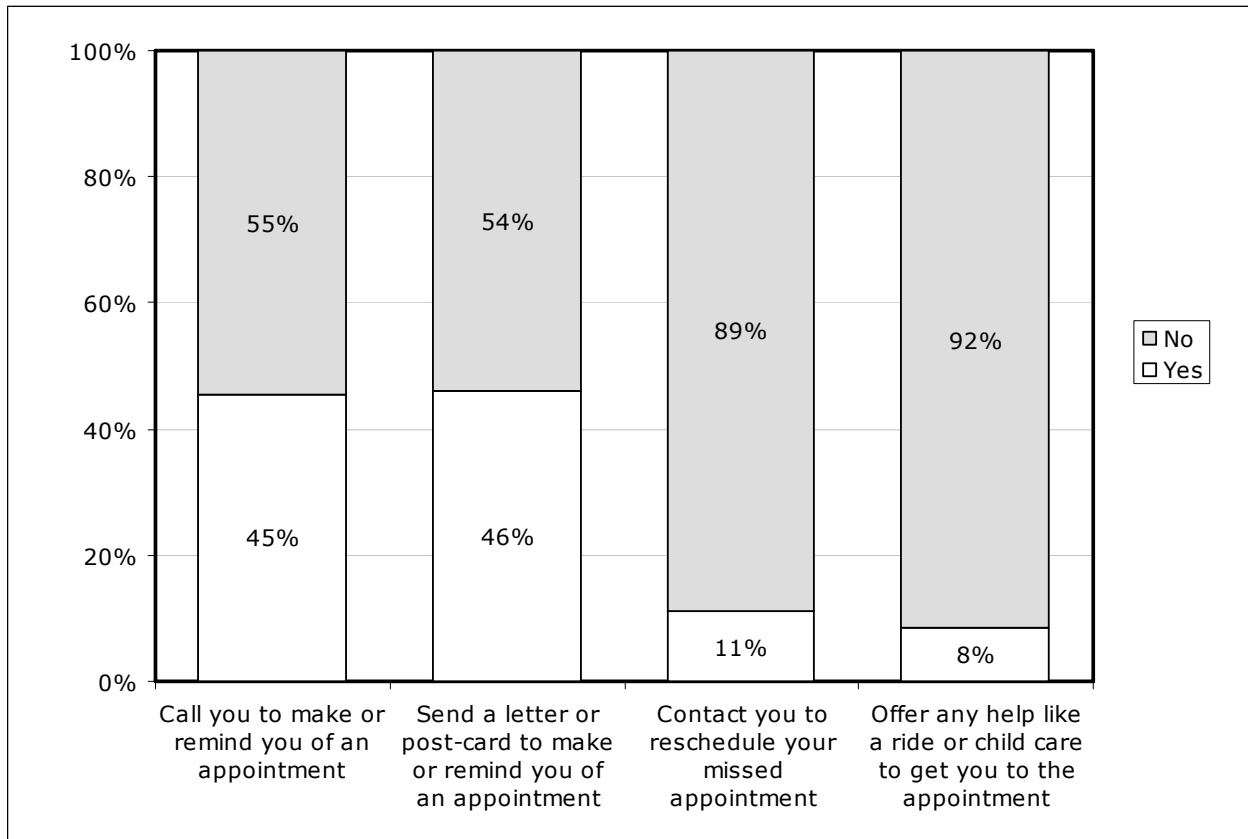
- Almost two thirds of those surveyed (62%) responded that the hospital or doctor's office had made the follow-up appointment directly.
- Thirty-one percent of respondents were given a list of places to call that provided audiological services.
- Less than one tenth of respondents had to find out where to go to receive follow-up services on their own (6%) or never found out about where to go for follow-up evaluation (1%).

Figure 4-34. Location of Follow-Up Appointment



Respondents were asked to indicate the location of their follow-up appointment.

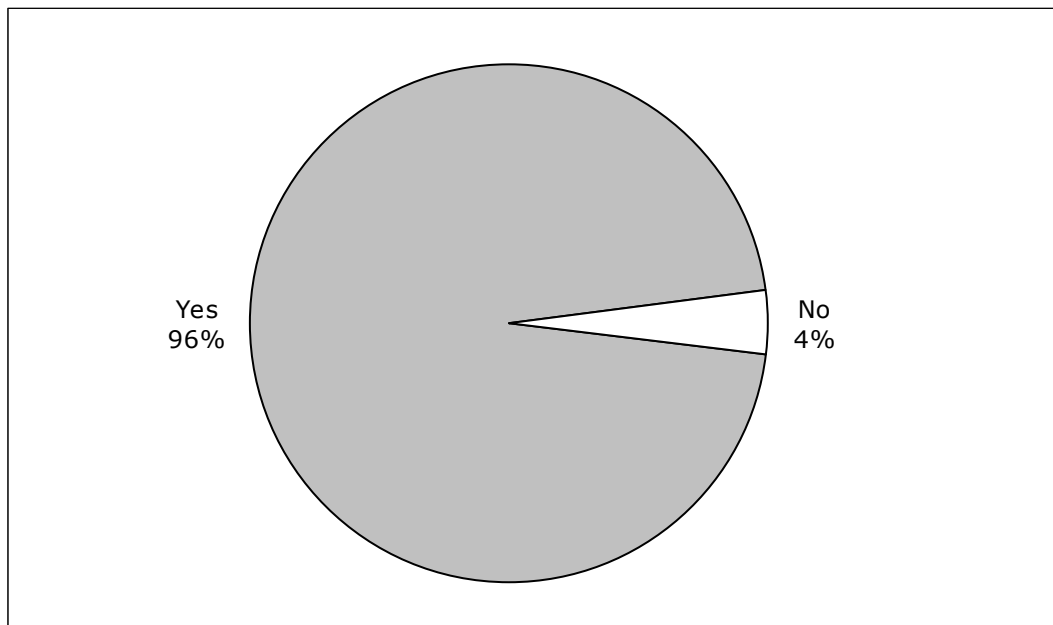
- Almost two thirds of those surveyed indicated that the follow-up appointment was either at the same hospital where the infant was born (41%) or at another hospital (20%).
- Almost one third of those surveyed indicated that the follow-up appointment was at a hearing clinic (18%) or at a doctor's office (12%).
- Seven percent of respondents indicated that the follow-up appointment was at a public health clinic (2%) or some other location (5%).

Figure 4-35. Assistance with Follow-Up Services

Respondents indicated whether anyone had helped them with various administrative issues and transportation assistance for the follow-up appointment.

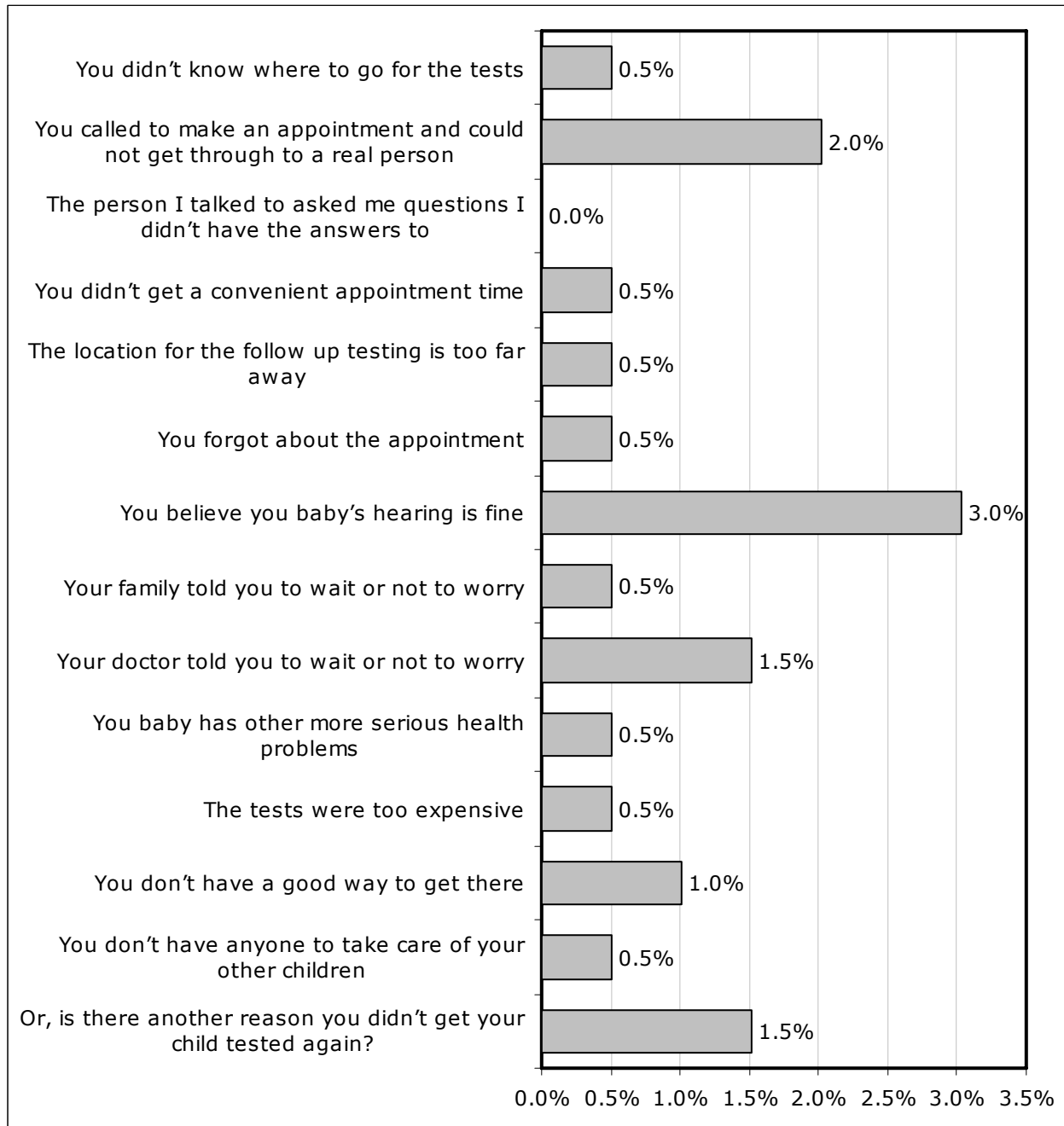
- More than half of respondents indicated that no one had called (55%) or sent them a letter (54%) to remind them about their follow-up appointment.
- Most of the respondents (89%) reported that no one had contacted them to reschedule any missed follow-up appointments.
- Most of the respondents (92%) were offered no assistance with transportation to and from the appointment, or infant care during the follow-up appointment.

Figure 4-36. Compliance with Follow-Up Evaluation



Respondents were asked whether they had attended the follow-up appointment.

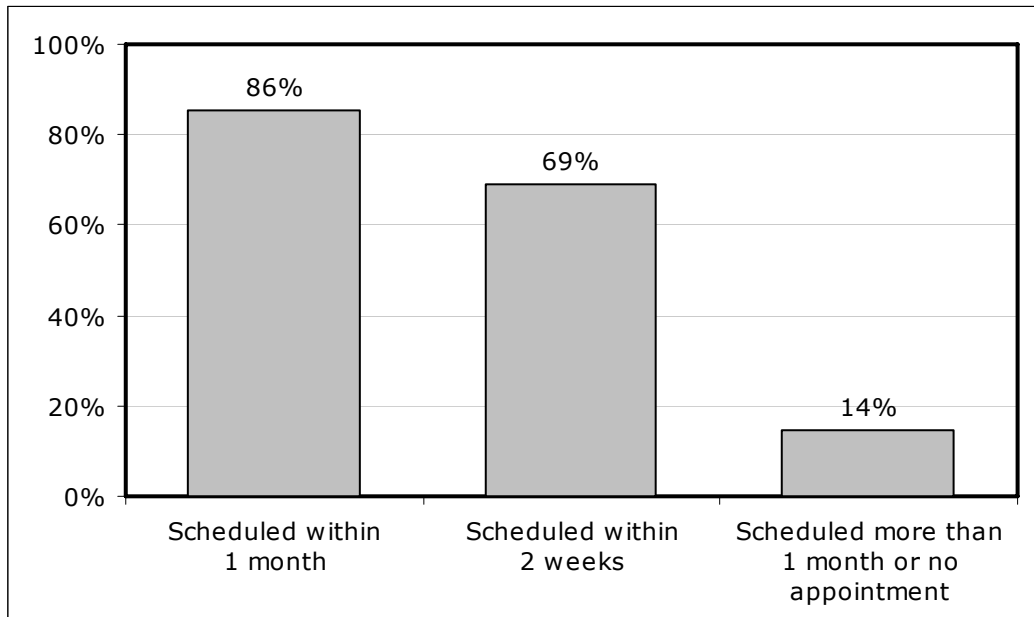
- Almost all of those surveyed (96%) indicated that they had gone to the follow-up appointment.

Figure 4-37. Reasons for Missing Follow-Up Evaluation Appointments

Respondents were given a list of common reasons parents might miss or fail to make follow-up appointments and were asked to indicate whether any of these reasons applied to them.

- The two most cited reasons given were *"The infant's hearing is fine"* (3%), and they *"called to make an appointment but could not get through to a real person"* (2.0%).

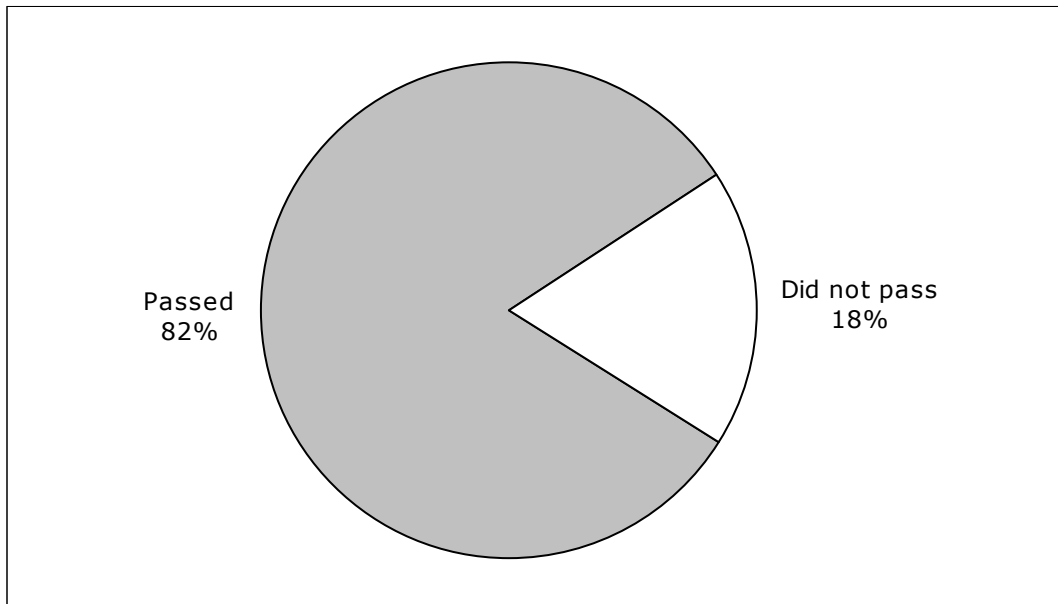
Figure 4-38. Timing of Follow-Up Appointment



Respondents were asked if they had scheduled an appointment for follow-up within a specified period of time of being discharged from the hospital.

- Over two thirds of respondents (69%) indicated that they had made a follow-up appointment within 2 weeks post-discharge from the hospital.
- Eighty-six percent of respondents made an appointment by 1 month post discharge from the hospital.

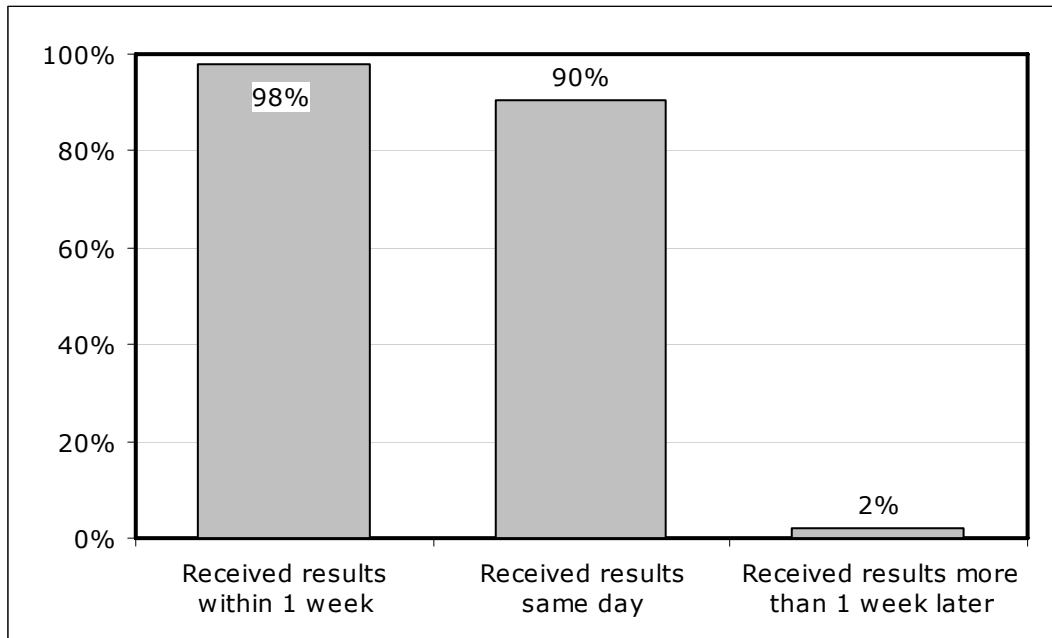
Figure 4-39. Results of Follow-Up Evaluation



Respondents were asked to disclose the results of their infant’s follow-up hearing test.

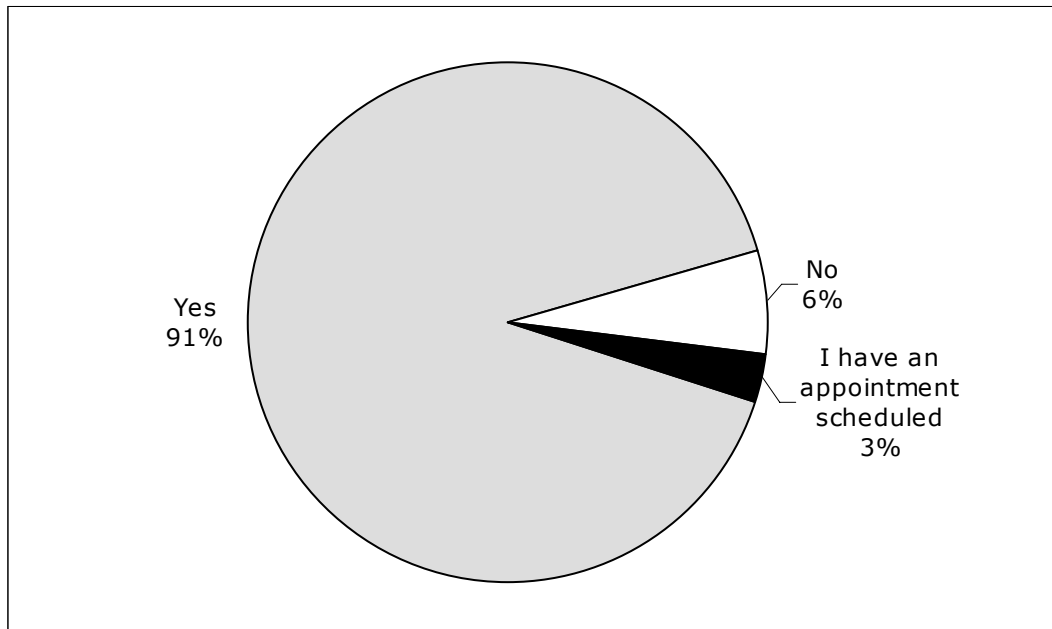
- Eighty-two percent of respondents indicated that their infant had passed the follow-up evaluation.
- Eighteen percent of respondents indicated their infant did not pass the follow-up evaluation.

Figure 4-40. When Respondent Received Follow-Up Evaluation Results



Respondents were asked to identify when they had received their infant’s follow up evaluation.

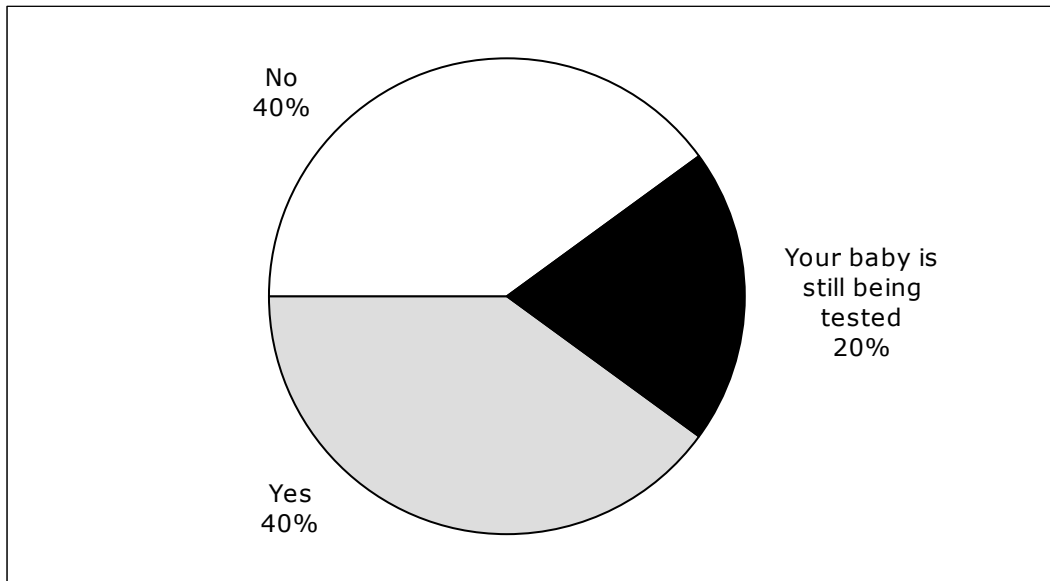
- Ninety-eight percent of respondents received results within 1 week of the exam.
- Ninety percent of respondents said that they had received follow-up evaluation results the same day of the exam.

Figure 4-41. Compliance with Diagnostic Evaluation

Respondents whose infant failed the follow-up hearing evaluation (n=32) indicated whether they had undergone additional diagnostic evaluation.

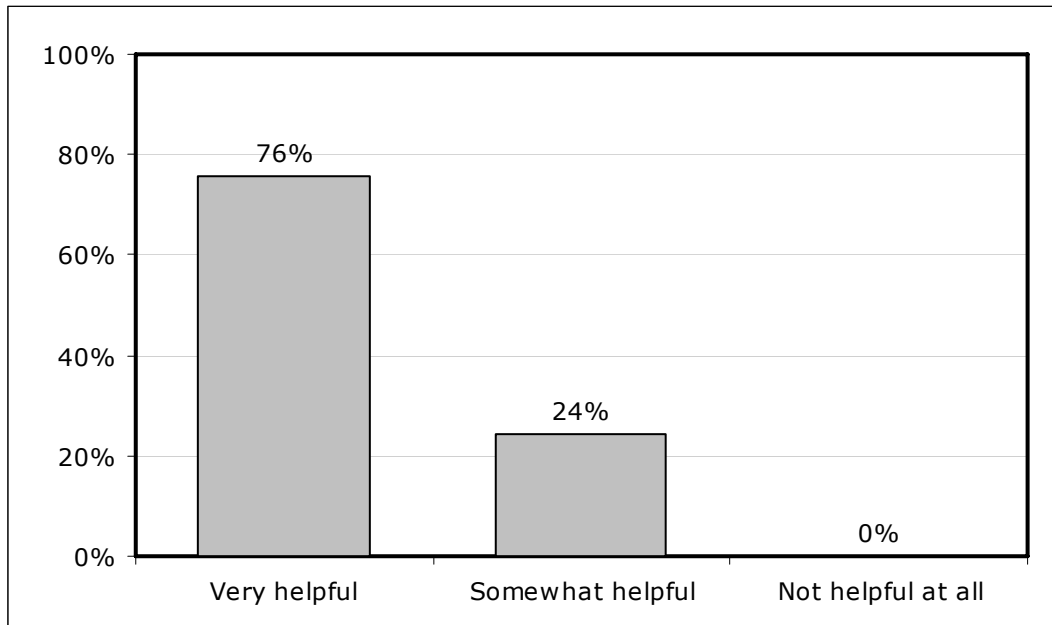
- Almost all the respondents had undergone further diagnostic evaluation (91%).
- Six percent of the respondents indicated that they had not received additional diagnostic evaluation.

Figure 4-42. Diagnosed Hearing Loss



The survey asked respondents who were referred for additional diagnostic evaluation to disclose the findings/status of that evaluation.

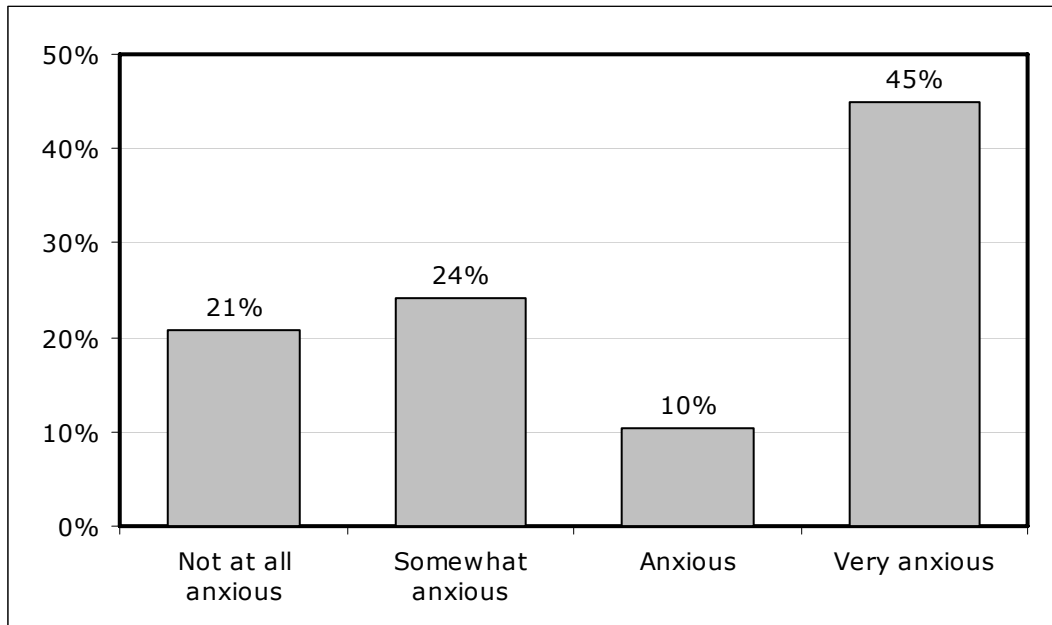
- Forty percent of respondents indicated that their infant was diagnosed with hearing loss.
- Forty percent of respondents indicated that their infant did not have diagnosed hearing loss.
- Twenty percent of respondents indicated their infant was still in the midst of testing.

Figure 4-43. Beliefs Regarding Early Intervention

The survey asked respondents whose infant had been referred for additional diagnostic evaluation to indicate how helpful it would be to begin an intervention for hearing loss before 1 year of age.

- All respondents indicated that it would be very helpful (76%) or somewhat helpful (24%) to have a hearing loss intervention for an infant before the age of one.

Figure 4-44. Anxiety about Effects of Hearing Loss

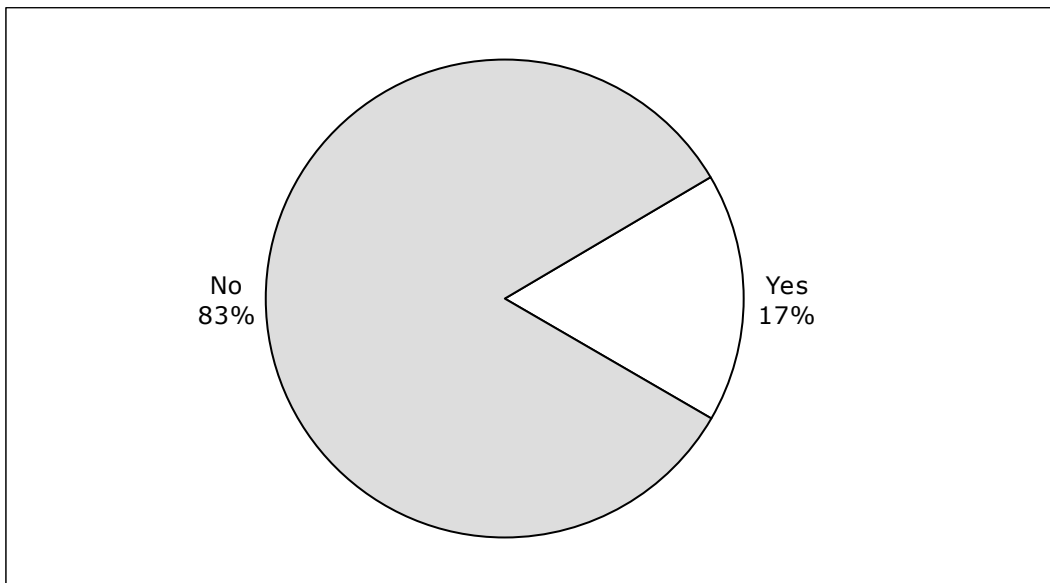


The survey asked respondents whose infant had been referred for additional diagnostic evaluation to indicate how anxious they were about the effects of possible hearing loss.

- Over half were either very anxious (45%) or anxious (10%) about the effects of the possible hearing loss of their infant.
- A quarter of the respondents (24%) were somewhat anxious.
- Twenty-one percent of those surveyed were not anxious at all about the effects of their infant's possible hearing loss.

4.2.7 Family Support Services

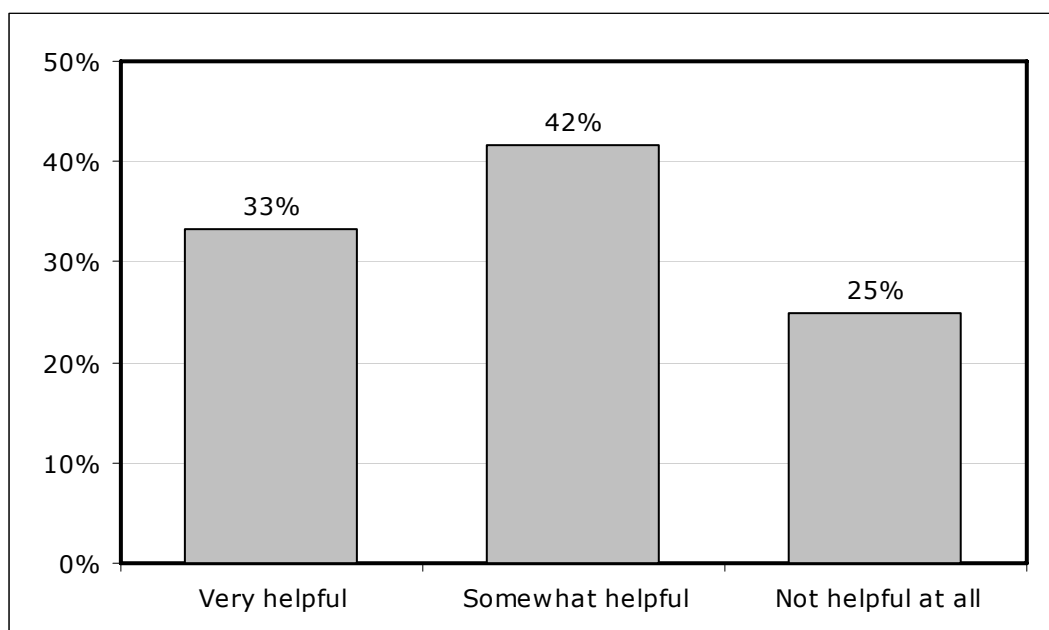
Figure 4-45. Links to Family Support



The survey asked respondents whose infant had diagnosed hearing loss (n=12) whether they had been contacted by someone who would put them in contact with another family of a child with hearing loss who could offer support and advice.

- Most of the respondents (83%) indicated that no one had contacted them to link them to another family.
- Seventeen percent of those surveyed reported that they had been in contact with another family.
- Of those who had been given contact information, half (50%) had contacted the family (data not shown)

Figure 4-46. Attitudes Regarding Family-to-Family Support



The survey asked respondents whose infant had diagnosed hearing loss to indicate how helpful it would be (or had been) to have a family-to-family support.

- Three quarters of respondents indicated that it would have been very helpful (33%) or somewhat helpful (42%) to have other families to talk to.
- One quarter of respondents (25%) indicated that it would not have been helpful at all to have other families to talk to.

4.3 Discussion

The CATI survey collected information on the demographic characteristics; screening and follow-up experiences; and knowledge, understanding, and attitudes regarding the results of the hearing screening and the follow-up evaluation of women whose infants had not passed the initial hearing screen at the hospital. We highlight here some of the key findings that may help shape and inform the VDH EHDI Program.

Receipt of information about infant hearing screening prior to birth was largely uncommon. Only 12% of those surveyed had received such information in their prenatal period. Nearly a third of the respondents either did not fully understand or did not read the materials they received at the hospital. These findings suggest a need to explore ways to disseminate EHDI information more widely as part of prenatal care and childbirth education and to examine more closely the comprehension and appeal of these materials.

Among Spanish-speaking mothers, the majority (81%) received hearing screening materials in Spanish but less than half (37%) did not have anyone explain to them the hearing

screening results in Spanish. The lack of translation services indicates a potential barrier to comprehension and warrants attention.

In assessing maternal knowledge, beliefs, and attitudes regarding the hearing screening, however, our findings suggest that there is a gap between what respondents think they know and what they actually know. Overall, the majority of the respondents thought they had gotten all the information they needed (89%) and understood what the results of the hearing screening meant (89%). However, a quarter of the respondents (26%) thought the “do not pass” hearing screening result meant their infant had hearing loss. About half of the respondents thought this test result meant that their infant had “*fluid in the ears it was nothing to worry about*” (47%) and/or that their infant “*was probably okay and there was a problem with the test*” (48%). A third of the respondents (29%) did not know that the “do not pass” result indicated the need for additional testing.

This lack of comprehension regarding the hearing screening result may in part be related to the manner in which the test results were communicated and follow-up procedures explained. Nearly a third of the respondents (32%) indicated that they had received only oral confirmation of the test results and nearly one in five (18%) of those surveyed indicated that the hospital staff had not spent enough time explaining the results. Furthermore, almost the same percentage (17%) reported that no one had explained to them what would happen at the follow-up testing. Communication procedures at the hospital might be improved by ensuring that all patients receive both written and verbal confirmation of the hearing screening results. Moreover, while time is often limited, it is important for hospital staff to fully explain the test results and follow-up procedures as much as possible and solicit feedback from patients to ensure that all their questions and concerns have been addressed.

The majority of respondents (93%) reported that they understood what to do next in terms of follow-up evaluation and the high proportion of those who completed a follow-up appointment (96%) indicates that this was most likely the case. Moreover, the timeliness of follow-up appears not to have been a major problem for the majority of those surveyed. The majority (86%) had scheduled an appointment within 1 month of discharge from the hospital.

The high rates of compliance with follow-up may have been due at least in part to the resources and assistance offered in scheduling appointments. Approximately two thirds of the respondents (62%) reported that the hospital or doctor’s office had made the follow-up appointment directly. A third of the respondents (31%) were given a list of places to call. About half of the respondents received an appointment reminder either a call (45%) and/or a letter (46%). It appeared that very few of those surveyed encountered any notable problems in making those follow-up appointments. Only a small minority (2%–3%) indicated a reason for missing an appointment. The high rates of compliance and timeliness

for follow-up evaluation were also evidenced in compliance with diagnostic evaluation. Nearly all those referred to diagnostic evaluation (91%) had done so.

Not surprisingly, a majority of respondents (86%) indicated that they felt anxious about the results of their infant's hearing screening test. Under half of the respondents (45%) whose infants were referred to diagnostic evaluation reported that they were "very anxious" about the possible effect of the hearing loss on their infant. Enhanced knowledge and communication appears to be associated with lower levels of maternal anxiety regarding the hearing screening (Crockett et al., 2006; Hewlett & Waisbren, 2006).

For families with an infant or child with special health care needs, the support of other families in similar circumstances can be helpful and reduce anxiety (Ireys et al., 2001) and this study's findings suggest that efforts in this regard could be improved. The majority of respondents (75%) whose infant was diagnosed with a hearing loss indicated that having another family to talk to would be very or somewhat helpful. However, most of these families (84%) did not receive any information linking them to another family.

Study Limitations. There are a number of limitations to bear in mind when interpreting the findings of this CATI. Most noteworthy is the extended period of time between the events and the administration of the CATI. Women whose infants were born during the early period of the sampling were probably less likely to remember with as much accuracy the timing and content of events as those in the latter periods. At the time the CATI was conducted some infants would have been as old as 18 months. Second, we were unable to trace more than half of the eligible sample and these women may have in systematic manner been different from those we were able to locate. We did not have access to demographic or other background information about these women who we could not locate to assess whether there was a potential selection bias.

5. REFERENCES

- Centers for Disease Control and Prevention (2003). "Infants tested for hearing loss—United States, 1999–2001." *Morbidity and Mortality Weekly Report* 52(41):981–984.
- Crockett, R., Wright, A.J., Uus, K., Bamford, J., and Marteau, T.M. (2006). "Maternal anxiety following infant hearing screening: The moderating role of knowledge." *Journal of Medical Screening* 13(1):20-25.
- Directors of Speech and Hearing Programs in State Health and Welfare Agencies (2004). *Data Summary: Reporting Year 2004: Version D*. http://www.cdc.gov/ncbddd/ehdi/2004/Data_Summary_04D_web.pdf.
- Health Resources and Services Administration (2002). *Universal Newborn Hearing Screening*. Retrieved July 12, 2002, from Health and Human Services website: <http://www.mchb.hrsa.gov/programs/genetics/hearingscreen.htm>.
- Hewlett, J., and Waisbren, S.E. (2006). "A review of the psychosocial effects of false-positive results on parents and current communication practices in infant screening." *Journal of Inherited Metabolic Disease* 29(5):677–682.
- Ireys, H.T., Chernoff, R., DeVet, K.A., and Kim, Y. (2001). "Maternal outcomes of a randomized controlled trial of a community-based support program for families of children with chronic illnesses." *Archives of Pediatrics & Adolescent Medicine* 155(7):771–777.
- Joint Committee on Infant Hearing (2000). "Year 2000 position statement principles and guidelines for early hearing detection and intervention programs." *American Speech-Language Association*. <http://professional.asha.org/continuing>.
- Karchmer, M.A., and Allen, T.E. (1999). "The functional assessment of deaf and hard of hearing students." *American Annals of the Deaf* 144(9):13–17.
- National Center for Hearing Assessment and Management (2001). *Virginia Abstract. Virginia Narrative. Maternal Child Health Bureau State Grant for Early Hearing Detection and Intervention*. Retrieved December 19, 2002, from Utah State University, National Center for Hearing Assessment and Management website: http://www.infanthearing.org/stategrants/mchb2001/mchb2001_virginia.html.
- National Center for Hearing Assessment and Management (2002). *Universal Newborn Hearing Screening: Fact Sheet*. Retrieved July 12, 2002, from Utah State University, National Center for Hearing Assessment and Management website: <http://www.infanthearing.org/screening/index.html>.
- Strickland, B. (2002). *Connecting EHDI with the Medical Home. Presented at MCHB/CDC Annual Meeting on Successful Statewide Early Hearing Detection and Intervention Programs, February 11–13, 2002*. Retrieved July 12, 2002, from Utah State University, National Center for Hearing Assessment and Management website: <http://www.infanthearing.org/meeting/ehdi2002/presentations/index.html>.

- Virginia Department of Health (2002a). *Newborn Hearing Screening*. Retrieved December 18, 2002, from Virginia Department of Health's website: <http://www.vahealth.org/hearing/>.
- Virginia Department of Health (2002b). *Protocols for Diagnostic Audiological Assessment: Follow-up for Newborn Hearing Screening*. Retrieved December 18, 2002, from Virginia Department of Health's website: <http://www.vahealth.org/hearing/protocol.pdf>.
- White, K.R. (1997). *Universal Newborn Hearing Screening Issues and Evidence*. CDC Workshop on Early Detection and Intervention, Atlanta, Georgia, October 22–23.
- White, K.R. (2002). *Evaluation of Utah's Early Hearing Detection and Intervention Program*. Presented at MCHB/CDC Annual Meeting on Successful Statewide Early Hearing Detection and Intervention Programs, February 11–13. Retrieved July 12, 2002, from Utah State University, National Center for Hearing Assessment and Management website: <http://www.infanthearing.org/meeting/ehdi2002/presentations/index.html>.
- Yoshinaga, I.C., Sedey, A.L., Coulter, D.K., and Mehl, A.L. (1998). "Language of early and later identified children with hearing loss." *Pediatrics* 102(5):1161–1171.

**APPENDIX A:
ATTACHMENT 1
MATERNAL EXIT SURVEY INSTRUMENT**

Maternal Exit Survey Instrument

Public reporting burden of this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).

1. YOUR BABY'S HEARING

A SURVEY ABOUT THE SCREENING PROCESS

This hospital, the [STATE EHDI PROGRAM] and the Centers for Disease Control and Prevention (CDC), wants to learn more about the hearing screening system for newborns and how well it is working. All women giving birth to a live infant at this hospital this week are being asked to answer the following short survey. Your answers will help us make the hearing screening program better.

The survey is voluntary and will take about 5 minutes to complete. You can skip any question you don't want to answer. The information you provide will be kept strictly private to the extent allowed by law. The care and services you will receive from this hospital will not be affected in any way, whether you decide to answer these questions or not.

We hope that you will complete the survey because the information you provide will help us to better serve mothers like you. We really appreciate your help.

If you have any questions about this study, you can call the study director, Lucia Rojas Smith at 800-334-8571, extension 2053. If you have questions about your rights as a research participant, you can contact the Office of Research Protection at RTI at 1-866-214-2043, a toll-free number

1. **Did you receive any information about newborn hearing testing or hearing loss before you came to the hospital to deliver your baby? *This testing is also referred to as "universal newborn hearing screening" or "infant hearing screening."* (Please check all that apply.)**

- Yes, written information from a childbirth education class
- Yes, written information from my doctor's or clinic's office
- Yes, verbal information from a childbirth education class
- Yes, verbal information from my doctor or clinic staff
- No, I did not receive any of the above information

2. **Have you received any written information about newborn hearing testing or hearing loss since you have been in the hospital to deliver your baby?**

- Yes
- No

3. **Did your baby have a hearing test?**

- Yes
- No ➔ Go to question #12
- I don't know ➔ Go to question #12

4. **Did any hospital staff talk to you about newborn hearing testing before your baby was tested?**

- Yes
- No

5. **Were you informed of the result of the hearing test in person, in writing, or both?**

- In person
- In writing ➔ Go to question #7
- Both in person and in writing
- I have not been informed yet ➔ Go to question #7

6. **Who informed you of your baby's hearing test result? (Please check all that apply.)**

- Doctor
- The person who did the screening test
- Nurse
- Audiologist
- A hospital staff person, but I don't remember his/her title
- Other (please specify) _____

7. Thinking about your experience with the hearing test, please indicate whether you strongly agree, agree, disagree, or strongly disagree with the following three statements. (For each statement, please put a check mark in the box that best fits your answer.)

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. I got all the information I needed about the hearing test	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Hospital staff spent enough time with me explaining the test result	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I understand the meaning of the hearing test result.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. What was the result of your baby's hearing test?

- My baby passed the test → Go to question #12
- My baby did not pass and was referred for more hearing testing
- My baby passed but was referred for more hearing testing
- I have not been informed of the result yet → Go to question #12

If your baby **DID NOT pass** the hearing screening test,
please **go to Question 9** below and continue.

If your baby passed the hearing screening test
please **go to Question 12**.

9. Thinking about your baby's hearing test result, please indicate whether you strongly agree, agree, disagree, or strongly disagree with the following statements. (For each of these items, please put a check mark in the box that best fits your answer.)

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. I believe the test result	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I understand what I need to do next	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I think it is important to retest my baby soon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I am feeling anxious about the hearing test result	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Were you given information about where you can go for a follow-up hearing test? (Please check all that apply.)

- Yes, I was given outpatient hospital clinic location
- Yes, I was given contact information for audiologist(s)
- Yes, I was given contact information for an ear doctor
- Yes, I was told to return to this hospital
- No information was given to me
- I don't remember

11. Did the hospital make a follow-up hearing test appointment for you?

- Yes
- No
- I don't remember

The following questions are about you and your family. This information will help us understand who is answering the survey.

12. How old are you? (Please check the box beside the age category.)

- 19 or younger
- 20–24
- 25–29
- 30–34
- 35 or older

13. Are you Hispanic or Latino?

- Yes
- No

14. Which of the following categories best describes your race? Please select one or more categories.

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian, Alaska Native

15. What language is used in your home most of the time?

- English
- Spanish
- American Sign language
- Other (please specify) _____

16. What is the highest level of school you completed?

- Less than high school
- High school graduate
- Some college/technical school
- College graduate or more

Spanish Version Only

17. Were you provided with any written information explaining newborn hearing testing in Spanish?

- Yes
- No
- I did not need materials in Spanish

18. Did someone explain the result of the hearing test to you in Spanish?

- Yes
- No
- I did not need a translator

Thank you.

APPENDIX B:
VA HOSPITAL DATA

1. Did you receive any information about newborn hearing testing or hearing loss before you came to the hospital to deliver your baby?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Written information from a childbirth education class	9	9.00%	7	6.93%	8	8.16%	5	10.20%	29	8.33%
Written information from my doctor's or clinic's office	12	12.00%	15	14.85%	17	17.35%	3	6.12%	47	13.51%
Verbal information from a childbirth education class	8	8.00%	6	5.94%	2	2.04%	7	14.29%	23	6.61%
Verbal information from my doctor or clinic staff	9	9.00%	28	27.72%	11	11.22%	8	16.33%	56	16.09%
Did not receive any of the above information	71	71.00%	62	61.39%	64	65.31%	28	57.14%	225	64.66%
Total Sample	100	.	101	.	98	.	49	.	348	.
NA	1	.	3	.	5	.	4	.	13	.

[Results will not equal to 100%; more than one response can be checked.]

2. Have you received any written information about newborn hearing testing or hearing loss since you have been in the hospital to deliver your baby?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	60	60.61%	77	79.38%	87	85.29%	30	58.82%	254	72.78%
No	39	39.39%	20	20.62%	15	14.71%	21	41.18%	95	27.22%
Total Sample	99	.	97	.	102	.	51	.	349	.
NA	2	.	7	.	1	.	2	.	12	.

3. Did your baby have a hearing test?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	99	99.00%	102	99.03%	95	100.0%	44	97.78%	340	99.13%
No	1	1.00%	1	0.97%	0	0.00%	1	2.22%	3	0.87%
Total Sample	100	.	103	.	95	.	45	.	343	.
NA	1	.	1	.	8	.	8	.	18	.

4. Did any hospital staff talk to you about newborn hearing testing before your baby was tested?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	56	57.14%	77	77.78%	60	61.86%	31	67.39%	224	65.88%
No	42	42.86%	22	22.22%	37	38.14%	15	32.61%	116	34.12%
Total Sample	98	.	99	.	97	.	46	.	340	.
NA	3	.	5	.	6	.	7	.	21	.

5. Were you informed of the result of the hearing test in person, in writing, or both?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
In person	45	45.45%	78	76.47%	21	21.88%	17	35.42%	161	46.67%
In writing	2	2.02%	2	1.96%	17	17.71%	3	6.25%	24	6.96%
Both	50	50.51%	18	17.65%	41	42.71%	24	50.00%	133	38.55%
Have not been informed yet	2	2.02%	4	3.92%	17	17.71%	4	8.33%	27	7.83%
Total Sample	99	.	102	.	96	.	48	.	345	.
NA	2	.	2	.	7	.	5	.	16	.

6. Who informed you of your baby's hearing test result?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Doctor	2	2.13%	8	8.33%	7	10.94%	3	8.11%	20	6.87%
Person who did the screening test	52	55.32%	35	36.46%	7	10.94%	8	21.62%	102	35.05%
Nurse	38	40.43%	72	75.00%	37	57.81%	22	59.46%	169	58.08%
Audiologist	0	0.00%	2	2.08%	1	1.56%	1	2.70%	4	1.37%
Hospital staff person	13	13.83%	5	5.21%	14	21.88%	4	10.81%	36	12.37%
Other	0	0.00%	0	0.00%	5	7.81%	2	5.41%	7	2.41%
Total Sample	94	.	96	.	64	.	37	.	291	.
NA	7	.	8	.	39	.	16	.	70	.

[Results will not equal to 100%; more than one response can be checked.]

7a. Please indicate whether you got all the information you needed about the hearing test.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	17	17.71%	33	32.67%	26	27.96%	12	27.27%	88	26.35%
Agree	46	47.92%	54	53.47%	42	45.16%	24	54.55%	166	49.70%
Disagree	27	28.13%	12	11.88%	17	18.28%	7	15.91%	63	18.86%
Strongly Disagree	6	6.25%	2	1.98%	8	8.60%	1	2.27%	17	5.09%
Total Sample	96	.	101	.	93	.	44	.	334	.
NA	5	.	3	.	10	.	9	.	27	.

7b. Please indicate whether the hospital staff spent enough time with you explaining the test result.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	15	15.63%	36	36.36%	21	23.33%	12	27.27%	84	25.53%
Agree	49	51.04%	54	54.55%	34	37.78%	24	54.55%	161	48.94%
Disagree	27	28.13%	6	6.06%	19	21.11%	7	15.91%	59	17.93%
Strongly Disagree	5	5.21%	3	3.03%	16	17.78%	1	2.27%	25	7.60%
Total Sample	96	.	99	.	90	.	44	.	329	.
NA	5	.	5	.	13	.	9	.	32	.

7c. Please indicate whether you understand the meaning of the hearing test result.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	26	26.80%	36	36.36%	28	30.77%	11	28.21%	101	30.98%
Agree	54	55.67%	57	57.58%	47	51.65%	26	66.67%	184	56.44%
Disagree	16	16.49%	3	3.03%	6	6.59%	2	5.13%	27	8.28%
Strongly Disagree	1	1.03%	3	3.03%	10	10.99%	0	0.00%	14	4.29%
Total Sample	97	.	99	.	91	.	39	.	326	.
NA	4	.	5	.	12	.	14	.	35	.

8. What was the result of your baby's hearing test?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Passed the test	92	93.88%	81	80.20%	64	67.37%	39	86.67%	276	81.42%
Did not pass and referred	2	2.04%	13	12.87%	5	5.26%	1	2.22%	21	6.19%
Passed but referred	3	3.06%	3	2.97%	5	5.26%	2	4.44%	13	3.83%
Have not been informed yet	1	1.02%	4	3.96%	21	22.11%	3	6.67%	29	8.55%
Total Sample	98	.	101	.	95	.	45	.	339	.
NA	3	.	3	.	8	.	8	.	22	.

9a. Thinking about your baby's hearing test result, please indicate whether you believe the test result.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	0	0.00%	3	20.00%	2	22.22%	2	50.00%	7	21.88%
Agree	3	75.00%	8	53.33%	5	55.56%	1	25.00%	17	53.13%
Disagree	1	25.00%	2	13.33%	2	22.22%	0	0.00%	5	15.63%
Strongly Disagree	0	0.00%	2	13.33%	0	0.00%	1	25.00%	3	9.38%
Total Sample	4	.	15	.	9	.	4	.	32	.
NA	97	.	89	.	94	.	49	.	329	.

9b. Thinking about your baby's hearing test result, please indicate whether you understand what you need to do next.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	0	0.00%	7	50.00%	3	30.00%	2	66.67%	12	38.71%
Agree	4	100.0%	7	50.00%	5	50.00%	1	33.33%	17	54.84%
Disagree	0	0.00%	0	0.00%	1	10.00%	0	0.00%	1	3.23%
Strongly Disagree	0	0.00%	0	0.00%	1	10.00%	0	0.00%	1	3.23%
Total Sample	4	.	14	.	10	.	3	.	31	.
NA	97	.	90	.	93	.	50	.	330	.

9c. Thinking about your baby's hearing test result, please indicate whether you think it is important to retest your baby soon.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	2	50.00%	10	62.50%	5	50.00%	1	50.00%	18	56.25%
Agree	2	50.00%	6	37.50%	5	50.00%	1	50.00%	14	43.75%
Disagree	0	0.00%	0	0.00%	0	0.00%	0	0.00%	0	0.00%
Strongly Disagree	0	0.00%	0	0.00%	0	0.00%	0	0.00%	0	0.00%
Total Sample	4	.	16	.	10	.	2	.	32	.
NA	97	.	88	.	93	.	51	.	329	.

9d. Thinking about your baby's hearing test result, please indicate whether you are feeling anxious about the hearing test result.

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Strongly Agree	0	0.00%	5	35.71%	4	44.44%	1	50.00%	10	34.48%
Agree	2	50.00%	6	42.86%	3	33.33%	0	0.00%	11	37.93%
Disagree	1	25.00%	3	21.43%	2	22.22%	0	0.00%	6	20.69%
Strongly Disagree	1	25.00%	0	0.00%	0	0.00%	1	50.00%	2	6.90%
Total Sample	4	.	14	.	9	.	2	.	29	.
NA	97	.	90	.	94	.	51	.	332	.

10. Were you given information about where you can go for a follow-up hearing test?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes, I was given outpatient hospital clinic location	2	50.00%	6	40.00%	4	40.00%	2	50.00%	14	42.42%
Yes, I was give contact information for an audiologist	0	0.00%	3	20.00%	1	10.00%	1	25.00%	5	15.15%
Yes, given contact information for an ear doctor	0	0.00%	0	0.00%	0	0.00%	1	25.00%	1	3.03%
Yes, told to return to this hospital	0	0.00%	6	40.00%	1	10.00%	0	0.00%	7	21.21%
No information given	2	50.00%	2	13.33%	4	40.00%	0	0.00%	8	24.24%
Total Sample	4	.	15	.	10	.	4	.	33	.
NA	97	.	89	.	93	.	49	.	328	.

[Results will not equal to 100%; more than one response can be checked.]

11. Did the hospital make a follow-up hearing test appointment for you?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	1	25.00%	15	88.24%	2	25.00%	0	0.00%	18	56.25%
No	3	75.00%	2	11.76%	6	75.00%	3	100.0%	14	43.75%
Total Sample	4	.	17	.	8	.	3	.	32	.
NA	97	.	87	.	95	.	50	.	329	.

12. How old are you?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
19 or younger	1	1.04%	15	14.71%	12	11.65%	2	3.92%	30	8.52%
20-24	10	10.42%	38	37.25%	31	30.10%	17	33.33%	96	27.27%
25-29	26	27.08%	26	25.49%	20	19.42%	15	29.41%	87	24.72%
30-34	30	31.25%	14	13.73%	23	22.33%	7	13.73%	74	21.02%
35 or older	29	30.21%	9	8.82%	17	16.50%	10	19.61%	65	18.47%
Total Sample	96	.	102	.	103	.	51	.	352	.
NA	5	.	2	.	0	.	2	.	9	.

13. Are you Hispanic or Latino?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	3	3.13%	12	11.76%	3	2.91%	3	5.88%	21	5.97%
No	93	96.88%	90	88.24%	100	97.09%	48	94.12%	331	94.03%
Total Sample	96	.	102	.	103	.	51	.	352	.
NA	5	.	2	.	0	.	2	.	9	.

14. Which of the following categories best describes your race?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
White	63	66.32%	94	95.92%	32	32.32%	34	70.83%	223	65.59%
Black	24	25.26%	5	5.10%	67	67.68%	13	27.08%	109	32.06%
Asian	10	10.53%	0	0.00%	0	0.00%	1	2.08%	11	3.24%
Hawaiian/ Pacific Islander	0	0.00%	0	0.00%	1	1.01%	0	0.00%	1	0.29%
American Indian/Alaska Native	1	1.05%	0	0.00%	0	0.00%	0	0.00%	1	0.29%
Total Sample	95	.	98	.	99	.	48	.	340	.
NA	6	.	6	.	4	.	5	.	21	.

[Results will not equal to 100%; more than one response can be checked.]

15. What language is used in your home most of the time?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
English	85	88.54%	87	85.29%	102	99.03%	49	96.08%	323	91.76%
Spanish	2	2.08%	13	12.75%	0	0.00%	0	0.00%	15	4.26%
American Sign Language	0	0.00%	0	0.00%	0	0.00%	0	0.00%	0	0.00%
Other	9	9.38%	2	1.96%	1	0.97%	2	3.92%	14	3.98%
Total Sample	96	.	102	.	103	.	51	.	352	.
NA	5	.	2	.	0	.	2	.	9	.

16. What is the highest level of school you completed?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Less than high school	4	4.17%	19	18.63%	15	14.56%	1	1.96%	39	11.08%
High school	9	9.38%	43	42.16%	30	29.13%	10	19.61%	92	26.14%
Some college/technical school	23	23.96%	20	19.61%	34	33.01%	20	39.22%	97	27.56%
College or more	60	62.50%	20	19.61%	24	23.30%	20	39.22%	124	35.23%
Total Sample	96	.	102	.	103	.	51	.	352	.
NA	5	.	2	.	0	.	2	.	9	.

17. Were you provided written information on the hearing test in Spanish?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	1	50.00%	7	70.00%	0	.	0	.	8	66.67%
No	1	50.00%	3	30.00%	0	.	0	.	4	33.33%
Total Sample	2	.	10	.	0	.	0	.	12	.
Did not need materials in Spanish	99	.	94	.	103	.	53	.	349	.

18. Did someone explain the test results in Spanish?

	Hospital A		Hospital B		Hospital C		Hospital D		Total Sample	
	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
Yes	1	50.00%	4	44.44%	0	.	0	.	5	45.45%
No	1	50.00%	5	55.56%	0	.	0	.	6	54.55%
Total Sample	2	.	9	.	0	.	0	.	11	.
Did not need a translator	99	.	95	.	103	.	53	.	350	.

**APPENDIX C:
CATI INTERVIEW INSTRUMENT**

Public reporting burden of this collection of information is estimated to average 18 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).

Early Hearing Detection & Intervention (EHDI) Potential Survey Items—CATI ITEMS ONLY

Introduction

May I please speak to _____.

Yes, this is she. → *continue*

No → when would be a more convenient time for me to call?

RECORD TIME

I'm [NAME] calling from the Research Triangle Institute on behalf of the Centers for Disease Control and Prevention. You should have received a letter from the STATE Department of Health about ___ weeks ago describing the study and letting you know that we would be calling.

I would like to tell you a little more about the study now.

Verbal Consent

The [State EHDI Program] and the Centers for Disease Control and Prevention (CDC) want to learn more about the hearing screening system in [STATE]. So, they have asked RTI International, a non-profit research center, to survey parents like you about their experience with the hearing screening system. You have been selected for this study because your infant received a hearing screening test in the past year.

The information obtained from your participation in this study will assist the [State EHDI Program] and CDC to develop a better hearing screening system for all newborns, as well as for children with hearing loss.

Your participation is voluntary. All your answers will be kept private to the extent allowed by law. None of your answers will be linked to you by your name or your child. If any of the questions make you uncomfortable or you don't know the answers, you don't have to answer them. You can also stop at any time. Your decision to participate or not to participate will not affect your healthcare or that of your child. The survey will only take about 20 minutes, on average, but the exact time depends on your answers. [Upon completion of the survey, RTI will send you a \$10 gift card to thank you for your participation.]

If you have any questions about the study, I can give you some numbers to call. Would you like those numbers?

Yes → If you have any questions about the study you can call the study director, Dr. Lucia Rojas Smith, at 800-334-8571, extension 2053. If you have questions about this study or your rights as a research participant, you can contact the Office of Research Protection at RTI at 1-866-214-2043, a toll-free number.

No→Continue to Screener

Screener

Let's get started. I will be asking you questions about *your baby*. (If you had twins or more, then please think about the experience of the youngest child before answering each question.)

S1. Did your baby have his or her hearing tested? This test is also referred to as "universal newborn hearing screening" or "infant hearing screening."

Yes
No – EARLY EXIT B

REF #	PROPOSED ITEM
WARM-UP	
1	Did you have a boy or a girl? <i>[Do not read]</i> Boy Girl

REF #	PROPOSED ITEM
2	<p>Is [he/she] your first child?</p> <p><i>[Do not read]</i> Yes No</p>
3	<p>Was your baby in a special unit or NICU?</p> <p>Yes No</p> <p>[If asked: A NICU is a neonatal intensive care unit or special unit for babies that are born early.]</p>
4	<p>I wanted to start out by asking, Did you receive written information about newborn hearing testing before you went to the hospital to have your baby or after your were already admitted to the hospital?</p> <p>Before you went to the hospital to have baby After you were admitted to the hospital Didn't receive any information → SKIP to 6 DK</p>
5	<p>How well did you understand the written materials given to you? Would you say,</p> <p>You understood all the material You understood some of the material but not all of it You did not understand the material all that well</p> <p><i>[Do not read]</i> You haven't read the materials yet</p>
<p>SCREENING PRACTICES AND PROCEDURES</p> <p>The next set of questions will be about your baby's first hearing test. This is the hearing screening test that is usually done before the baby is discharged from the hospital.</p>	
6	<p>Did your baby have [his/her] hearing tested before or after [he/she] was discharged from the hospital?</p> <p>Before baby was discharged from the hospital After baby was discharged from the hospital → Go to 8 DK → Go to 8</p>

REF #	PROPOSED ITEM
7	<p>Were you informed of the result of the hearing test before your baby left the hospital?</p> <p>Yes No DK</p>
8	<p>What was the result of your baby's hearing test?</p> <p>[Do not read unless necessary] your baby passed → Go to Early Exit B your baby did not pass and was referred for more testing your baby passed but was referred for more testing You have not been informed of the result yet → Go to Early Exit A You don't remember → Go to Early Exit A</p>
9	<p>Who informed you of your baby's hearing test result?</p> <p>[Interviewer: Please check all that apply]</p> <p>Doctor The person who did the screening test Nurse Audiologist A hospital staff person, but I don't remember his/her title Other (please specify) _____</p>
10	<p>Were you informed of the result of the hearing test in person, in writing, or both?</p> <p>In person In writing (e.g., card or note) Both</p>
11	<p>Thinking about your baby's hearing test, please tell me whether you strongly agree, agree, disagree, or strongly disagree with the following statements:</p> <p style="text-align: center;">Strongly agree — Agree — Disagree — Strongly disagree</p> <p>You understood what the hearing test result meant You believed the test result You got all the information you needed about the hearing test Hospital staff spent enough time with you explaining the test result You understood what you needed to do next You were anxious about the hearing test result</p>

REF #	PROPOSED ITEM
CULTURAL COMPETENCY – SPANISH VERSION ONLY	
Span-1	<p>Were you provided with any written information explaining newborn hearing testing in Spanish?</p> <p>Yes No</p>
Span-2	<p>Did someone explain the result of the hearing test to you in Spanish?</p> <p>Yes No I did not need a translator</p>
MATERNAL KAP	
12	<p>I'm going to read you several statements that describe what many parents think when they receive their baby's test result. Please tell me whether you strongly agree, agree, disagree, or strongly disagree:</p> <p style="text-align: center;">Strongly agree — Agree — Disagree — Strongly disagree</p> <p>Your baby: has a hearing loss only has difficulty hearing soft or high pitch sounds because he/she responds to loud sounds has fluid in the ears and it's nothing to worry about should get another test is probably ok but there was a problem with the testing</p> <p>[Do not read] DK</p>
13	<p>I am going to read you three statements about infant care. Please tell me whether you strongly agree, agree, disagree, or strongly disagree with the statement:</p> <p style="text-align: center;">Strongly agree — Agree — Disagree — Strongly disagree</p> <p>It is important for a baby to get all recommended immunizations on schedule It is important for a baby to get all well-baby check-ups at the recommended time It is important to find out whether a child has hearing loss as soon as possible</p> <p>[Do not read] DK</p>

REF #	PROPOSED ITEM
<p>REFERRAL AND FOLLOW-UP PRACTICES AND PROCEDURES</p> <p>The questions you just answered were about your baby's first hearing test. The next set of questions have to do with any follow-up testing your baby received. Follow-up testing is also called a re-screen.</p>	
<p>14</p>	<p>Who explained to you what would happen at the follow-up testing?</p> <p>Audiologist Doctor You received a letter</p> <p>[Do not read] Other (please specify) _____ I don't remember No one explained what would happen</p>
<p>15</p>	<p>How did you know where to go for follow-up testing?</p> <p>[Read]</p> <p>The hospital or doctor's office made the appointment You were given a list of places to call You found out where to go on your own</p> <p>[Do not read] You don't remember You didn't find out where to go</p>
<p>16</p>	<p>Did anyone do any of the following for you:</p> <p>Call you to make or remind you of an appointment Send a letter or postcard to make or remind you of an appointment Contact you to reschedule your missed appointment Offer any help like a ride or child care to get you to the appointment</p> <p>Yes No I don't remember</p> <p>If yes to help: What kind of help were you offered?</p>

REF #	PROPOSED ITEM
17	<p>Where was the appointment?</p> <p>Do not read:</p> <p>At the hospital where the baby was born At another hospital At a hearing clinic At a public health clinic or health department At the doctor’s office Other (specify) _____ I don’t remember No appointment was ever made→Go to #19</p>
18	<p>Did you go to your appointment?</p> <p>Yes No</p>
19	<p>I’m going to read a list of common reasons why parents do not get follow-up testing for their child. Please tell me if you any experienced any of the following:</p> <p>You didn’t know where to go for the tests You called to make an appointment but could not get through to a real person The person I talked to asked me questions I didn’t have the answers to You couldn’t get a convenient appointment time The location for the follow-up testing is too far away You forgot about the appointment</p> <p>You believe your baby’s hearing is fine Your family told you to wait or not worry Your doctor told you to wait or not worry Your baby has other more serious health problems</p> <p>The tests are too expensive You don’t have a good way to get there You don’t have anyone to take care of your other children</p> <p>Or is there another reason why you didn’t get your baby tested again? (specify) _____</p> <p>IF ANSWERED “NO APPOINTMENT MADE” #17 OR “NO” #18 →Go to Basic Demographics</p>

REF #	PROPOSED ITEM
WAITING TIMES (FOR RETEST)	
Okay, I just want to let you know that we are more than halfway through. Your answers will help us a lot so please bear with me.	
20	<p>Did you schedule an appointment within 2 weeks after you left the hospital?</p> <p>Yes No</p> <p>If no, did you schedule an appointment within 1 month after you left the hospital?</p> <p>Yes No</p>
21	<p>Did you get the results of the follow-up testing on the same day of the testing?</p> <p>Yes No</p> <p>If no, then did you get the results within 1 week of the follow-up testing?</p> <p>Yes No</p>
22	<p>What was the result of your baby's follow-up testing?</p> <p>Passed → Go Basic Demographics Did not pass</p>
23	<p>Have you gone for further testing?</p> <p>Yes No I have an appointment scheduled</p>

REF #	PROPOSED ITEM
24	<p>I'm going to read a list of common reasons why parents do not get diagnostic testing for their child. Please tell me if you any experienced any of the following:</p> <p>You didn't know where to go for the tests You called to make an appointment but could not get through to a real person The person you talked to asked you questions you didn't have the answers to You couldn't get a convenient appointment time The location for the follow-up testing is too far away You forgot about the appointment</p> <p>You believe your baby's hearing is fine Your family told you to wait or not worry Your doctor told you to wait or not worry Your baby has other more serious health problems</p> <p>The tests are too expensive You don't have a good way to get there You don't have anyone to take care of your other children</p> <p>Or is there another reason why you didn't get your baby tested again? (specify) _____</p> <p>IF ANSWERED "NO" OR "HAVE AN APPOINTMENT SCHEDULED" #23→Go to Basic Demographics</p>
25	<p>Does your baby have a diagnosed hearing loss, meaning that a hearing specialist told you the baby definitely has a hearing loss?</p> <p>Yes No→Go to Maternal KAP your baby is still being tested→Go to Maternal KAP</p>
FAMILY SUPPORT – ASK ONLY FOR MOTHERS WHOSE CHILDREN HAVE HEARING LOSS	
26	<p>Did someone put you in contact with another family with a child with a hearing loss to whom you can turn to for support or advice?</p> <p>Yes No DK Refused</p> <p>b. If yes, have you contacted the family?</p> <p>Yes No</p>

REF #	PROPOSED ITEM
27	<p>How helpful has it been or would it be for you to have another family(ies) to talk to? Would you say it has been or would be...</p> <p>Very helpful Somewhat helpful Not helpful at all DK Refused</p>
MOTHERS KAP	
28	<p>How helpful do you think it is to begin intervention for hearing loss before 1 year of age? Would you say it is...</p> <p>Very helpful Somewhat helpful Not at all helpful DK Refused</p>
29	<p>How anxious are/were you about the effects of a possible hearing loss?</p> <p>Not at all anxious Somewhat anxious Anxious Very anxious DK Refused</p>
BASIC DEMOGRAPHICS	
<p>The questions I will ask you now don't have anything to do with newborn testing. They are questions about you and your family. We collect this type of information so we can understand better the types of people who are answering this survey.</p>	
30	<p>Does your child currently have a chronic health condition that requires ongoing medical care?</p> <p>Yes No DK Refused</p>
31	<p>Do you have a person you think of as your personal doctor or health care provider for your baby?</p> <p>Yes, only one More than one No Don't know/not sure Refused</p>

REF #	PROPOSED ITEM
32	<p>How were your baby's medical expenses paid?</p> <p>Private insurance coverage or HMO Medicaid or [INSERT STATE-SPECIFIC CHIP PROGRAM NAME HERE] Self Pay Other ____ [specify] Don't know</p> <p>[Utility: good demographic/background question]</p>
33	<p>How old are you?</p> <p>19 or younger 20 - 24 25 - 29 30 - 34 35 or older</p>
34	<p>Are you Hispanic or Latino?</p> <p>Yes No</p>
35	<p>Which of the following categories best describes your race? Please select one or more categories.</p> <p>White Black or African American Asian Native Hawaiian or Other Pacific Islander American Indian, Alaska Native Don't know/Not sure</p>
36	<p>What is the highest level of school you completed?</p> <p>Less than high school High school graduate Some college/technical College graduate or more</p>

REF #	PROPOSED ITEM
37	<p>a. Are you currently...</p> <p>Married Divorced Widowed Separated Never married</p> <p>[Do not read] Refused</p> <p>b. <u>If never married</u>, "Do you live with a companion or partner?" Yes No</p>
38	How many children are in your family?
39	<p>Do you have friends or family who can help you with your baby?</p> <p>Yes No</p>
40	<p>Is there anyone else in your family who was deaf or hard of hearing before the age of 12?</p> <p>Yes No</p>
41	<p>What is the primary language used in your home?</p> <p>English Spanish American Sign language Other, specify _____</p>
42	<p>What was your total household income from all sources in 2005?</p> <p>Was it less than \$35,000? Yes No</p> <p><u>If yes</u>, was it less than \$20,000? Yes No</p> <p><u>If no</u>, was it less than \$50,000? Yes No</p>

REF #	PROPOSED ITEM
WRAP-UP	
43	Is there anything that really has helped you get through the follow-up process?
44	Is there anything that made the follow-up process difficult?
EXIT	
	<p>We are finished with the survey. On behalf of CDC, the [State EHDI] and RTI International I'd like to thank you very much for participating in our study.</p> <p>Do you have any questions about the study?</p> <p>Before I go, just let me verify your address so we can send your gift card [Verify Address].</p> <p>Again thank you for participating our study and have a nice day.</p>
EARLY EXIT	
A	<p>I'm sorry you are not eligible to participate in this survey. This survey is interested in learning more about infants who we know failed their first hearing test. Before you go, could I ask you some basic demographic questions that would help us with our study?</p> <p>No→ Just let me verify your address so we can send your gift card [Verify Address]. Thanks for your interest in our study and have a nice day.</p> <p>Yes→ go to Basic Demographics</p>
B	<p>I'm sorry you are not eligible to participate in this survey. This survey is interested in learning more about infants who failed their first hearing test. Before you go, would you give us permission to have the state EHDI office check the results of the baby's hearing test?</p> <p>No→All right that's ok but if you have any questions about your baby's test later, here's the contact information:</p> <p>Yes→Ok, someone from the State EHDI office will be in touch with you in the next few weeks with more information about your baby's hearing test.</p> <p>Could we ask you some basic demographic questions that would help us with our study?</p> <p>No→Just let me verify your address so we can send your gift card [Verify Address]. Thanks for your interest in our study and have a nice day.</p> <p>Yes→ go to Basic Demographics</p>

APPENDIX D:
VA CATI DATA

Early Hearing Detection Virginia Intervention (EHDI) CATI Survey Results

WARM UP

1. Did you have a boy or a girl?

	Virginia	
	Number	Percentage
Boy	117	59.39%
Girl	80	40.61%
Total Sample	197	
N/A	1	

2. Is [he/she] your first child?

	Virginia	
	Number	Percentage
Yes	89	45.18%
No	108	54.82%
Total Sample	197	
N/A	1	

3. Was your baby in a special unit or NICU?

	Virginia	
	Number	Percentage
Yes	28	14.21%
No	169	85.79%
Total Sample	197	
N/A	1	

4. Did you receive written information about newborn testing before you went to the hospital to have your baby or after you were already admitted to the hospital?

	Virginia	
	Number	Percentage
Before you went to the hospital to have a baby	22	11.58%
After you were admitted to the hospital	157	82.63%
Didn't receive any information SKIP to 6	11	5.79%
Total Sample	190	
N/A	8	

5. How well did you understand the written materials given to you?

	Virginia	
	Number	Percentage
You understood all the materials	129	72.88%
You understood some of the material, but not all of it	31	17.51%
You did not understand the materials all that well	7	3.95%
You haven't read the materials yet	10	5.65%
Total Sample	177	
N/A	21	

SCREENING PRACTICES AND PROCEDURES

6. Did your baby have [his/her] hearing tested before or after [he/she] was discharged from the hospital?

	Virginia	
	Number	Percentage
Before baby was discharged from hospital	188	95.43%
After baby was discharged from hospital <input type="checkbox"/> SKIP to 8	9	4.57%
Total Sample	197	
N/A	1	

7. Were you informed of the result of the hearing test before your baby left the hospital?

	Virginia	
	Number	Percentage
Yes	181	97.31%
No	5	2.69%
Total Sample	186	
N/A	12	

8. What was the result of your baby's hearing test?

	Virginia	
	Number	Percentage
Your baby passes <input type="checkbox"/> SKIP to Early Exit B	7	3.55%
Your baby did not pass and was referred for more testing	176	89.34%
Your baby passed but was referred for more testing	14	7.11%
You have not been informed of the result yet <input type="checkbox"/> SKIP to Early Exit A	0	0.00%
Total Sample	197	
N/A	1	

9. Who informed you of your baby's hearing test result?

	Virginia	
	Number	Percentage
Doctor	55	27.78%
The person who did the screening test	71	35.86%
Nurse	74	37.37%
Audiologist	7	3.54%
A hospital staff person, but I don't remember their title	7	3.54%
Other, specified	12	6.06%
Total Sample	185	
N/A	13	

(Results will not equal 100%; more than one response may be marked)

10. Were you informed of the results of the hearing test in person, in writing, or both?

	Virginia	
	Number	Percentage
In person	61	32.11%
In writing	5	2.63%
Both	124	65.26%
Total Sample	190	
N/A	8	

CULTURAL COMPETENCY-SPANISH VERSION ONLY

Span-1 (Spanish version only) Were you provided with any written information explaining newborn hearing testing in Spanish?

	Virginia	
	Number	Percentage
Yes	22	81.48%
No	5	18.52%
Total Sample	27	
N/A	171	

Span-2 (Spanish version only) Did someone explain the result of the hearing tests to you in Spanish?

	Virginia	
	Number	Percentage
Yes	12	44.44%
No	10	37.04%
I did not need a translator	5	18.52%
Total Sample	27	
N/A	171	

11. Thinking about your baby's hearing test, please tell me whether you strongly agree, agree, disagree, or strongly disagree with the following statements:

You understood what the hearing test result meant

	Virginia	
	Number	Percentage
Strongly Agree	67	35.26%
Agree	102	53.68%
Disagree	17	8.95%
Strongly Disagree	4	2.11%
Total Sample	190	
N/A	8	

You believed the test result

	Virginia	
	Number	Percentage
Strongly Agree	57	30.48%
Agree	100	53.48%
Disagree	22	11.76%
Strongly Disagree	8	4.28%
Total Sample	187	
N/A	11	

You got all the information you needed about the hearing test

	Virginia	
	Number	Percentage
Strongly Agree	57	30.16%
Agree	112	59.26%
Disagree	17	8.99%
Strongly Disagree	3	1.59%
Total Sample	189	
N/A	9	

The hospital staff spent enough time with you explaining the hearing test result

	Virginia	
	Number	Percentage
Strongly Agree	50	26.74%
Agree	102	54.55%
Disagree	27	14.44%
Strongly Disagree	8	4.28%
Total Sample	187	
N/A	11	

You understood what you needed to do next

	Virginia	
	Number	Percentage
Strongly Agree	68	35.98%
Agree	108	57.14%
Disagree	12	6.35%
Strongly Disagree	1	0.53%
Total Sample	189	
N/A	9	

You were anxious about the hearing test result

	Virginia	
	Number	Percentage
Strongly Agree	66	35.11%
Agree	95	50.53%
Disagree	23	12.23%
Strongly Disagree	4	2.13%
Total Sample	188	
N/A	10	

MATERNAL KAP

12. I'm going to read you several statements that describe what many parents think when they receive their baby's test result. Please tell me whether you strongly agree, agree, disagree, or strongly disagree: Your baby:

Has a hearing loss

	Virginia	
	Number	Percentage
Strongly Agree	19	10.11%
Agree	30	15.96%
Disagree	81	43.09%
Strongly Disagree	58	30.85%
Total Sample	188	
N/A	10	

Only has difficulty hearing soft or high pitch sounds because he/she responds to loud sounds

	Virginia	
	Number	Percentage
Strongly Agree	8	4.55%
Agree	36	20.45%
Disagree	85	48.30%
Strongly Disagree	47	26.70%
Total Sample	176	
N/A	22	

Has fluid in the ears and it's nothing to worry about

	Virginia	
	Number	Percentage
Strongly Agree	32	17.11%
Agree	56	29.95%
Disagree	71	37.97%
Strongly Disagree	28	14.97%
Total Sample	187	
N/A	11	

Should get another test

	Virginia	
	Number	Percentage
Strongly Agree	57	30.32%
Agree	76	40.43%
Disagree	38	20.21%
Strongly Disagree	17	9.04%
Total Sample	188	
N/A	10	

Is probably ok but there was a problem with the testing

	Virginia	
	Number	Percentage
Strongly Agree	23	12.64%
Agree	65	35.71%
Disagree	78	42.86%
Strongly Disagree	16	8.79%
Total Sample	182	
N/A	16	

13. I am going to read you 3 statements about infant care. Please tell me whether you strongly agree, agree, disagree, or strongly disagree with the statement:

It is important for a baby to get all recommended immunizations on schedule

	Virginia	
	Number	Percentage
Strongly Agree	123	64.74%
Agree	61	32.11%
Disagree	4	2.11%
Strongly Disagree	2	1.05%
Total Sample	190	
N/A	8	

It is important for a baby to get all well-baby check-ups at the recommended time

	Virginia	
	Number	Percentage
Strongly Agree	134	70.53%
Agree	56	29.47%
Disagree	0	0.00%
Strongly Disagree	0	0.00%
Total Sample	190	
N/A	8	

It is important to find out whether a child has hearing loss as soon as possible

	Virginia	
	Number	Percentage
Strongly Agree	138	72.63%
Agree	50	26.32%
Disagree	2	1.05%
Strongly Disagree	0	0.00%
Total Sample	190	
N/A	8	

REFERRAL AND FOLLOW-UP PRACTICES AND PROCEDURES**14. Who explained to you what would happen at the follow-up testing?**

	Virginia	
	Number	Percentage
Audiologist	49	26.49%
Doctor	37	20.00%
You received a letter	30	16.22%
Other	37	20.00%
No one explained what would happen	32	17.30%
Total Sample	185	
N/A	13	

15. How did you know where to go for follow up testing?

	Virginia	
	Number	Percentage
The hospital or doctor's office made the appointment	116	61.38%
You were given a list of places to call	59	31.22%
You found out where to go on your own	12	6.35%
You didn't find out where to go	2	1.06%
Total Sample	189	
N/A	9	

16. Did anyone do any of the following for you?**Call you to make or remind you of an appointment**

	Virginia	
	Number	Percentage
Yes	83	45.36%
No	100	54.64%
Total Sample	183	
N/A	15	

Send a letter or post-card to make or remind you of an appointment

	Virginia	
	Number	Percentage
Yes	86	45.99%
No	101	54.01%
Total Sample	187	
N/A	11	

Contact you to reschedule your missed appointment

	Virginia	
	Number	Percentage
Yes	21	11.05%
No	169	88.95%
Total Sample	190	
N/A	8	

Offer any help like a ride or child care to get you to the appointment

	Virginia	
	Number	Percentage
Yes (If yes to help: What kind of help were you offered?)	16	8.47%
No	173	91.53%
Total Sample	189	
N/A	9	

17. Where was the appointment?

	Virginia	
	Number	Percentage
At the hospital where the baby was born	78	41.27%
At another hospital	38	20.11%
At a hearing clinic	34	17.99%
At a public health clinic or health department	3	1.59%
At the doctors office	22	11.64%
Other (specify)	10	5.29%
No appointment was ever made SKIP to #19	4	2.12%
Total Sample	189	
N/A	9	

18. Did you go to your appointment?

	Virginia	
	Number	Percentage
Yes	179	96.24%
No	7	3.76%
Total Sample	186	
N/A	12	

19. I'm going to read a list of common reasons why parents do not get follow up testing for their child. Please tell me if you experienced any of the following:

	Virginia	
	Number	Percentage
You didn't know where to go for the tests	1	0.51%
You called to make an appointment and could not get through to a real person	4	2.02%
The person I talked to asked me questions I didn't have the answers to	0	0.00%
You didn't get a convenient appointment time	1	0.51%
The location for the follow up testing is too far away	1	0.51%
You forgot about the appointment	1	0.51%
You believe you baby's hearing is fine	6	3.03%
Your family told you to wait or not to worry	1	0.51%
Your doctor told you to wait or not to worry	3	1.52%
You baby has other more serious health problems	1	0.51%
The tests were too expensive	1	0.51%
You don't have a good way to get there	2	1.01%
You don't have anyone to take care of your other children	1	0.51%
Or, is there another reason you didn't get your child tested again?	3	1.52%
Total Sample	11	
N/A	187	

(Results will not equal 100%; more than one response may be marked)

If answered **No Appointment Made (#17)** or **No (#18)** Go to Basic Demographics (#30)

WAITING TIMES (FOR RETEST)

20. Did you schedule an appointment within 2 weeks after you left the hospital?

	Virginia	
	Number	Percentage
Yes	122	68.93%
No	55	31.07%
Total Sample	177	
N/A	21	

If **no**, did you schedule an appointment within 1 month after you left the hospital?

	Virginia	
	Number	Percentage
Yes	30	53.57%
No	26	46.43%
Total Sample	56	
N/A	142	

21. Did you get the results of the follow up testing the same day of testing?

	Virginia	
	Number	Percentage
Yes	161	90.45%
No	17	9.55%
Total Sample	178	
N/A	20	

If **no**, did you get the results within one week of the follow-up testing?

	Virginia	
	Number	Percentage
Yes	13	76.47%
No	4	23.53%
Total Sample	17	
N/A	181	

22. What was the result of your baby’s follow-up testing?

	Virginia	
	Number	Percentage
Passed Go to basic demographics (#30)	145	81.92%
Did not pass	32	18.08%
Total Sample	177	
N/A	21	

23. Have you gone for further testing?

	Virginia	
	Number	Percentage
Yes	29	90.63%
No	2	6.25%
I have an appointment schedules	1	3.13%
Total Sample	32	
N/A	166	

24. I’m going to read a list of common reasons why parents did not get diagnostic testing for their child. Please tell me if you experience any of these:

	Virginia	
	Number	Percentage
You didn’t know where to go for the tests	0	0.00%
You called to make an appointment and could not get through to a real person	0	0.00%
The person I talked to asked me questions I didn’t have the answers to	0	0.00%
You didn’t get a convenient appointment time	0	0.00%
The location for the follow up testing is too far away	0	0.00%
You forgot about the appointment	0	0.00%
You believe you baby’s hearing is fine	0	0.00%
Your family told you to wait or not to worry	0	0.00%
Your doctor told you to wait or not to worry	1	0.51%
You baby has other more serious health problems	1	0.51%
The tests were too expensive	0	0.00%
You don’t have a good way to get there	0	0.00%
You don’t have anyone to take care of your other children	0	0.00%
Or, is there another reason you didn’t get your child tested again?	1	0.51%
Total Sample	2	
N/A	196	

(Results will not equal 100%; more than one response may be marked)

If answered **No Appointment or Have an Appointment Scheduled #23** Go to Basic Demographics (#30)

25. Does your baby have diagnosed hearing loss meaning that a hearing specialist told you the baby definitely has a hearing loss?

	Virginia	
	Number	Percentage
Yes	12	40.00%
No SKIP to Maternal KAP #28	12	40.00%
Your baby is still being tested SKIP to Maternal KAP #28	6	20.00%
Total Sample	30	
N/A	168	

FAMILY SUPPORT

26. Did someone put you in contact with another family with a child with a hearing loss to whom you can turn to for support and advice?

	Virginia	
	Number	Percentage
Yes	2	16.67%
No	10	83.33%
Total Sample	12	
N/A	186	

If yes, have you contacted the family?

	Virginia	
	Number	Percentage
Yes	1	50.00%
No	1	50.00%
Total Sample	2	
N/A	196	

27. How helpful has it been or would it be for you to have another family(ies) to talk to? Would you say it has been or would be...

	Virginia	
	Number	Percentage
Very helpful	4	33.33%
Somewhat helpful	5	41.67%
Not helpful at all	3	25.00%
Total Sample	12	
N/A	186	

28. How helpful do you think it is to begin intervention for hearing loss before one year of age? Would you say it is...

	Virginia	
	Number	Percentage
Very helpful	22	75.86%
Somewhat helpful	7	24.14%
Not helpful at all	0	0.00%
Total Sample	29	
N/A	169	

29. How anxious are/were you about the effects of a possible hearing loss?

	Virginia	
	Number	Percentage
Not at all anxious	6	20.69%
Somewhat anxious	7	24.14%
Anxious	3	10.34%
Very anxious	13	44.83%
Total Sample	29	
N/A	169	

BASIC DEMOGRAPHICS

30. Does your child currently have a chronic health condition that requires on-going medical care?

	Virginia	
	Number	Percentage
Yes	23	11.62%
No	175	88.38%
Total Sample	198	
N/A	0	

31. Do you have a person you think of as your personal doctor or health care provider for your baby?

	Virginia	
	Number	Percentage
Yes, only one	124	62.63%
More than one	63	31.82%
No	11	5.56%
Total Sample	198	
N/A	0	

32. How were your baby's medical expenses paid?

	Virginia	
	Number	Percentage
Private insurance coverage or HMO	102	51.52%
Medicaid or state specific CHIP program	65	32.83%
Self pay	5	2.53%
Other, specify	26	13.13%
DK		
Total Sample	198	
N/A	0	

33. How old are you?

	Virginia	
	Number	Percentage
19 or younger	5	2.53%
20-24	45	22.73%
25-29	49	24.75%
30-34	49	24.75%
35 or older	50	25.25%
Total Sample	198	
N/A	0	

34. Are you Hispanic or Latino?

	Virginia	
	Number	Percentage
Yes	43	21.94%
No	153	78.06%
Total Sample	196	
N/A	2	

35. Which of the following categories best described your race? Please select one or more of the categories.

	Virginia	
	Number	Percentage
White	130	65.66%
Black or African American	37	18.69%
Asian	7	3.54%
Native Hawaiian or Other Pacific Islander	4	2.02%
American Indian, Alaskan Native	4	2.02%
DK, not sure		
Total Sample	178	
N/A	20	

(Results will not equal 100%; more than one response may be marked)

36. What is the highest level of school you completed?

	Virginia	
	Number	Percentage
Less than high school	25	12.63%
High school graduate	46	23.23%
Some college/technical	60	30.30%
College graduate or more	67	33.84%
Total Sample	198	
N/A	0	

37. Are you currently...

	Virginia	
	Number	Percentage
Married	139	70.20%
Divorced	4	2.02%
Widowed	0	0.00%
Separated	6	3.03%
Never Married	49	24.75%
Total Sample	198	
N/A	0	

If never married, do you live with a companion or partner?

	Virginia	
	Number	Percentage
Yes	27	45.76%
No	32	54.24%
Total Sample	59	
N/A	139	

38. How many children are in your family?

	Virginia	
	Number	Percentage
1	79	40.10%
2	67	34.01%
3	32	16.24%
4	5	2.54%
≥5	14	7.11%
Total Sample	197	
N/A	1	

39. Do you have friends or family who can help with your baby?

	Virginia	
	Number	Percentage
Yes	171	86.36%
No	27	13.64%
Total Sample	198	
N/A	0	

40. Is there anyone else in your family who was deaf or hard of hearing before the age of 12?

	Virginia	
	Number	Percentage
Yes	13	6.63%
No	183	93.37%
Total Sample	196	
N/A	2	

41. What is the primary language in your home?

	Virginia	
	Number	Percentage
English	160	80.81%
Spanish	36	18.18%
American Sign Language	0	0.00%
Other, specify	2	1.01%
Total Sample	198	
N/A	0	

42. What was the total household income from all sources in 2005?

Was it less than \$35,000?

	Virginia	
	Number	Percentage
Yes	82	44.57%
No	102	55.43%
Total Sample	184	
N/A	14	

If yes, was it less than \$20,000?

	Virginia	
	Number	Percentage
Yes	34	44.16%
No	43	55.84%
Total Sample	77	
N/A	121	

If no, was it less than \$50,000?

	Virginia	
	Number	Percentage
Yes	22	21.36%
No	81	78.64%
Total Sample	103	
N/A	95	