

Institute of Government
University of Arkansas at Little Rock

Outreach Activities regarding
Infants Lost to Follow-up Hearing Testing

A Study of Selected Arkansas Counties

Conducted for the Infant Hearing Program
Arkansas Department of Health

November 2008

Executive Summary

A greater-than-desired percentage of newborn infants who are not retested after failing the initial hearing screen drives the request for this study. The Infant Screening Program of the Arkansas Department of Health contracted with the UALR Institute of Government to study one aspect of this problem; namely the performance of birthing hospitals in a selected number of Arkansas counties.

Although the primary responsibility for having infants retested appears to lie with parents, birthing hospitals can play an important role in encouraging such follow-up. Using telephone and in-person interviews and asking both closed and open-ended questions, Institute staff members collected valuable information about the practices of nurses and nursing administrators in hospital nurseries. Based on these data, we proposed seven categories of recommendations intended to improve the chances that infants who fail hearing tests not be lost to follow-up. Given the critical importance of testing and long-term negative impacts to those who are not diagnosed early enough to benefit from various interventions, closely examining each step in the testing process is vital.

Practices in 18 hospitals throughout the state were studied to determine what could be done to improve the lost-to-follow-up rate and to share strategies that seem to work. Care was taken to study a wide array of hospitals. We sought diversity in terms of size and number of births, as well as the makeup of their service area populations, specifically regarding poverty, race, and rural-urban nature. A majority of those hospitals studied (11 of 18) exceeds state standards for hearing failure. Similarly, lost-to-follow-up rates are unacceptably high.

In general, our findings are that the staff of hospital nurseries we interviewed are performing well and regularly go beyond standard protocol in an effort to assure that parents bring their infants back for retesting. Most indicated that they test several times during the short hospital stay of mother and infant until they are reasonably sure that they have an accurate reading of the baby's hearing ability. Discharge nurses are reliable in their briefings of parents as they exit the hospital. Further, most schedule an appointment for the infant to return for further testing. A few respondents make follow-up phone calls to encourage families to have their infants retested. Beyond this point, further follow-up is not feasible.

Many of the interviewees expressed frustration that they are unable to have a stronger effect on the lost-to-follow-up results. They reported a variety of impediments that they feel keep parents from following-through on a negative test

result. Failure to keep appointments, lack of adequate transportation, a lack of communication and understanding by parents, and the negative influence on parents by the extended family, are all reasons for a higher-than-acceptable retesting rate. The small number and mal-distribution of audiologists in the state likely contribute to a failure to retest.

Based on this study, seven categories of recommendations are forthcoming:

- (1) Parents, physicians, and the birthing hospital must share the responsibility.
- (2) Care providers and parents should examine and improve communications to increase the likelihood that an infant will be returned for retesting.
- (3) Education of parents must be emphasized.
- (4) Better reporting by hospitals and information-sharing by ADH is necessary.
- (5) The Arkansas Department of Health should work with care providers to improve services.
- (6) Hearing testing equipment must be available and in functioning order.
- (7) Further research should include attention to the roles of family care physicians, audiologists and ENTs, and parents.

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Study of Outreach Activities Regarding Infants Lost-to-Follow-up in a Selected Number of Arkansas Counties

Introduction

In response to a request by the Infant Hearing Program of the Arkansas Department of Health, the UALR Institute of Government conducted a three-month study in 2008 of local and state service providers in 18 hospitals and their efforts to ensure the testing of all infants for hearing loss and follow-up for those infants who do not pass the hearing screen. The focus was on primarily infant hearing program (IHP) administrators, nursery nurses, and others who conduct and report initial and follow-up hearing tests.

The concern that drives this needs assessment is an unacceptably high percentage of newborns who are not retested after failing the initial hearing screen. Although the primary responsibility for this failure to follow-up appears to lie with the parents, birthing hospital staffs seek to provide services and institute practices encouraging retesting and/or diagnoses. Their relative successes in this effort may be instructive to Department of Health staff and to other hospital nurses in seeking to reduce the number of infants lost to-follow-up. Conversely, gaps in service delivery or an absence of aggressive efforts may be reasons for high rates of loss-to-follow-up. While cause-and-effect dilemmas prevent absolute explanation, such tendencies may suggest intervention targets that will contribute to improved performance.

This report is organized by evaluation methods, namely 1) telephone interviews, 2) closed-ended, in-person questioning, and 3) open-ended, in-person interviews. Following those reports, we analyze our findings, draw conclusions from all sections, and make recommendations for further action and research.

Evaluation Method

The purpose of this study is to identify challenges in the initial screening and follow-up testing of infants' hearing, as well as to suggest recommendations for program improvement. Thus, we conducted a qualitative study based on the experiences of hospital-based, IHP Administrators and other nursery nurses involved in infant hearing screening. The basic approach included two sets of telephone surveys followed by in-depth, on-site interviews.

First, county health units were contacted by telephone to identify the birthing hospitals serving the residents of the 10 sample counties. Second, the IHP administrators were contacted for a telephone survey. This survey was used to determine the infant hearing screening and reporting procedures in their hospitals. Next, the evaluation team made site visits to hospitals in each of the sample counties. In the case of two sample counties--Grant and Sevier--there was no birthing hospital; hence, we selected nearby hospitals at which women who live in the sample counties chose to have their babies. There, we conducted person-to-person interviews with each hospital's IHP administrator, and if available, other nursery nurses. These interviews explored stakeholder perceptions of the strengths and weaknesses of the program, challenges faced by program implementers, challenges faced by parents, and possibilities for program improvements. Copies of the telephone and interview scripts are included as an attachment to this document.

In the final section the telephone and person-to-person interviews are summarized and analyzed. Analyses include descriptive statistics on population and interval statistics, as well as qualitative analyses of the open-ended responses. Results are used to provide feedback and recommendations for decreased lost-to-follow-ups and general program effectiveness.

Study Sample

Given the geographic and demographic diversity of the state, a purposive sample was used to select 10 Arkansas counties. Selection for the evaluation is based on region, number of births, percent below poverty, and the percent of African Americans below poverty. The selected counties and distributions are presented in Table 1.

Table 1: Counties Selected for Participation

County	Region	Births	% Poverty	% of AA Poverty
Pulaski	Central	3000+	13.3	25.5
Desha	Southeast	200-400	28.9	44.1
St. Francis	East	200-400	27.5	41
Boone	Northwest	400-999	14.8	17.4
Benton	Northwest	3000+	10.1	7.7
Grant	Central	<200	10.2	12.6
White	Central	400-999	14	31.8
Sevier	Southwest	200-400	19.2	31.7
Ouachita	South	200-400	19.5	34
Garland	Central	1000-2999	14.6	32

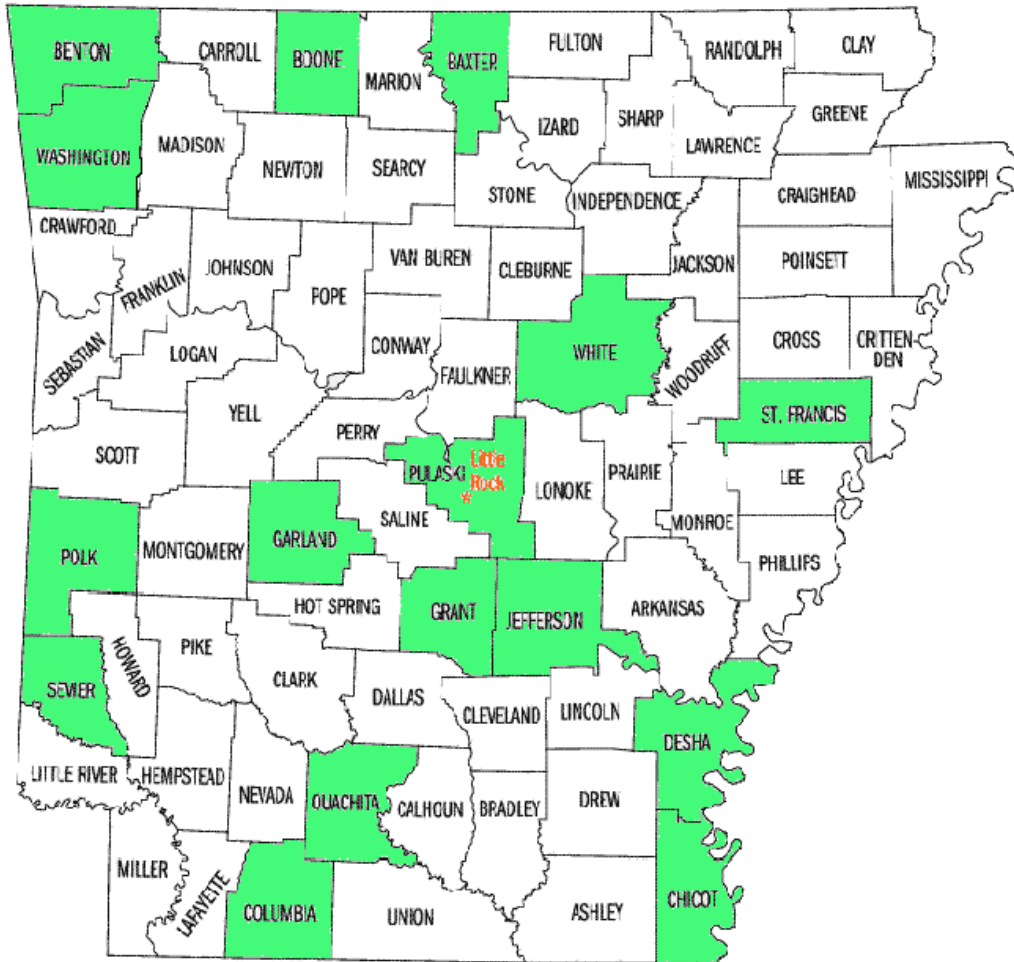
Having identified the counties of interest, the next step was to identify the birthing hospitals that serve the county populations. County Health Department Nurse Administrators for each of the selected counties were interviewed via telephone to identify the major birthing hospitals in each county. To ensure full coverage of births in a county, nurse administrators were asked to identify birthing hospitals in adjacent counties that serve the same study population. Nurse administrators were also asked to estimate the number or percentage of home births in their county, but none indicated that this represented a meaningful percentage of births. Based on these interviews, hospitals in six additional counties were included in the sample. For these 16 counties, we identified 18 hospitals whose staff we interviewed either by telephone, face-to-face, or both. The shaded areas in the map below indicate all counties that participated in the study.¹

Sample Demographics

The number of births in each county in 2007 ranged from 175 in Chicot County to 6,009 Pulaski County. The total number of births in participating counties was 19,356, with a mean of 1,209. While the average number of births for all Arkansas counties is 542, our sample is

¹ While Sevier County was originally selected for participation, the nearest hospital with an Infant Hearing Program Administrator is Mena Regional Health System, which is in Polk County.

Figure 1: Map of Participating Counties



skewed by the inclusion of Pulaski County. Current poverty rates for all Arkansas counties are not available. Therefore, we use Medicaid eligibility as a proxy for economic disadvantage.

Medicaid eligibility is also a meaningful measure of healthcare coverage. The percentage of county residents eligible for Medicaid for these counties ranged from 17.81 percent in Benton County to 43.72 percent in Chicot County. The average poverty rate for the selected counties, 18.1 percent, is only slightly higher than the overall state poverty rate of 15.8 percent.

Table 2: Sample Demographics

	<i>Population</i>	<i>Births</i>	<i>percent Medicaid</i>
Mean	83147.6875	1209.75	29.285625
Median	38856	426	28.985
Standard Deviation	96120.64	1641.64	7.40
Range	354404	5834	25.91
Minimum	12915	175	17.81
Maximum	367319	6009	43.72
Sum	1330363	19356	
N	16	16	16

Study

Infant Hearing Screening Fails and Lost-to-Follow-up

In our 18 sample hospitals, there was a total of 16,486 infants screened in 2007. Of these, 857, or 5.2 percent, failed the screening test. Screens per hospital ranged from 93 to 2,781, with an average of 915. Fifty percent of the hospitals in our sample screened more than 762 infants. The standard deviation of 685.25 indicates that there is a great deal of variation among the hospitals in our sample.

While infant hearing loss screening and lost-to-follow-up rates are clearly an area of concern, it is important to understand exactly how much of a problem these rates are. The Arkansas Department of Health Infant Hearing Program provided us with the annual infant screening data for 2007. State guidelines require that hospitals have no more than a 10 percent failure rate for infant hearing screens, and the target rate is fewer than 5 percent.² Among the 18 birthing hospitals whose staff we spoke with, eight had failure rates above the target rate of 5 percent, and three had failure rates over 10 percent, and thus are not considered to be in compliance. The average fail rate is 6.34 percent, which is above the target rate. The median rate, however, is 4.7 percent, meaning that at least half of the hospitals in the sample are within the target range. The summary screening statistics for the hospitals in our sample are presented below in Table 3.

² *ARKANSAS RULES AND REGULATIONS PERTAINING TO THE UNIVERSAL NEWBORN/ INFANT HEARING SCREENING, TRACKING, AND INTERVENTION PROGRAM* pursuant to Arkansas Act 1559 of 1999.

Table 3: Screening and Lost-to-Follow-up in Participating Counties

	# of Annual Screens	# of Fails	# of Fails w/o Follow-up	% Fails	% of Fails w/o Follow-up
Mean	915.89	47.61	20.44	6.34%	41.78%
Median	762.00	41.50	13.00	4.70%	37.90%
Standard Deviation	685.24	40.37	21.06	5.15%	23.05%
Range	2688.00	133.00	75.00	19.52%	85.71%
Minimum	93.00	1.00	0.00	0.18%	0.00%
Maximum	2781.00	134.00	75.00	19.70%	85.71%
Total	16486.00	857.00	368.00		
N	18	18	18	18	18

The lost-to-follow-up rate ranged from a low of 0 percent, to a high of 85.7 percent. It is important to note that this high rate is in a county with fewer than 10 fails. However, 14 hospitals, or 77.8 percent have lost-to-follow-up rates higher than 25 percent, and six of these hospitals have lost-to-follow-up rates of 50 percent or greater. The number of fails in these six hospitals ranges from 4 to 134. This means that these high lost-to-follow-up rates are not exclusively in hospitals with small numbers of failing screens. Overall, these data seem to indicate that lost-to-follow-up rates in the sample are at unacceptable levels. If, as we believe, our sample counties are representative of all Arkansas counties, infants lost-to-follow-up is a significant problem for the program.

Telephone Interviews

All birthing hospitals in Arkansas have Infant Hearing Program (IHP) administrators who are responsible for making sure that all infants born in their hospitals have their hearing tested. They, or one of their nurses, are responsible for explaining the results to the parents. This is standard practice.

We contacted Infant Hearing administrators in 18 birthing hospitals in the ten study counties or in adjacent counties that may serve residents from our original sample. We wanted to confirm

that such required procedures were, in fact, being followed. Further, we were interested in learning about options available for parents regarding retesting, diagnosis, and intervention, since the first required testing is merely a start to the retesting process.

Infant Hearing Screens and Explanations to Parents

In each case, we found that the IHP administrator is a member of the nursing staff, most often (although not always) assigned to nursing duty in the hospital's nursery. Nurses in the nursery who are trained on hearing testing equipment all perform screening and they or another nurse inform the parents of testing results. All nurses are trained to use hearing testing equipment except those who have just arrived on the unit. All indicated that they perform frequent in-service training that focuses on hearing screens.

In cases where different nurses screen and explain results to the parents, the cause has more to do with scheduling than assignment. For example, some of the hospitals perform testing on the night shift and meet with parents during the day, necessitating different nurses. Some discuss test results with parents during the hospital stay and others upon discharge. One IHP administrator indicated that the pediatrician or family practice physician sometimes inform the parents, although a nurse always performs the testing. In two instances, a nurse is assigned to an infant and completes both testing and informing. In almost all cases, the IHP administrator is the nurse who sends testing reports to the Department of Health.

Options for Follow-up Testing

It is at this stage of the follow-up that a variety of procedures begins. A third of the respondents indicated that parents are encouraged to bring their infants back to the birthing hospital for retesting. The discharge nurse often will book an appointment for them no further than seven days out. Parents who live some distance from the hospital will be referred to pediatricians or hospitals closer to their homes. However, nurses in hospitals that birth babies of women from nearby adjacent states do not contact the baby's "medical home" (pediatrician, PCP, or family practice doctor). In those cases, the interviewees did not seem to know much or at least reveal much about the reasons for this trans-state option or access to audiologists or other care providers. Within Arkansas, several hospitals refer to audiologists who practice in that same city

or nearby city. Two others indicated that the PCP will refer parents to an audiologist. Pediatricians on staff at the hospital are informed of test results and in several cases regularly refer to an audiologist. Several refer directly to Arkansas Children's Hospital. Two hospitals do not perform follow-up testing and refer to local ENTs.

Tracking Babies Not Re-screened in Hospital

With just one exception, none of the IHP administrators we interviewed by phone collects data on babies who are not re-screened in their hospitals, and that one hospital attempts to contact the parents twice before closing the record. Tracking beyond the initial screen and referral to a pediatrician, PHP, or audiologist is not seen as a responsibility of any of the birthing hospitals.

In-person interviews

The telephone interviews with 18 program coordinators helped us identify possible points in the testing and retesting chain at which further research would be revealing. Hence, we made site visits to 11 birthing hospitals and talked with IHP program administrators in interviews that each lasted from 45 minutes to an hour. In several cases, we conducted the actual interview among newborns *in* the nursery with nurses who were keeping a watchful eye over their charges just a few feet away while responding to our questions! (In those cases, we followed appropriate hygienic practices.) Interviewees were cooperative and forthcoming, although only a few indicated that they had examined their practices and procedures in light of higher-than-desirable lost-to-follow-up rates.

We interviewed persons in the following 11 hospitals:

Forrest City Medical Center (St. Francis County)

White County Medical Center (White)

No. Little Rock Baptist Hospital (Pulaski)

Jefferson Regional Medical Center (Jefferson)

National Park Hospital (Garland)

Delta Memorial Hospital (Desha)

Chicot Memorial Hospital (Chicot)

Siloam Springs Hospital (Benton)

Mena Regional Health System (Polk)
North Arkansas Regional Hospital (Boone)
Ouachita County Medical Center (Ouachita)

During the site visits, IHP administrators were asked 27 fixed response scale questions and 14 open-ended questions. The questionnaires were created based on the results of the telephone interviews and literature on Infant Hearing programs.

Fixed Response Questions

The fixed response questions were divided into four categories: Information, Program Procedures, Program Actors, and Other Challenges. Respondents were asked to identify if each of the items in each category were *Very Challenging*, *Somewhat Challenging*, or *Not Challenging At All*. They were then asked to elaborate on any items they identified as *Very Challenging*. The results of these sections are discussed in the following section.

Information

The first category of potential challenges is *Information*. It is hypothesized that lack of adequate information about the importance and process of infant hearing testing may contribute to lower re-screen rates. The table below presents the results of the *Information* questions.

Only one respondent indicated that training for hearing professionals outside the hospital was a challenge, and one felt that the availability of convincing research was a challenge. In both cases, the respondent felt that these were problems external to the hospital. Only one of the administrators felt that the availability or adequacy of materials for parents represented any challenge. Overall, *Lack of Information* does not appear to be a significant challenge in the hospitals visited. While some indicated that there were some challenges associated with the availability of information, they stressed that this referred only to those professionals *outside* of the nursery or hospital. Further, these perceptions were largely based on parent accounts of their interaction with these professionals.

TABLE 4: Information Challenges

INFORMATION			
	Very Challenging	Somewhat Challenging	Not Challenging
Lack of Materials to Educate Parents	0	1	10
Lack of Materials to Educate Physicians	0	2	9
Physicians Do Not Know Enough to Encourage Parents	0	2	9
Research Not Convincing Enough	1	1	9
Lack of Training for Physicians & Audiologists Outside the Hospital	1	0	10

Program Procedures

The next category was about challenges associated with the Infant Hearing Program procedures. We wished to determine if the individuals responsible for implementing the program found the process difficult, time consuming, or cost prohibitive. The results for these questions are presented in Table 5.

The area that presented a challenge to the greatest number of hospitals was the cost of the equipment. Administrators indicated that if they were able to purchase more or better equipment, they would be more effective in getting infants re-tested before they left the hospital. Two respondents answered *Very Challenging* to first question, which asked about short hospital stays. Most hospitals indicated that mothers and infants were released at 24 hours. For some,

Table 5: Program Procedure Problems

PROGRAM PROCEDURES			
	Very Challenging	Somewhat Challenging	Not Challenging
Short Hospital Stays	2	3	6
Screening Procedures Too Complex / Time Consuming	0	3	8
Recording Requirements Too Complex / Time Consuming	0	2	9
Lack of Staff Training on Equipment	0	1	10
Lack of Staff Training on Reporting Results	0	2	9
Equipment is Too Expensive	5	1	3
False Alarm Rates are Too High	0	2	9

this made it difficult to screen or re-screen before the infants left the hospital. While some felt that the complexity of testing and/or recording was somewhat challenging, most felt that the process was manageable. Training in testing or reporting did not present a challenge for the majority of the administrators. While some respondents mentioned that they conducted multiple tests to insure accurate results, no one considered false-alarms to be *Very Challenging*, and only two indicated that false-alarm rates were *Somewhat Challenging*.

Program Actors

We recognize that not all individuals involved in infant screening are associated with the actors within the hospital. Therefore, we asked the IHP administrators if these other actors presented them with any challenges. We were particularly interested in third party payers, pediatricians, and parents. Table 6 summarizes the results to these questions.

Table 6: Program Actor Challenges

PROGRAM ACTORS			
	Very Challenging	Somewhat Challenging	Not Challenging
Third-party Payers Do Not Cover Screening Costs	0	3	8
Not Enough Coordination with Other Infant Programs	0	1	10
Not Enough Audiologists to Provide Re-screens	4	1	6
Not Enough Audiologists to Provide Diagnostic Evaluations	4	2	4
Physicians Are Opposed to Hospital-based Hearing Screening	0	1	10
Parents Are Opposed to Hospital-based Hearing Screening	1	0	10
Administrators Are Opposed to Hospital-based Hearing Screening	0	0	11

The greatest challenge in this category faced by our sample is that there are not enough audiologists in the area to provide re-screens. While several hospitals indicated that they at least attempted to conduct re-screens at the hospital, five of the eleven said that there is a need for more options for referrals. One administrator mentioned that the only local audiologist will not test before six months of age. Another mentioned that the closest audiologist is over an hour away.

While the administrators generally told us they were not involved with billing, three mentioned that third party payers are somewhat challenging. While most economically disadvantaged parents or children are covered by Medicaid (or ARKids), there is some concern that those who are under-insured will not have the cost of the re-screens covered. Only one hospital mentioned physician opposition as a challenge, and that respondent was referring to a single case.

Opposition from parents was also mentioned in only one case; however, the respondent indicated that parental opposition was *Very Challenging*.” None of our respondents reported any opposition from hospital administrators.

Other Factors

In the final section of our fixed-response section, we asked administrators about other factors that might present a challenge to the administration of the Infant Hearing Program. These factors focused mainly on issues facing parents that might prevent them from having their infant re-screened. We also asked if there were additional funding issues that might present a challenge. The results of these questions are summarized in Table 7.

Table 7: Challenges from Other Factors

OTHER FACTORS			
	Very Challenging	Somewhat Challenging	Not Challenging
Transportation for Parents	6	4	1
Lack of Health Insurance	0	1	10
Lack of Child Care	1	5	5
Parents Do Not Understand the Impact of Hearing Loss	3	4	4
Parents Overwhelmed by the Amount of Information	4	4	3
Inability to Contact Parents After Discharge	4	2	5
Language Barriers	0	4	7
Funding	4	1	4

The area that posed the least challenge to our sample was *Lack of Health Insurance*. As mentioned in the previous section, the nurses we spoke with generally were not involved with billing. Those who did comment generally mention the high percentage of infants covered by

public health care assistance. The individual who indicated that this was a challenge explained that if the infant were not re-screened before discharge, the parent would have to readmit the infant to be tested.

The greatest challenges in this category all had to do with infants' parents. All but one of our eleven participants reported that *Transportation* and *Parents Overwhelmed by the Amount of Information* were either *Very Challenging* or *Somewhat Challenging*. Transportation was considered a problem not only when there was no transportation available. Respondents also told us when parents had to bring their infant to several locations for well-baby appointments that they were less likely to bring their infant back for follow-up hearing tests. While the administrators indicated that they tried to cover the importance of Healthy Hearing to parents, most acknowledged that parents probably did not go back and read the materials unless they thought there was a problem.

Seven of the eleven said that parents' lack of understanding of the impact of hearing loss was *Very* or *Somewhat Challenging*. One nurse commented that, more than not understanding the impact of hearing loss on the child, parents did not understand the impact hearing loss has on the family as a whole. Another nurse mentioned that it was difficult to impress on parents that "some" hearing loss would, long term, have a negative impact on their child's development.

Another common challenge mentioned by our respondents was the inability of hospitals to contact parents after discharge. Nurses commented that the telephone numbers were either false or disconnected, or that parents would not return messages left on answering machines. Some nurses mentioned that if they suspected a parent might not provide 'good' contact information, they would try especially hard to get the infant to pass the screening before discharge.

Language barriers were not found to be a significant challenge in the hospitals we visited. While four nurses said language was *Somewhat Challenging*, they also indicated that there were resources available, such as Spanish language materials, and a telephone interpretation service. Some of the more challenging aspects mentioned were the time needed to access translation

services, an increase in foreign languages other than Spanish, and lack of training on the ATT interpretation services. Funding was seen by five respondents as a challenge as well.

Overall, the greatest challenges appear to be focused around resources and parental cooperation. Staff in several hospitals said that they have attempted to work around these challenges, but that they are limited in what they can do.

Open-Ended Questions

The nurses we interviewed have worked in their hospitals an average of 16 years and almost all have spent that entire time in their hospital's nursery, OB/GYN, or women's center. (Names vary across the sample.) As indicated above in the telephone interview report, all licensed nurses who have been trained to conduct hearing screens and record/report results do so. All interviewees are conversant with the hearing testing program, although few seem to know about practices in other hospitals around the state nor reflect on finding proactive methods of reducing higher-than-hoped-for testing and retesting outcomes.

Responsibility for Assuring Retesting

This question and ones that follow reflect a significant break-point in the process. One head nurse called this hand-off from the nursery to the parent or to the baby's medical home the "weakest point" in the retesting process. As long as the IHP administrator and discharge nurse control the process, testing is universal and timely. In other words, we found that the sample hospitals administer the initial test at the appropriate time while the infant and mother are still in the hospital. Almost all indicated that they test several times until they are confident that they have an accurate read on both ears. As one explained, "An infant's ears are so malleable or they have excess fluid that prevent an accurate reading. We test repeatedly to make sure." Several others acknowledged other difficulties such as getting the baby to settle down enough to be tested, outside noise in and around the nursery, and occasional faulty equipment. (Note: Testing equipment is loaned by the IHP division of the Department of Health while faulty equipment is being repaired.) The majority of respondents indicated that they see infants who have failed the initial screening and normally set up a return visit within seven days of the first test.

For those infants who are referred for retesting, most although not all return to the same hospital. Nurses in most of the hospitals are diligent about improving the odds that the parents return with their baby for retesting. Several are quite proactive. At North Arkansas Regional Hospital in Harrison, for example, the nursery unit secretary calls at least three times in an effort to assure that the infant is returned for retesting. Several other nurseries, such as Delta Memorial Hospital in Dumas, St. Joseph's Hospital in Hot Springs, and White County Medical Center in Searcy, make appointments and then follow-up to make sure that mother and infant return. All send letters reminding them of their appointments and the importance of the test to the infant.

Several were perceived as less proactive, as they indicated that they are "overwhelmed with paperwork and do the best [they] can," that "nurses are very busy and can't track down parents who refuse to take responsibility," and that once [the baby] is referred, "that's it." For us, it was hard to discern whether these statements reflected disinterest or more likely frustration.

"You'd be amazed how many wrong phone numbers or disconnects we get that make tracking and reminding all the more difficult," said one nurse. "We really don't have much recourse after that." Three nurseries make retesting appointments for the mother and infant and/or forward testing information to the medical home. Several attempt phone follow-up for at least three weeks after birth, but admitted that phone pursuit is a lower priority, given the ongoing demand of frequent births. The rest end their pursuit once the infant's medical home has been informed of test results.

"We're lucky if the mother makes it home with the appointment reminder," reported one nursery nurse. "We've taken to stuffing the hearing report and appointment date in their diaper bag as the best chance that they will find it later. Whether they act on it is pretty much up to them."

Overall, the nurses indicated that there is only so much they can do to reduce the lost to follow-up incidence once the infant and mother had been discharged. They are concerned about high lost-to-follow-up rates (see Table 3 above and Table 8 below), but feel limited in their pursuit of those parents who fail to return their baby for follow-up testing.

High lost-to-follow-up rates may be partly a product of incomplete communications. It appears that there is no assured reporting of a follow-up once the infant and mother are discharged from the birthing hospital. Further research might be targeted at PCPs, audiologists, and family practice physicians to determine if they are assiduously reporting follow-up appointments, diagnoses, and interventions. Better reporting in itself may not encourage greater follow-up, but would permit birthing hospitals and the Arkansas Department of Health to perform better their efforts to be accountable.

The Infant's Medical Home

Most respondents said that infants born in their hospitals have medical homes who take responsibility for follow-up testing after discharge. As stated above, there may be many more infants being retested than birthing hospital records indicate. If the problem is, indeed, uneven reporting, that shortcoming should be easier to correct than if the babies are not being retested at all. Respondents said that they make sure that all babies born in their hospitals are assigned a physician. One nurse, however, said that guaranteeing that an infant had a medical home to be discharged to could be frustrating. "There are no pediatricians in this town and many of our families live a considerable distance from here or from a pediatrician."

Several lamented that more prospective mothers don't avail themselves of pre-natal classes, but assured us that once the mother is in their care, they make sure that mother and baby's well-being are paramount. All of those interviewed said that they make sure that the mother and infant have a medical caregiver assigned before discharge. Most often, it is the doctor who delivered the baby who continues to function as the medical home. In several instances, a family practice center works closely with the birthing hospital to perform retests. All said that they would not discharge without a doctor being assigned.

Notifying the Medical Home

In almost all cases, the nursery forwards the form for retesting on to the physician and provides the mother with a copy. In several cases, where all of the physicians are on staff at the local hospital, they have mailboxes in the hospital where the nurses leave the testing forms. Several indicated that they have created special forms that alert the medical home of a need for retesting.

Others said they attach a large, brightly colored sticker to the form that indicates a need for hearing retesting. One hospital follows-up for a week after discharge to make sure that the mother takes the infant for retesting. Beyond that, the responsibility appears to shift to the medical home and mother, out of the sphere of influence and responsibility of the birthing hospital.

Native Language of Parents

Accurate communication between the nursery where almost all nurses speak only English and the mother who speaks Spanish does not appear to be a problem; hospitals have arranged various techniques that the interviewees told us facilitate understanding. Several lauded the Spanish version of the DOH pamphlet, “Milestones”. Most hospitals have interpreters available, either on staff or in nearby clinics. For example, at Mena Regional Health Systems, nursery personnel are in frequent contact with an in-town husband-and-wife physician team who speak Spanish and English fluently. Since Mena is a primary birthing hospital for expectant mothers in the sample county of Sevier, which has a large Spanish-speaking population, this appears to be a working arrangement. Others have Spanish-speaking personnel in the nursery or on staff of the hospital. Most of the respondents said that they rely on the telephone or on-line translating service, although one nurse has proposed more training in using the telephone interpreter service. A small percentage of mothers giving birth speak Hindi, Urdu, or Chinese, but none of the hospitals indicated that to be a problem. Several urged a translation of various other related materials into other languages.

Babies Born at Home

Most respondents were unaware of the number of mothers who were birthing their babies at home, perhaps with the aid of a mid-wife. Nurses at hospitals in southeast Arkansas were complementary of the Delta AHEC for providing information to expectant mothers. Saint Joseph Hospital in Garland County mentioned the First Step nutritional education program as helpful. None was aware of parental support networks or other advocacy groups, although several lamented the cessation of pre-natal classes at the county health unit or in their own hospital. Otherwise, the medical community does not have contact with this small population and cannot predict how many infants born at home have hearing difficulties.

Suggestions for Change

We sought suggestions for improvement from the respondent nurses on the assumption that front-line medical staff are aware of problems and their possible solutions. One comment seems to capture their concern: “The system is a good one; it ought to work, but it doesn’t.” Most felt that persuading parents to return to the hospital for rescreening was the most critical and the most difficult part. One nurse commented that although parents have the primary responsibility for making sure that rescreening occurs, we as a society must assure that it happens by funding education programs in our communities. She said “it takes a village” to raise a child and we must all work at assuring that babies receive the services they need to grow up healthy.

Several urged more pre-natal education, but realize that it is at the expectant mother’s volition that such preparation will take place. Some felt that pregnant women in their communities are not prepared to be mothers and one believed that mothers were more casual about preparing for second and subsequent births. Several nurses applauded the Department of Health’s Mother/Infant program, but feared it is short-handed and can’t spend the time necessary to assure that mothers, especially those in rural areas, are adequately caring for their newborn.

“Mothers tend to listen to members of their extended families for advice,” lamented one. “You know who we compete against the most, don’t you?” one asked. “It’s the grandmother. Maybe we ought to be educating them,” said one, only partly in jest.

Others looked inside their nurseries for answers. One nurse said that the key for nurses is to develop a good rapport with parents; another referred to an “extended family” as their approach to persuading mothers to make sure their babies were well taken-care of. One other expressed a concern of many of those interviewed: the hospital’s standard stay is too short. “We cram so much in to a 24-hour period that the mother is likely to get confused about all the information we throw at her.” One respondent credited experienced nurses with an awareness—a sixth sense perhaps—of those mothers who were unlikely to return their child for retesting, and therefore

tested repeatedly and thoroughly while the child was still in the nursery as a counter-balance to the anticipated negligence.

Table 8: Number and Percentage of Initial Screen Failures and Lack of Follow-up

Hospital	# of annl screens	*# of fails	fail rate percent	# of fails w/o follow-up	**% of fails w/o follow-up
Baptist Medical Center - Little Rock	2833	151	5.3%	54	35.8%
Baptist Medical Center - Little Rock North Little Rock	1611	75	4.7%	28	37.3%
Baxter County Regional Medical Center	772	79	10.2%	22	27.8%
Chicot Memorial	148	7	4.7%	6	85.7%
Delta Memorial	93	15	15.6%	3	20.0%
Drew Memorial	178	13	7.0%	3	23.1%
Forrest City Medical Center	693	61	8.7%	49	80.3%
Jefferson Regional	1361	134	9.8%	75	56.0%
Magnolia	208	13	6.3%	5	38.5%
Mena Regional	425	85	19.7%	14	16.5%
National Park	752	34	4.5%	24	70.6%
North Arkansas Regional	547	1	0.18%	0	0.0%
North Metro	437	64	14.7%	33	51.6%
Northwest - Benton County	854	50	5.9%	17	34.0%
Northwest Springdale	n/a	n/a	n/a	n/a	n/a
Ouachita County Medical	350	4	1.1%	2	50.0%
St Joseph's	954	18	1.9%	6	33.3%
St John's - Berryville	285	23	7.0%	13	56.5%
St Mary's - Rogers	1362	62	4.5%	12	19.4%
St Vincent Doctors	1816	23	1.3%	7	30.4%
Siloam Springs	531	49	8.8%	33	67.3%
White County Med Center	1228	20	1.6%	8	40.0%
Willow Creek	2781	127	4.6%	57	44.9%

* Note - Numerator (#of fails) divided by Denominator (# of annual screens)
Fail Rate Percent state guidelines is 0-10% fail rate within compliance levels- **target fail rate less than 5%**

**Note - Numerator (%of fails without follow-up) divided by Denominator (# of fails)
% of fails without follow-up

Source: Infant Hearing Program, Arkansas Department of Health

A Discrepancy between Perception and Reality

Table 8 above was generated by the Infant Hearing Program of the Arkansas Department of Health. As it shows, just one of the hospitals depicted has an acceptable percentage of follow-up, yet we sense that few of those we interviewed were aware of this report. We did not share the data during our telephone or in-person interviews with personnel in the sample hospitals. If we had, we suspect that most would have been dubious about their accuracy, yet we have confidence that the IHP data are correct as based on reports received from all sources. Inconsistent reporting by hospitals, the infants' medical homes, or audiologists may be part of an explanation. Still, we are concerned by a likely discrepancy between perception (as reflected in positive responses from the birthing hospitals) and reality (as depicted by the negative data from the IHP).

Summary and Recommendations

Making sure that an infant who has tested positive on the initial hearing screen is retested is the joint responsibility of parents, the physician, and the birthing hospital. Based on our interviews with nurses in Arkansas birthing hospitals, we conclude that the primary responsibility is with the parents in close consultation with their pediatrician or family care physician. Some of our strongest recommendations below reflect this reality. Others focus on improved communication, more timely reporting, and affordable and available equipment.

(1) Parents, physicians, and the birthing hospital must share the responsibility.

To fulfill its role, the birthing hospital should 1) create a nurturing environment and extend a helping hand as if the mother and infant were part of a team or family; 2) take care to flag those cases where the infant must be rescreened; 3) inform the pediatrician, PCP, or family practice physician of the need for prompt retesting; and, 4) make repeated attempts to assure that the mother keeps the retesting appointment. The parents and the physician should make every effort to 1) see that the infant is rescreened; 2) refer those who fail the retest to an audiologist or ENT for diagnoses; and, (3) inform the ADH and birthing hospital of this action. The key then is action, followed by communication.

(2) Care providers and parents should examine and improve communications to increase the likelihood that an infant will be returned for retesting.

The birthing hospitals appear to be doing their part to assure that parents understand that they should return their infant for retesting. Perhaps what is called for is a review of the communications links to assure that all parties understand the grave consequences of failing to follow-through. Are retesting forms following the infant between all steps? Are physicians promptly informing ADH and the birthing hospital of retesting results?

(3) Education of parents must be emphasized.

Intensive pre-natal and post-natal education is a key to increasing the likelihood that an infant who fails the initial hearing test is retested promptly. Given the multiple demands on the new mother's attention during the short hospital stay, nurses must make sure that they are explaining clearly and directly the consequences that may result from a failure to catch and treat a hearing impairment. Perhaps incentives, such as a diaper voucher to be redeemed upon return for retesting, should be tried. ADH should explore other methods of educating expectant mothers, including re-establishing educational programs in their county units and extending post-natal services that include education and awareness of the importance of good hearing.

(4) Better reporting by hospitals and information-sharing by ADH is necessary.

It appears that hospitals lack a clear understanding of their lost-to-follow-up rates. ADH should send a bi-monthly or quarterly report showing how each hospital stands. To accomplish this, ADH must receive more timely reports from the hospitals. A switch to electronic communication would expedite this exchange. Also, ADH should maintain and up-to-date audiologist referral list.

(5) The Arkansas Department of Health should work with care providers to improve services.

This recommendation is premised on some sort of interorganizational collaboration among stakeholders in the Infant Hearing Program. For example, is it possible to improve the provision of services by audiologists and ENTs, especially in the more rural parts of the state? Can additional workers be assigned to various outreach programs such as the Mother/Infant program

to extend education and awareness into all parts of the state? Can funding be designated to help small hospitals purchase hearing testing equipment?

(6) Hearing testing equipment must be available and in functioning order.

For some hospitals, especially small, rural units, the cost of testing equipment may be prohibitive. These hospitals should explore alternative funding sources to assist in buying equipment. Temporary replacement equipment, already available from ADH, should be advertised more widely. Some concern was expressed that testing equipment must be housed in other locations within hospitals and not in the nursery, so as to provide a quiet venue for retesting. A mobile testing van to visit areas with limited options for retesting should be considered. Perhaps additional testing units can be furnished to county health units to increase accessibility.

(7) Further research should include attention to the roles of family care physicians, audiologists and ENTs, and parents.

A review of infant hearing programs in other states and discussions with other stakeholders in the hearing testing process would broaden our awareness of other practices and understanding of what might help Arkansas lower its incidence of lost-to-follow-up testing.

Other improvements that would raise the incidence of retesting infants who have failed the initial hearing test are far beyond this report and the efforts of the Department of Health. For example, the incidence of poverty, especially in the rural parts of the state, manifests in the lack of good transportation to carry mothers and their infants over long distances to medical facilities. Lack of good education makes understanding of medical conditions and consequences more unlikely. Inconsistent communications make contacting parents about test results and appointments more problematic. But only when hearing care providers can demonstrate that they have removed all barriers to retesting can they point to environmental factors as the sole cause of this failure.