

Parents' Perceptions of an Emerging Community-Based Newborn Hearing Screening Program: A Case Study

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Abstract

Thirty-six parents of 106 children (34% response rate) born between March 2000 and February 2003 retrospectively completed the "Probe of Parents' Perceptions: An Early Hearing Detection and Intervention (EHDI) Outcome Measure" (PPP) assessing their participation in an emerging community-based newborn hearing screening program (NHSP) involving three hospitals in Santa Barbara County, California. The PPP, an 11-item questionnaire (in both English and Spanish versions), asks parents about their impressions of the explanations of the purpose of the screening and of the results, and the referral process. The parents were generally positive about all phases of the NHSP; nearly all parents said the program had no negative effects on their ability to bond with their babies, and they would recommend NHSPs to others. These parents' positive impressions in this case study of an emerging community-/private practice-based NHSP were consistent with those from studies involving parents participating in hospital-based programs.

Key Words: Newborn hearing screening, outcome measure, parents

Abbreviations: EHDI = early hearing detection and intervention; GVCH = Goleta Valley Cottage Hospital; HCC = Hearing Consultants of California; LHDH = Lompoc Healthcare District Hospital; NHSP = newborn hearing screening program; NICU = neonatal intensive care unit; PPP = "Probe of Parents' Perceptions"; SBCH = Santa Barbara Cottage Hospital; SCHCC = Southern California Hearing Coordination Center

Sumario

Treinta y seis progenitores de 106 niños (tasa de respuesta del 34%) nacidos entre Marzo del 2000 y Febrero del 2003, completaron retrospectivamente el "Sondeo de Percepciones de los Progenitores (PPP): Una Medida de Resultados en la Detección e Intervención Auditiva Temprana (EHDI)", evaluando su participación en un programa comunitario de tamizaje auditivo en recién nacidos (NHSP), que involucró a tres hospitales en el condado de Santa Bárbara, California. El PPP, un cuestionario de 11 pregunta (tanto en inglés como en español) interroga a los progenitores sobre sus impresiones al respecto de la explicación sobre el propósito del programa, de los resultados y el proceso de referencias. Los progenitores se expresaron positivamente sobre las fases del NHSP; casi todos dijeron que el programa no tenía efectos negativos en su capacidad de vincularse afectivamente con sus bebés, y que recomen-

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darían un NHSP a otros. Estas impresiones positivas de los progenitores en un estudio de caso de un NHSP emergente basado en una práctica comunitaria/privada, fueron consistentes con aquellos de estudios que involucran progenitores que participan de un programa hospitalario.

Palabras Clave: Tamizaje auditivo de recién nacidos, medida de resultado, progenitor

Abreviaturas: EHDI = Detección e intervención auditiva temprana; GVCH = Hospital Rural del Valle de Goleta; HCC = Consultores Auditivos de California; LHDH = Hospital de Distrito de Lompoc; NHSP = programa de tamizaje auditivo en recién nacidos; NICU = unidad de cuidado intensivo neonatal; PPP = Sondeo de Progenitores; SBCH = Hospital Rural de Santa Bárbara; SCHCC = Centro de Coordinación Auditiva de California del Sur

By 2004, newborn hearing screening programs (NHSPs) were implemented in all 50 states and the District of Columbia. Although over 86% of all babies nationwide receive hearing screenings before they leave the hospital, states vary in the percent of infants screened (National Center for Hearing Assessment and Management [NCHAM], 2004). This rapid development of numerous NHSPs having great variability across and within states, ranging from self-contained hospital-based to diffuse community-based offerings, mandates vigilant monitoring of their quality to ensure that programs meet their goals. Recently, a team of authors (Thompson et al, 2001) completed a systemic review of early hearing detection and intervention (EHDI) program outcomes to identify strengths, weaknesses, and gaps in the evidence supporting NHSPs over simply screening high-risk infants. They searched MEDLINE, CINAHL, and PsycINFO databases for relevant articles published from 1994 to August of 2001, contacted experts, and hand-searched additional articles published before 1994. They concluded that although physiological screening tests for hearing loss can enhance the identification of children with peripheral hearing loss, the efficacy of NHSPs to improve long-term language outcomes of these children remains uncertain. Similarly, although NHSPs can be cost-effective with low referral rates and developmental outcomes for children in EHDI programs are encouraging, compliance in follow-up testing

must be improved (Baroch, 2003).

The percentages of newborns being screened annually vary widely across the states (NCHAM, 2004). For example, Ohio and California only screened 17.6% and 26.1% of their babies, respectively, while Rhode Island screened 99.8% of all babies in 2001 (Gaffney et al, 2003). Although screening rates for Ohio and California have increased to 33% and 66%, respectively, they still have considerable room for improvement, while most other states presently screen over 80% of their babies (NCHAM, 2004). Of further concern are national data indicating that parents of nearly half of all newborns who do not pass their initial hearing screenings fail to keep follow-up appointments for hearing rescreening, audiometric diagnostic, and/or medical services. Clearly, in many parts of the country, NHSPs and the necessary community infrastructure for effective follow-up are nonexistent or just emerging. In these communities, the success of NHSPs and follow-up depends on a team effort from hospital staff and dedicated audiologists, and especially on parents. Although parents are the critical link in compliance for follow-up testing and services, few studies have investigated their impressions of NHSPs and the referral process as a means of monitoring the quality and success of such programs.

Surveys like the ten-item questionnaire about parents' perceptions of NHSPs using evoked otoacoustic emissions performed by obstetric nurses at Logan Regional Hospital in Logan, Utah (Barringer et al, 1997), have

been useful in evaluating specific NHSPs. That survey was administered by the nurses to parents of 169 babies born between June 1, 1994, and July 15, 1994. Results indicated that only 62% of the parents were aware that their baby's hearing was screened, and only 50% of those unaware of the screening would have wanted to be informed. Parents who were aware of the screenings were informed in a variety of ways; most of those who were unaware wanted to be informed due to general interest. Further, 98% of the parents would have consented to have their baby participate in the NHSP if asked; 95% would still have preferred to have the hearing screening done even if they found that their child did not pass; and 85% believed that any anxiety from referrals would be outweighed by the benefits of early intervention. The results suggested that those parents had positive attitudes toward that hospital-based NHSP. The study was limited somewhat because the sample was from a single hospital and lacked anonymity in parents' responses to the survey, which was administered by hospital nurses.

In an attempt to secure more candid parent responses, Abdala de Uzategui and Yoshinaga-Itano (1997) mailed a seven-item questionnaire to the total population of parents of 201 children referred for additional hearing testing at two participating hospitals in Colorado from January 1995 to April 1996. One suburban hospital had 6,611 births per year, and patients of mostly middle-to-upper income. Of the 100 surveys mailed, three were undeliverable and 53 were returned (55% return rate). The other was an urban, inner-city hospital with 6,610 births per year, and patients of lower-to-middle incomes. Of the 101 surveys mailed, 27 were undeliverable and 16 were returned (22% return rate). Descriptive statistics were compared for all variables. Two sets of T-tests were used to compare the hospitals' and parents' responses for children having hearing loss to those of a false positive group. The results indicated that parents had positive perceptions of these NHSPs, and that parents of children with confirmed hearing loss had greater frustrations with the process than parents in the false positive group. Further, parents who had children with confirmed hearing loss expressed more anger, depression, and confusion than those in the false-positive group. Nevertheless,

only a small percentage of the sample that was referred for further hearing testing reported negative reactions toward the NHSP process.

Those earlier studies investigating parents' reactions were conducted in self-contained NHSPs in which the screening and follow-up testing were completed in the same hospital. Thus, those NHSPs had the advantage of precluding parents from having to travel to another location for testing by hearing health-care professionals not employed by the hospital. However, many other hospitals, particularly smaller ones, either do not have NHSPs or audiologists on-site to perform follow-up testing, which adds another variable that may frustrate parents and reduce their compliance with the referral process. These NHSPs require the consultation of audiologists employed in other settings (e.g., private practice) in the community to provide initial screening, rescreening, and/or diagnostic evaluations and follow up. Actually, these community-based NHSPs are probably more the rule than the exception in many suburban and rural areas of the country.

The Joint Committee on Infant Hearing (2000) clearly stated that hospital and state NHSPs should establish periodic reviews to evaluate how program quality indicators compare to established benchmarks; that success of EHDI programs depends on professionals working with families in partnership as a well-coordinated team; that audiologists should be program managers involved in the design, implementation, and evaluations of programs (including small and rural hospitals); and that outcomes and quality indicators obtained at the hospital, community, state, and national levels should permit the community to draw conclusions about the EHDI process.

We conducted a literature search using MEDLINE and ComDisDome databases and found no published studies that have assessed parents' perceptions of community-/private practice-based NHSPs in which the screening and/or follow-up testing do not necessarily occur within the birthing hospital. Certainly, no such formal appraisals have been conducted on a California NHSP, especially not on the local Santa Barbara County program. Clearly, data from these types of NHSPs are needed in order to evaluate how well they are doing nationwide. Further, we

need to develop materials that will allow outcomes to be assessed effectively and efficiently. The purpose of this retrospective investigation was to assess parents' perceptions of an emerging community-based NHSP in which screening and/or follow-up testing was provided on an "outpatient" basis through a private practice. The results of the survey developed here provide insight into parents' perceptions of this and other community-based NHSPs.

METHODS

NHSP: State and County

The community-/private practice-based NHSP described here is in Santa Barbara County in California. A brief discussion of NHSP coordination at the state and regional levels is presented here. In California, the Children's Medical Services Branch provides a comprehensive system of health care for children, including NHSPs. Only hospitals

receiving funding for California Children's Services are mandated to provide NHSPs; other hospitals are not required to provide these services, which is partly why the annual screening numbers reported earlier are so low. California's NHSPs provide an opportunity for: (1) screening the hearing of approximately 400,000 infants a year; (2) tracking and monitoring about 25,000 infants; (3) accessing medical management and other services; and (4) coordinating care for early intervention. California's NHSPs have three components: (1) outreach and awareness campaigns, (2) hearing screenings with otoacoustic emissions and/or automated auditory brainstem responses, and (3) three geographically based hearing coordination centers. The Southern California Hearing Coordination Center (SCHCC) located in Long Beach serves the southern part of the state including Santa Barbara County. The 2000 census estimated the Santa Barbara County population to be 386,844 with about 37% reporting to be Hispanic. The three largest cities in this area are Santa Barbara, Goleta, and Lompoc.

The NHSP in Santa Barbara County can be described as "emerging" with follow-

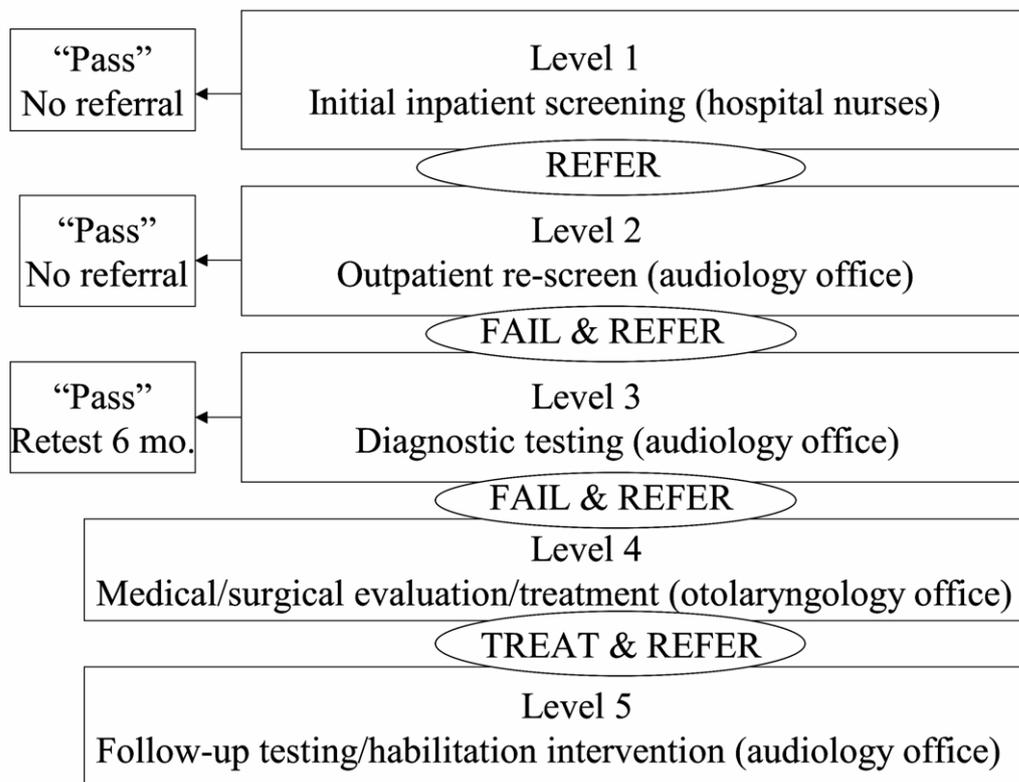


Figure 1. Flowchart of the community-/private practice-based NHSP.

up audiologic services provided mainly by Hearing Consultants of California (HCC), an audiology private practice with offices in Lompoc and Santa Barbara. Babies in this study were born at three different hospitals. The Cottage Health System operates both the Santa Barbara Cottage Hospital (SBCH) and the Goleta Valley Cottage Hospital (GVCH). The SBCH is a 436-bed acute-care facility, and is the largest teaching hospital between San Francisco and Los Angeles. It has over 18,000 admissions and 2,200 births per year. The SBCH has an extensive maternal-child health program with a newborn intensive care unit (NICU) and began an NHSP in March 2000. All babies who did not pass automated auditory brainstem response screenings administered by nurses in the well-baby or NICU nurseries of the hospital NHSP were referred to HCC for follow-up screening and/or diagnostic transient- and/or distortion-product-otoacoustic emission and/or auditory brainstem response testing (as necessary) by an audiologist. The GVCH is a 122-bed acute-care hospital with nearly 1,500 admissions each year. It has over 300 births per year, no NICU or formal NHSP, and the hospital staff and pediatricians referred babies inconsistently to HCC for hearing screening. The third hospital, Lompoc Healthcare District Hospital (LHDH), is a 60-bed acute-care hospital having over 500 births per year, but no NICU; all babies with medical issues are transferred to the NICU at SBCH. During this study, the hospital did not have a formal NHSP in place (it received certification in 2004), and babies were referred to HCC for initial hearing screening by the hospital staff and pediatricians. The numbers of babies seen for outpatient NHSP services at HCC during this study were 19 in 2000, 28 in 2001, 31 in 2002, and 28 in 2003. All testing took place in either the Lompoc or Santa Barbara offices of HCC. Possible patient scenarios for referral are depicted in the flowchart on Figure 1. Although SBCH had its own NHSP, babies who were either missed prior to hospital discharge or did not pass screening on an inpatient basis were referred to HCC for outpatient services. Because GVCH and LHDH had no NHSPs, their babies were referred to HCC for initial screening and necessary follow-up on an outpatient basis.

Subjects

Potential subjects were parents of 106 infants (52 boys and 54 girls) born between March 2000 and February 2003. All babies had been referred to a private practice (HCC) for initial screening and/or follow-up testing. The parents were diverse regarding socioeconomic status, and 26 of the infants' parents were primarily Spanish speaking. Of the 106 babies, 11 spent some time in the neonatal intensive care unit (NICU), and 95 babies were from the well-baby nursery. Thus, questionnaires designed for this study (discussed below) were mailed to the parents of the 106 babies; 36 were returned for a response rate of 34%.

Respondents returning the questionnaires were parents of 36 infants (21 boys and 15 girls) whose dates of birth ranged from March 2000 to February 2003. Six of the respondents were primarily Spanish speaking, and 30 were English speaking. Six infants spent some time in the NICU. Sixteen of the respondents had babies born in the SBCH but were referred to HCC for initial screening because they were missed in the hospital, or for rescreening and/or diagnostic testing. The other 20 babies were born at either the GVCH, LHDH, or outside of these hospital settings.

Instrument

The "Probe of Parents' Perceptions: An Early Hearing Detection and Intervention (EHDI) Outcome Measure" (PPP) was used to elicit parents' impressions of this local emerging NHSP. The PPP is an 11-item process-driven questionnaire that sequentially elicits information about respondents' demographic information and perceptions of the service-delivery continuum of NHSPs. The PPP asks parents about consent issues for the NHSP, the explanations provided for the purpose of the screening and the screening results, and, if necessary, the referral process.

Because no process-driven parent questionnaire has been published, we developed the PPP for use in this study, and for assessing similar programs nationally. For some items, we borrowed or modified questions from other surveys to suit our needs; for the rest, we generated completely

new questions. The entire PPP was developed through an exhaustive iterative process using input from staff at the local hospitals, the SCHCC, and other experts in the field. Several versions of the PPP were constructed and pilot tested until we arrived at the final forms shown in the Appendixes. We developed the PPP in both English and Spanish versions because of the Hispanic segment of the population in Santa Barbara County. A team of native Spanish bilingual speakers directly translated the PPP into Spanish to match the final English version. Entire phrases and sentences were translated from English into Spanish in order to preserve the content of the English version. Once the team of bilingual speakers completed the translation process, the final Spanish version was pilot tested on a small group of Hispanic parents. Small focus groups of English-speaking and Spanish-speaking parents then determined that each questionnaire was easy to understand and complete in less than ten minutes. Appropriate psychometric steps were completed in the development of the final versions of the PPP. The English version of the PPP appears in Appendix 1 and the Spanish version appears in Appendix 2.

Procedure

The PPP was mailed to parents of 106 infants who had been referred to HCC for outpatient initial screening and/or follow-up. All parents had signed consent forms prior to receiving services at the hospitals and/or HCC. Prior to mailing, the questionnaires were numbered and coded according to birthing hospital, screening results, and outcome. Information in the HCC patient charts was used to determine whether the English or Spanish version of the PPP was mailed to parents. If there was any doubt about the primary language spoken in the home by the parents, then both versions were mailed for the parents to self-select the appropriate form. Each questionnaire was accompanied by a cover letter in the appropriate language explaining the purpose of the survey and requesting the parents' participation in the study. Returned questionnaires were analyzed for parents' responses, and the results were entered onto an Excel spreadsheet. The number of each questionnaire item (rather than just a check

mark) was used in tallying the responses in order to match respondents' overall ratings of various aspects of the program to answers about respective parts of the NHSP. In this way, for example, the answers of respondents who might have rated the referral process negatively (e.g., a "5" on question 9[f]) could be analyzed relative to their experiences with the sensitivity of the hospital staff (i.e., question 9[a]) or their understanding for the need for rescreening (i.e., question 9[b]).

Data Analysis

At the conclusion of data collection, the number of responses in each category was tallied and percent of respondents' answers for each item were computed. Mean ratings were computed for items 3(b), 6(b), and 9(f), which measured parents' impressions of various aspects of the NHSP on a scale of "1" being positive to "5" being "negative." The results are provided descriptively because the sample size was too small to assess any significant differences in parents' impressions between or among different aspects of the NHSP (e.g., SBCH vs. GVCH vs. LHDH).

RESULTS AND DISCUSSION

This study involved 106 parents of children born between March 2000 and February 2003, who were retrospectively sent surveys regarding their participation in an emerging community-based NHSP in Santa Barbara County, California. The community-/private practice-based NHSP involved three hospitals with only one having screening done on-site, and with initial screenings, rescreenings, and/or diagnostic evaluations completed by a private practice for the other two hospitals. Thirty-six of the 106 parents (34% response rate) returned the "Probe of Parents' Perceptions: An Early Hearing Detection and Intervention (EHDI) Outcome Measure." This response rate compares favorably with those reported by Abdala de Uzcategui and Yoshinaga-Itano (1997) for suburban (55%) and urban (22%) parents in their hospital-based study. The PPP is a process-driven, 11-item questionnaire that asks parents about their impressions of the explanation of the purpose of the screening, explanation of the results, and the referral process. The results

of the study provide parents' impressions of specific components of the process, a qualitative response analysis of neutral-to-negative impressions of the NHSP, and participants' overall recommendations regarding involvement in the NHSP.

Parents' Impressions of Specific Components of the Program

The results are summarized on the following tables with the percent and number of subjects responding on items coinciding with the PPP questionnaire items as seen in the Appendixes. Some of the responses to items on the tables total over or under 100% responding due to the rounding of decimals in the calculation of percentages for response options. The number of respondents is

typically 36 but may vary due to appropriateness of items for respondents on certain questions.

Demographics and Informed Consent

Table 1 contains respondents' demographics and information about the informed consent process. Item 1 on the PPP revealed that 66.7% (24/36) of the respondents reported that their babies were born in the well-baby nursery, and 16.7% (6/36) were born in or transferred to the neonatal intensive care unit (NICU). Item 2(a) showed that nearly half or 41.6% (15/36) of the respondents said they were notified of the screening before it took place, 16.6% (6/36) after it took place, and nearly one-third or 30.5% (11/36) was not informed at all. This finding agrees with the

Table 1. Demographics and Consent (percent and number responding)

Item	Question/Responses	%	Number
1	Which nursery was your baby in?		
	Well-baby nursery	66.7	24
	Neonatal intensive care unit (NICU)	16.7	6
	Not applicable	2.8	1
	No response	11.1	4
	Not born in hospital	2.8	1
	Total	100.1	36
2(a)	When were you informed that your baby might receive a hearing screening before leaving the hospital?		
	Before the screening occurred	41.6	15
	After the screening occurred	16.6	6
	Was not informed	30.5	11
	No response	11.1	4
		99.8	36
2(b)	Did you give permission to have your baby's hearing screened?		
	Yes	69.4	25
	No	25.0	9
	No response	5.6	2
		100.0	36
	If no, explain why not?		
	<ul style="list-style-type: none"> • It was done, then we were informed. We would have agreed though. • I was told it was mandatory (in the hospital). • Hospital staff reported that it was state mandated. • Was not advised until after the procedure was done. • They didn't ask me for permission. • We wanted to wait and research the different types of screening tests available to decide which type is most effective. • No one asked us. It was great they did it. But not told prior to the test. • Nobody asked me. • Because I was not informed. 		

results of other studies (e.g., Barringer et al, 1997), which reported that only 62% of the parents in their study were aware that their baby's hearing had been screened.

Item 2(b) revealed that the majority or 69.4% (25/36) of our respondents said they gave their permission for their baby's hearing to be screened, whereas 25% (9/36) did not. The main reasons why parents did not give consent were that they were unaware of the screening, told that the procedure was mandatory, or simply not asked. Our discussions with the hospital staff revealed that they are not required to obtain additional parental consent for hearing screenings as long as parents sign all necessary consent forms during the admission process, which may explain why some parents said they were not informed and/or did not give specific consent for hearing screening in our survey.

Interestingly, our interactions with parents during outpatient follow-up audiologic sessions revealed that some admitted that they simply did not recall if their babies were screened in the hospital or if they ever gave their consent. This could become a problem with data management for NHSPs in years to come as children are seen for audiologic services when they are

older and their parents fail to recall the details of hospital NHSP screenings and the specific findings for their children. Indeed, we are now seeing children in our offices who are 3 and 4 years of age and who should have been screened as infants in NHSPs, but their parents have no recollection of the screening and its outcome. Because there is no paper trail for infants who pass their NHSP screenings, we must rely on parents' (often hazy) memories. Unfortunately, data are not always available even for those who were referred from NHSPs for further testing by private-practice audiologists. The lack of baseline-birth data could be critical in cases of late-onset or hereditary hearing losses.

Explanation of the Purpose of the Hearing Screening

Table 2 displays the results regarding the explanation of the purpose of the hearing screening. Item 3(a) showed that a large majority or 91.7% (33/36) of the respondents said they understood the explanation of the purpose of the hearing screening. Respondents' mean rating of the explanation

Table 2. Explanation of Purpose of the Screening (percent and number responding)

Item	Question/Response	%	Number
3(a)	Did you understand the purpose of the screening?		
	Yes	91.7	33
	No	5.6	2
	No response	2.8	1
	Total	100.1	36
3(b)	Overall, how do you rate the explanation of the purpose of the hearing screening program? (Circle a number)		
	1 Positively	33.3	12
	2	33.3	12
	3	13.9	5
	4	2.8	1
	5 Negatively	8.3	3
	No response	8.3	3
		99.9	36
3(c)	Please list any suggestions you have for improving how parents are informed about this program.		
	• Explain it before they do it.		
	• Let the staff/nurses at Goleta Valley Hospital know about this program.		
	• Let them know before hand that they're different types of screening tests available and the hospital is just one option.		
	• Brochure/handout		
	• I'm not sure if the hospital informed me of the program. I think it was our pediatrician who let us know. I'm not clear if this program is required or recommended, or how it is funded.		
	• Before releasing newborns, inform the hospital.		
	• Send more information about the program to parents.		

Table 3. Explanation of Screening Results (percent and number responding)

Item	Question/Response	%	Number
4(a)	When were you told the results of the screening		
	Right after it took place	75.0	27
	Before you left the hospital	16.7	6
	After you left the hospital	2.8	1
	No response	5.6	2
	Total	100.1	36
4(b)	Would you liked to have been told at a different time?		
	Yes	8.3	3
	No	86.1	31
	No response	5.6	2
		100.0	36
4(c)	What were the results of your baby's hearing screening? (Check all that apply)		
	Pass	42.2	19
	Fail	8.9	4
	Did not pass	15.6	7
	Refer for diagnostic testing	20.0	9
	Other	8.9	4
	No response	4.4	2
		100.0	45
5(a)	How were you told of the results of the hearing screening? (Check all that apply)		
	Written message	11.4	5
	Nurse	22.8	10
	Audiologist	38.6	17
	Doctor	9.1	4
	Pediatrician	6.8	3
	Other	4.5	2
	No response	6.8	3
		100.0	44
5(b)	If a person informed you about the screening results, was he/she knowledgeable about this program?		
	Yes	75.0	27
	No	13.9	5
	Does not apply	0	0
	Other	2.8	1
	No response	8.3	3
		100.0	36
6(a)	Did you clearly understand the explanation of the results?		
	Yes	88.8	32
	No	5.6	2
	No response	5.6	2
		100.0	36
6(b)	How would you rate the explanation of the results of your baby's hearing screening? (Circle a number)		
	1 Positively	33.3	12
	2	27.8	10
	3	11.1	4
	4	11.1	4
	5 Negatively	8.3	3
	No response	8.3	3
		99.9	36
6(c)	Please list any suggestions you have for improving the way parents are given the screening results.		
	<ul style="list-style-type: none"> • Written explanation and possible outcome. • The audiologist showed the computer screen and the different "waves." That was helpful in understanding the results and how the test is conducted. 		

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Table 3. (continued)

7(a)	Do you believe that the UNHS program had any affect on your ability to bond with your baby?		
	Yes	13.9	5
	No	77.8	28
	No response	8.3	3
		100.0	36
	If yes, please explain how:		
	<ul style="list-style-type: none"> • It helped us to look for less visible problems in our baby's health. • Thankfully, he passed, but if he hadn't I feel that it would be harder to bond due to the hearing impairment. I know that when I talk/sing to him, he hears me and responds. • Me a ayudado a entender mas a mi nino y sus problemas. • I feel more confident knowing my daughter can hear us both. • I'm not quite sure how, but I hope it will improve her hearing. 		
8	Was the hospital staff helpful in assisting you with obtaining further information about the program and follow-up?		
	Yes	41.7	15
	No	33.3	12
	Does not apply	13.9	5
	No response	11.1	4
		100.0	36
	If yes, in what form? (Check all that apply)		
	Phone numbers	40.7	11
	Pamphlets	22.2	6
	Verbal reassurance/support	18.5	5
	Other	18.5	5
		99.9	27
	Other (Please list)		
	<ul style="list-style-type: none"> • Appointment with audiologist. • Sent information to doctor. • Was given appointment and referral. • They helped with the referral, but I was upset that the screening was missed during the hospitalization. 		

of the purpose of the hearing screening on item 3(b) was generally more positive than negative (2.12) on a scale of "1" being "positive" and "5" being "negative." Item 3(c) revealed that respondents' comments regarding how to improve the explanation of the purpose of the NHSP included informing parents prior to the screening, providing different options for screening, and using brochures or handouts.

Explanation of the Results of the Hearing Screening

Table 3 shows information regarding the explanation of the hearing screening results to parents. Item 4(a) showed that 75% (27/36) of the respondents said they were told about the results of the hearing screening right after it took place, and item 4(b) revealed

that 86.1% (31/36) of the respondents were satisfied with being told at that time. Item 4(c) showed that 42.2% (19/45) of the respondents' infants received a result of "pass," while 8.9% (4/45) of the respondents stated that the results were reported as a "fail." It is important to note that the number of respondents reporting "fail" or anything other than "pass" here is high because this sample mainly involved parents whose infants were referred by the hospitals and seen for outpatient follow-up at an audiology practice. Thus, this sample would naturally contain more true hearing losses and false positives than would be reported for the total inpatient screenings performed in the hospitals. We note that the hospital staff should avoid using words like "fail" and "deaf" in reporting screening results to parents, because they may contribute to parental anxiety. This is one example of how the results

of this study have already been useful in monitoring and making changes in our NHSP. Once we received this feedback from the parents, we counseled the hospital staff about “when” and “what” to say to parents in discussing screening results. The feedback was well received by the staff, and appropriate changes were made immediately to improve the program.

The number of responses to PPP item 4(c) was greater than the number of respondents because parents were instructed to check all options that applied. The same was true for item 5(a), which asked how respondents were told about the results of the screening, and which revealed that audiologists explained the results 38.6% (17/44) of the time, followed by nurses at 22.8% (10/44) and written messages at 11.4% (5/44). Item 5(b) showed that 75% (27/36) felt that the person explaining the results to them was knowledgeable about the program, and item 6(a) revealed that 88.8% (32/36) of the respondents understood the explanation of the results. Item 6(b) revealed that respondents’ mean rating of the explanation of the results of the screening was generally more positive than negative (2.27) on a scale of “1” being “positive” and “5” being “negative.” Because item 6(c) failed to produce many useful suggestions for improving the way parents are given the screening outcomes and, taken with the results on item 6(a) and 6(b), we infer that these parents were pleased overall with the explanation of the screening results for their babies. Thus, we conclude that this part of the NHSP is successful, because the Joint Committee on Infant Hearing (2000) stated that screening results should be communicated to families verbally and in writing by health-care professionals who are knowledgeable about hearing loss and making appropriate interpretations.

Item 7(a) revealed that over three-fourths or 77.8% (28/36) of these parents did not feel that the NHSP had any affect on their ability to bond with their babies. In fact, the 13.9% (5/36) who felt that the NHSP did affect the bonding process made only positive comments about the program. For example, one respondent commented that the screening process “helped us to look for less visible problems in our baby’s health,” while another said, “I feel more confident knowing my daughter can hear us both.” These results are consistent with those of previous research

demonstrating that little parental anxiety results from NHSPs (Barringer et al, 1997; Magnuson and Hergils, 1999; Clemens et al, 2000; Hergils and Hergils, 2000; Stuart et al, 2000). Item 8 showed that 41.7% (15/36) of the parents said the hospital staff was helpful in providing further information (e.g., getting phone numbers, setting follow-up appointments, giving pamphlets, and offering verbal support) about the program and follow-up, while 33.3% (12/36) said the staff was not helpful; the rest either did not reply or said this did not apply.

Impressions of the Referral Process

Table 4 illustrates information regarding parents’ perceptions of the referral process. Nearly half or 47.2% (17/36) of the parents indicated that they participated in the referral process; most of these were referred from the SBCH. Item 9(a) in Table 4 showed that 88.2% (15/17) of these parents reported that the hospital staff was sensitive to the needs of their baby and family; 88.2% (15/17) understood the need for rescreening as seen in item 9(b); and all but one or 94.1% (16/17) kept their baby’s outpatient hearing (re)screening appointment within two days to six months of discharge from the hospital as seen in item 9(c). Most appointments were made within one month of discharge. Item 9(d) revealed that nearly half or 47.0% (8/17) of the infants passed the rescreening, and item 9(e) showed that 88.2% (15/17) of these parents understood the need for further testing. Respondents’ mean rating of the referral process shown in item 9(f) was mostly positive (2.12) on a scale of “1” being “positive” and “5” being “negative.” These parents provided a few useful suggestions for improving the referral process as listed in item 9(g) of Table 4.

Qualitative Response Analysis of Parents’ Impressions

Respondents’ qualitative responses were analyzed according to how positively or negatively they perceived each aspect of the NHSP. Recall that respondents had an opportunity to rate, on a scale of 1 to 5 with “1” being “positive” and “5” being “negative,” the explanation of the purpose of the

Table 4. Referral Process (percent and number responding)

Item	Question/Response	%	Number
9(a)	Was the hospital staff sensitive to the needs of your baby and family?		
	Yes	88.2	15
	No	5.9	1
	No response	5.9	1
		100.0	17
9(b)	Did you clearly understand the need for hearing rescreening?		
	Yes	88.2	15
	No	5.9	1
	No response	5.9	1
		100.0	17
9(c)	Did you keep your baby's hearing screening appointment?		
	Yes	94.1	16
	No	0	0
	No response	5.9	1
		100.0	17
	If yes, how soon after you left the hospital did you go?		
	<ul style="list-style-type: none"> • 1 week • Couple weeks • Within 1 month • 3 days • As soon as we returned to California and our doctor referred us • 2 days • 3 weeks • Within 1 week • 1 month • 2 weeks • 40 days • I set the appointment myself when she was a few months old. • I made the appointment at his 4-month well-baby exam. • 6 months • When I found out she needed to go to re-screening program 		
9(d)	What were the results of the rescreening?		
	Pass	47.0	8
	Fail	29.4	5
	Refer for diagnostic testing	11.8	2
	No response	11.8	2
		100.0	17
9(e)	Is it clear to you why there is a need for further testing?		
	Yes	88.2	15
	No	11.8	2
		100.0	17
9(f)	Overall, how would you rate the referral process? (Circle a number)		
	1 Positively	47.0	8
	2	11.8	2
	3	17.6	3
	4	11.8	2
	5 Negatively	5.9	1
	No response	5.9	1
		100.0	17
9(g)	Please list any suggestions you have for improving the referral process.		
	<ul style="list-style-type: none"> • I was very stressed that I was told I would have to keep my baby very still and to bring her asleep. I wonder how many 6 month-olds are actually sleeping during their test. As it went, it was no big deal. My daughter sat still enough for the test. • I think the receptionist should tell parents that the child will need to be still and if the child is asleep this is even better. • Let the parents know as soon as possible. 		

screening on question 3(b), explanation of the screening results on question 6(b), and the referral process on question 9(f). This analysis explored in greater detail the experiences of respondents who perceived aspects of the program as being either neutral or more negative (i.e., ratings of 3 to 5). For example, six out of nine respondents who had either neutral or negative views of the explanation of the purpose of the screening said they were either informed of the screening only after it occurred or not at all, suggesting that they may have wanted some information prior to the screening. Support for this assumption is reflected in the respondents' qualitative comments for improving the explanation of the purpose of the screening as shown in question 2(b). These findings are in agreement with those of another study (Weichbold et al, 2001) which found that mothers who were advocates of NHSPs were more likely to have been better informed about the NHSP than those who were not. Surprisingly, only one of nine respondents who rated the explanation of the purpose of screening as either neutral or negative did not understand what was explained, suggesting that prior explanation of the purpose of hearing screening may be a factor in parents' overall impressions of NHSPs.

Item 6(b) revealed that 11 of the 36 respondents had neutral-to-negative impressions about the explanation of the screening results. Closer analysis revealed that 10 of these 11 respondents' babies had results of "fail," "did not pass," or "refer for diagnostic testing." Thus, their neutral-to-negative ratings of the explanation of the screening results may be related to the anxiety these parents may have felt when receiving referrals for their infants (Magnuson and Hergils, 1999; Hergils and Hergils, 2000). No consistent pattern emerged regarding either the method (e.g., verbal or written) or the job description of the informer (e.g., nurse, audiologist, doctor, etc.) that could provide an explanation of the respondents' neutral-to-negative impressions. However, 4 of 11 of these respondents felt that the person who explained the screening results did not seem knowledgeable about the NHSP, suggesting that parents want to feel that the informant is confident and competent with the program.

Eight of 11 of these respondents said they were informed of the hearing screening

results right after it took place. Similarly, only 2 of these 11 respondents wanted to be informed at a different time, suggesting that timing probably was not an issue for most of the respondents who gave less than positive ratings of the explanation of the screening results. Only 3 of 11 of the respondents providing neutral-to-negative ratings said they did not have a clear understanding of the explanation of the screening results. Respondents' written comments on item 6(c) indicated a desire to have results explained in written form. Another parent expressed appreciation for the time that the audiologist spent in explaining the specifics of the test protocol. In summary, negative screening results for their babies, rather than other factors (e.g., method of notification, type of health-care professional, and timing of notification), may have contributed to some of these respondents' less than positive impressions about the explanations of the screening results.

Although 6 of 17 respondents had neutral-to-negative impressions of the referral process, 5 out of these 6 said that the hospital staff was sensitive to the needs of their baby and family, and that they understood the need for rescreening. All of these respondents kept their baby's hearing rescreening appointments, indicating that they also understood the need for timely compliance for follow-up. Further, 3 of these 6 respondent's babies passed the rescreening, and 2 were referred for diagnostic testing. Five of these 6 said that the results of the rescreening were clear. One indicated that she was stressed when told that she would have to keep her baby very still and to bring her to the rescreening in a "sleepy state." In summary, no clear pattern of responses was gleaned from the data as to why these few respondents had neutral-to-negative impressions about the referral process.

Parents' Overall Impressions of the NHSP

Table 5 presents respondents' overall recommendations about the NHSP. Item 10 in Table 5 showed that 88.9% (32/36) of the respondents reported that they would recommend a NHSP if they knew someone who was expecting a baby or were anticipating another baby in their own family;

Table 5. Overall Recommendation of UNHSPs (percent and number responding)

Item	Question/Responses	%	Number
10	If you knew someone that was expecting a baby, or if you yourself were, would you recommend UNHS?		
	Yes	88.9	32
	No	5.6	2
	I don't know	2.8	1
	No response	2.8	1
		100.1	36
11	Please add any additional comments.		
	<ul style="list-style-type: none"> The hospital process is great for passing babies, but for mine, who half-passed, it was very precarious. Took about an hour to keep trying to pass his failing ear. Seems like they need more sensitive and efficient equipment. We found the screening process well done and explained to us from the beginning and the steps taken by the hospital personnel appropriate. The hearing test is very good so you can catch it early and hopefully prevent permanent damage. Luckily, my son had only fluid in his ears and passed. Thank you for your help. I would highly recommend the test and not until they are three months of age. Very difficult to test a 1 month-old baby the current way it is done. The probes do not stay in ears properly thus giving potentially erroneous results. There must be a better technique. We would have liked this at Lompoc Hospital, but it was not available. I really liked the doctor who did my daughter's hearing test. I like having everything explained to me like the doctor did. Our hospital was not set up for the test so they sent us a letter with a scheduled appointment with the doctor. There was some question about why it was scheduled and who would have to pay for it until I got to the appointment. I think every child should have this done. I would highly recommend it. 		

only two responded “no.” Respondents’ comments listed on item 11 were generally positive and useful. At least two parents commented on the difficulty in testing very young infants and suggested the need for better techniques and equipment. That these parents generally had positive impressions of this emerging community-/private practice-based NHSP is in agreement with the results of previous studies involving much larger hospital-based NHSPs (Abdala de Uzcatogui and Yoshinaga-Itano, 1997; Barringer et al, 1997; Magnuson and Hergils, 1999; Hergils and Hergils, 2000; Weichbold, et al, 2001). Our respondents’ perceived value of the process seemed to outweigh any inconveniences experienced in this emerging community-based NHSP. Although these parents’ positive impressions may be due in part to the efforts of the audiologists in this private practice, the scenario depicted here is probably a common service-delivery model in many communities throughout the United States. Audiologists in private practice need support from both hospital administrators and state agencies in coordinating the follow-up of infants who are referred to them for audiologic services to ensure that they do not “fall between the cracks.”

As for larger hospital-based NHSPs, outcomes measurement is critical for emerging community-/private practice-based NHSPs for tracking follow-up. Surveying parents’ impressions of the process is a vital component to these measures. The PPP was particularly useful in this study because it permitted us to isolate and analyze parents’ reactions to various stages in the service-delivery continuum. Process-driven outcome measures are useful in assessing critical junctures in NHSPs that can determine a positive or negative outcome for children and their parents. For example, Magnuson and Hergils (1999) found that a critical point for parents is when their child initially does not pass a second hearing screening. They found that parents whose children had to be tested more than twice had greater anxiety than parents whose children passed in the first or second hearing screening. They found that although these parents were particularly vulnerable during this time and required extra support and counseling, their anxiety diminished quickly when they received the test results, either positive or negative. The investigators identified critical transition points in the referral process and recommended that diagnostic evaluations

should be scheduled as soon as possible to minimize potential parental anxiety.

It is crucial that all NHSPs, whether hospital or community based, be evaluated constantly to monitor their success and to make changes to them as necessary. Parental perceptions of their experiences with these programs are a vital component to such evaluations. We conclude that process-driven outcome measures such as the PPP can provide program managers with important information about critical stages in the screening and follow-up process. Although most of the parents sampled here were satisfied with the program, perceived its value, and would recommend it to others, a few expressed negative appraisals about certain aspects of this NHSP. Their constructive suggestions have already been incorporated to make this a better NHSP. Thus, the PPP allowed us to identify some problem areas with this NHSP and to fix them quickly. We note, however, that the small number of participants and the unique nature of this study may limit the ability to generalize our findings to the population at large.

Nevertheless, the PPP can be used for both formative and summative evaluations of NHSPs. For example, this study was a retrospective survey completed *after* parents' participation in the NHSP (i.e., summative evaluation). The PPP can also be administered to address parents' immediate needs at different points *during* participation in the often incongruent NHSP service-delivery continuum (i.e., formative evaluation). Thus, the PPP can be used as an outcome measure for parents who report that continuity of care is critical for coping with the diagnoses of their children's hearing losses (Luterman and Kurtzer-White, 1999; English et al, 2004) in order to streamline and remedy problems with NHSPs in a timely manner.

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Disclaimer. The first author is the consulting audiologist for the hospitals and is the owner of the private practice described in this study.

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Appendix 1. Probe of Parents' Perceptions (PPP): An Early Hearing Detection and Intervention (EHDI) Outcome Measure

INSTRUCTIONS: Recently, your baby's hearing was screened as part of the Universal Newborn Hearing Screening (UNHS) Program. We are interested in obtaining information from you about your experience with this program to help us evaluate and improve parents' experiences with it. Your name will not be used and there are no "right" or "wrong" answers, so please respond as honestly as possible. Please ask for clarification if you have any questions, provide comments on the form if necessary, and complete both pages. Thank you for your help.

Demographics and Consent Check person completing this form:

mother father relative friend interpreter

1. Which nursery was your baby in?
 Well-baby nursery Neonatal Intensive Care Unit (NICU)
 2. a. When were you informed that your baby might receive a hearing screening before leaving the hospital?
 Before the screening occurred
 After the screening occurred
 Was not informed
 - b. Did you give permission to have your baby's hearing screened?
 Yes
 No => If no, please explain why not? _____
-

Explanation of Purpose of Screening

3. a. Did you clearly understand the explanation of the purpose of the hearing screening?
 Yes No
 - b. Overall, how do you rate the explanation of the purpose of UNHS? (Circle a number)
 Positively 1 2 3 4 5 Negatively
 - c. Please list any suggestions you have for improving how parents are informed about this program.
-

Explanation of Screening Results

4. a. When were you told the results of the screening?
 Right after it took place
 Before you left the hospital
 After you left the hospital
- b. Would you like to have been told at a different time?
 Yes => If yes, when? _____
 No
- c. What were the results of your baby's hearing screening? (Check all that apply)
 Pass Fail Did not pass Refer for diagnostic testing
 Other (Please List) _____
5. a. How were you told about the results of the hearing screening? (Check all that apply)
 Written message Nurse Audiologist Doctor
 Pediatrician
 Other (Please list) _____
- b. If a person informed you about the screening results, was he/she knowledgeable about this program?
 Yes No Does not apply

6. a. Did you clearly understand the explanation of the hearing screening results?
 Yes No
- b. How would you rate the explanation of the results of your baby's hearing screening? (Circle a number)
Positively 1 2 3 4 5 Negatively
- c. Please list any suggestions you have for improving the way parents are given the hearing screening results.

7. Do you believe that the UNHS program had any affect on your ability to bond with your baby?
 Yes => If yes, please explain how? _____
 No
8. Was the hospital staff helpful in assisting you with obtaining further information about the UNHS program and follow up?
 Yes => If yes, in what form?
(Check all that apply) phone numbers pamphlets
 Verbal reassurance/support Other (Please list) _____
 No
 Does not apply

If your baby passed the initial hearing screening and was not referred for a follow up appointment, go to question 10.

If your baby did not pass the initial hearing screening and was referred for a follow up appointment, go to question 9.

Referral Process

9. a. Was the hospital staff sensitive to the needs of your baby and family?
 Yes No
- b. Did you clearly understand the need for hearing rescreening?
 Yes No
- c. Did you keep your baby's hearing rescreening appointment?
 Yes => If yes, how soon after you left the hospital did you go? _____
 No => If no, please explain why not? _____ (Go to question 10e)
- d. What were the results of the hearing rescreening?
 Pass Fail Refer for diagnostic testing
- e. Is it clear to you why there is a need for further hearing testing?
 Yes No
- f. Overall, how would you rate the referral process? (Circle a number)
Positively 1 2 3 4 5 Negatively
- g. Please list any suggestions you have for improving the referral process.

10. If you knew someone who was expecting a baby, or if you yourself were, would you recommend UNHS?
 Yes
 No => If no, please explain why not? _____
11. Please add any additional comments.

Thank you for your participation. Please return the questionnaire in the stamped envelope provided.

OVER =>

Appendix 2. Investigación de la Percepción de los Padres: Medidas de los Resultados de los Programas para la Detección Auditiva e Intervención Temprana (PPP-S)

INSTRUCCIONES: Recientemente, su bebé tuvo una prueba del sentido del oído como parte del Programa de Pruebas del Sentido de Oído Para Recién Nacidos. Estamos interesados en su opinión sobre su experiencia con este programa para ayudarnos evaluar y mejorar las experiencias de otros padres. Su nombre no va ser usado y no hay respuestas correctas o incorrectas. Por favor responda lo mas honesto posible. Por favor pregunte por clarificación si tiene preguntas, haga comentarios en la forma y complete las dos paginas. Gracias por su ayuda.

Demográficos y Aprobación Marque persona que este completando este forma:

madre padre familiar amigo enterprete

1. ¿En cual guardería estaba su bebé?
 "Well-baby" guardería Neonatal Intensive Care Unit (NICU)
2. a. ¿Cuándo fue informado que su bebé probablemente recibiría una prueba del sonido del oído antes de salir del hospital?
 Antes de que la prueba ocurrió
 Después que la prueba ocurrió
 No fue informado
- b. ¿Usted dio su permiso para tomar la prueba del sonido del oído en su bebé?
 Si
 No => Por favor explique por que no _____

Explicación del Propósito de la Prueba

3. a. ¿Entendió claramente la explicación del objeto / objetivo de la la prueba?
 Si No
- b. En total, como calificaría la explicación del propósito del Programa del Sentido del Oído de recién nacidos? (Circule un numero)
 Positivo 1 2 3 4 5 Negativo
- c. Por favor liste cualquier comentario que usted tiene para mejorar como padres son informados sobre este programa. _____

Explicación de los Resultados de la Prueba

4. a. ¿Cuándo fue notificado de los resultados de la prueba?
 Imediatamente después de tomar la prueba
 Antes de salir del hospital
 Después de salir del hospital
- b. ¿Hubiera preferido enterarse de los resultados en otro momento?
 Si => ¿Cuándo? _____
 No
- c. ¿Que fueron los resultados de la prueba del sonido del oído de su bebé? (Marque todos los que aplican)
 Pasó Falló No Pasó Consultar con un audiólogo
 Otro (Por favor liste) _____
5. a. ¿Como fue informado de los resultados de la prueba? (Marque todo que aplica)
 Mensaje escrito Enfermera Audiologo Doctor Pediatra
 Otro (Liste por favor) _____
- b. ¿Si una persona le dijo de los resultados, estaba el / ella informado/a sobre este programa?
 Si No No aplica
6. a. ¿Entiende usted claramente la explicación de los resultados?
 Si No

- b. ¿Como califica la explicación de los resultados de la prueba de oír en su bebé?
(Circule un numero)
Positivo 1 2 3 4 5 Negativo
- c. Por favor liste cualquier comentario que tiene para mejorar la manera en que padres se enteran de los resultados de la prueba. _____

7. ¿Usted cree que el Programa del Sonido del Oído de Recién Nacidos tenia un afecto en su habilidad de encariñarse con su bebé?
___ Si => ¿Si acaso si, en que manera? _____
___ No
8. ¿Fue el personal del hospital de ayuda en asistirle a obtener mas información sobre el programa y pruebas adicionales?
___ Si => ¿Si acaso si, en que manera?(Marque todo lo que aplica) ___ Números de teléfono
___ folletos ___ apoyo verbal ___ Otro (liste por favor) _____
___ No
___ No aplica

Si su bebé paso la prueba inicial y no fue referido para una prueba adicional, siga a la pregunta 10. Si su bebé no paso la prueba inicial y fue referido para una prueba adicional, siga a la pregunta 9.

Proceso de Referir

9. a. ¿Fue el personal del hospital sensible hacia sus sentimientos y el bienestar de su bebé?
___ Si ___ No
- b. ¿Entendió usted claramente la necesidad de tomar la prueba otra vez?
___ Si ___ No
- c. ¿Asistió la cita para la prueba adicional de su bebé?
___ Si => ¿Si acaso si, que pronto fue a la cita después de salir del hospital? _____
___ No => ¿Porque no? _____ (Siga a la pregunta 10e)
- d. Que fueron los resultados de la prueba adicional?
___ Paso ___ No paso ___ Consultar para pruebas diagnósticos
- e. ¿Entiende claramente la necesidad de las pruebas adicionales?
___ Si ___ No
- f. ¿Sobre todo, como califica usted el proceso de referencia? (Circule un numero)
Positivo 1 2 3 4 5 Negativo
- g. Por favor liste cualquier comentario que tiene para mejorar el proceso de requerimiento.

10. ¿Si usted conociera a alguien que estuviera esperando un bebé o si usted estaba esperando un bebé, recomendaría la prueba del sentido del oído?
___ Sí ___ No => ¿Porque no? _____

11. Por favor incluya comentarios adicionales.

Gracias por su participación. Por favor devuelva el cuestionario en el sobre con estampilla.