

Parents' Compliance with and Impressions of a Maturing Community-Based Early Hearing Detection and Intervention Program: An Update

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Abstract

Background: For quality assurance reasons, it is important to monitor the services provided over time for infants and their families through both hospital and community-based early hearing detection and intervention programs (EHDIPs) and to compare results for local programs to national benchmarks. This two-part study is an update to earlier reports published for a particular EHDIP.

Purpose: To evaluate a maturing, diverse community-based EHDIP partially managed through a private practice in Santa Barbara, California, and to compare results to earlier reports for this program and to national data.

Research Design: A parent questionnaire and a retrospective case-report chart review process was used.

Study Sample: Charts were reviewed for 150 babies that were referred to the practice from two hospitals and were seen for screenings and follow-up. Also, parents of 34 infants seen beyond their initial or secondary screenings were surveyed about their experiences with and impressions of the program.

Data Collection and Analysis: Babies seen by the practice between May 2003 and November 2006 were tracked across five levels (from hospital screening through intervention) to determine if parents complied with professionals' recommendations, time taken to comply, and highest level reached and whether it was an appropriate termination point. Also, parents' responses to an 11-item questionnaire assessing their impressions about their participation in the program were analyzed and compared to the compliance data.

Results: Of the 150 babies, 116 passed initial or secondary screenings; compliance details at the subsequent levels of follow-up are provided for the remaining 34 infants. Seven of the 34 families completed the questionnaire. Compliance at early levels was excellent, meeting EHDIP benchmarks and previous results for this program; that for subsequent levels was poorer, possibly due to the diverse population. Parents' impressions of this program ranged from neutral to generally positive.

Conclusions: This maturing EHDIP generally met national benchmarks and continued to serve the infants and families well. However, parents' compliance with physician visits and audiologic follow-up for habilitation including hearing aids in a timely manner could still be improved.

Key Words: Benchmarks, diversity, early hearing detection and intervention programs, multicultural, newborn hearing screening programs, parents' compliance, parents' impressions, questionnaire

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Abbreviations: CCS = California Children's Services; EHDIP = early hearing detection and intervention program; GVCH = Goleta Valley Cottage Hospital; HCC = Hearing Consultants of California; JCIH = Joint Committee on Infant Hearing; NHSP = newborn hearing screening program; NICU = neonatal intensive care unit; PE = pressure equalization; *PPP* = Probe of Parents' Perceptions; SBCH = Santa Barbara Cottage Hospital; SCHCC = Southern California Hearing Coordination Center; WBN = well-baby nursery

Sumario

Antecedentes: Por razones de aseguramiento de calidad, es importante monitorear los servicios proporcionados en el tiempo para infantes y sus familias de programas de intervención y detección auditiva temprana basados tanto en el hospital como la comunidad (EHDIP) y comparar los resultados con programas locales para establecer punto de referencia nacional. Este estudio en dos partes es una actualización de reportes más tempranos publicados para un EHDIP particular.

Diseño de la Investigación: Se utilizó un cuestionario para los padres y un proceso de revisión de tablas de reporte de casos.

Muestra del Estudio: Se revisaron los expedientes de 150 bebés que fueron referidos de dos hospitales y que se vieron para tamizaje y seguimiento. También, los padres de 34 niños que fueron vistos más allá de sus tamizaje inicial y el secundario, fueron encuestados sobre sus experiencias e impresiones del programa.

Recolección y Análisis de los Datos: Los bebés visto institucionalmente entre mayo 2003 y noviembre 2006, fueron seguidos durante cinco niveles (del tamizaje hospitalario hasta la intervención) para determinar si los padres cumplían con las recomendaciones profesionales, el tiempo utilizado para cumplir, y el mejor nivel alcanzado, y si éste constituía un punto de terminación apropiado. También, se analizaron las respuestas de los padres ante un cuestionario de 11 preguntas que evaluó sus impresiones sobre su participación en el programa y se compararon con los datos de cumplimiento.

Resultados: De los 150 bebés, 116 pasaron el tamizaje inicial o el secundario; se aportan detalles de cumplimiento en los niveles subsecuentes de seguimiento de los 34 infantes restantes. Siete de las 34 familias completaron el cuestionario. El cumplimiento a niveles tempranos fue excelente, llegando a la marca de referencia del EHDIP y resultados previos para este programa; para niveles subsecuentes los resultados fueron más pobres, posiblemente debido a una población diversa. Las impresiones de los padres sobre el programa fueron de neutras a generalmente positivas.

Conclusiones: Este EHDIP en proceso de maduración generalmente cumple con las marcas de referencia nacionales y continúa sirviendo bien a infantes y familias. Sin embargo, el cumplimiento de los padres con citas médicas y seguimiento audiológico para una habilitación en forma oportuna, incluyendo audífonos, podría ser mejorado.

Palabras Clave: Marca de referencia, diversidad, programas de detección auditiva temprana e intervención, multicultural, programas de tamizaje auditivo neonatal, cumplimiento de los padres, impresiones de los padres, cuestionario

Abreviaturas: CCS = Servicios para Niños de California; EHDIP = programa de detección e intervención auditiva temprana; GVCH = Goleta Valley Cottage Hospital; HCC = Consultores Auditivos de California; JCIH = Comité Conjunto sobre Audición Infantil; NHSP = Programa de Tamizaje Auditivo de Recién Nacidos; NICU = Unidad de Cuidados Intensivos Neonatales; PE = ecualización de presiones; *PPP* = *Sondeo de Percepción de los Padres*; SBCH = Santa Barbara Cottage Hospital; SCHCC = Centro de Coordinación Auditivo de California del Sur; WBN = guardería del niño sano

Although all 50 states and the District of Columbia presently operate early hearing detection and intervention programs (EHDIPs), tracking babies to insure that they receive needed services and are not lost to follow-up continues to be problematic, especially for community-based programs that are managed mainly by small private audiology practices serving diverse, multicultural populations. Continual assessment of EHDIPs both nationally and locally is essential for ensuring that recommended

benchmarks are met and efforts are made to reduce negative outcomes. According to the Joint Committee on Infant Hearing (JCIH, 2000), all infants should receive a hearing screening by one month of age, and if a hearing loss is suspected, then infants must receive a confirmed diagnosis by three months and have intervention services initiated by six months of age (i.e., the 1-3-6 goals). Although these benchmarks were in effect at the time of this study and were used here, it is important to note that the *JCIH Year 2007 Position*

Statement recently updated them, stating that hearing aid fittings should occur within one month of diagnosis, among other recommendations (JCIH, 2007).

In 2005, 36 states screened over 90% of their infants, but the percentages varied for the remaining states (Department of Health Services Centers for Disease Control and Prevention, 2007; National Center for Hearing Assessment and Management [NCHAM] 2007). About 2% of the infants screened did not pass final testing, and nearly 67% of those received “no documented diagnosis” (i.e., “in process,” “died or parents declined services,” “non-residents or moved out of jurisdiction,” and “unable to contact/unresponsive/unknown”) with 60% (38,619) being lost to follow-up. Prevalence of hearing loss was estimated to be about 1/1,000 infants. Of those with hearing loss, nearly 84% were referred for early intervention, but only 70% were actually enrolled; 21% were not confirmed to be receiving services. Other estimates indicated that about 34% of infants who failed screenings did not get a confirmed diagnosis of hearing status afterward, and that 23% of those who did were never referred to early intervention services (Shafer, 2007).

Although California had the largest number (i.e., 540,997) of babies born in this country, it screened only about 78% of its babies in 2005, up from 66% in 2004 (NCHAM, 2007). California’s poor screening rates reflect aspects of the program’s design and the diversity of its population. As of January 2008, all California hospitals licensed for perinatal services will be required to have newborn hearing screening programs (NHSPs) that will screen 98% of their babies (California Legislature, 2006). However, until 2008, only hospitals approved by California Children’s Services (CCS), which provides health care to indigent children, are required to have NHSPs and report statistics (State of California, 2007; NCHAM, 2006, California Newborn Hearing Screening Program, 2007). As California’s population continues to increase and diversify, it will be important to monitor the individual components of its EHDIPs and evaluate ways to improve their success.

Persons of Hispanic or Latino origin constitute the largest minority population (32.4%) in California (U.S. Census Bureau, 2000a). It is important to investigate how successful EHDIPs are at serving the Hispanic community, which continues to increase annually. Recently, Steinberg and colleagues (2003) evaluated decisions that Hispanic families made following the diagnosis of deafness in a child and found that consideration of intervention services was complicated by language/cultural barriers and limited access to information and resources. They concluded that a “shared language” between families and medical professionals was necessary to optimize understanding of services and options. For example, although large

hospitals usually have translators and materials in several languages readily available, this is less often the case in smaller, community-based medical and audiology venues where follow-up services to EHDIPs must be obtained via a fragmented hearing health-care continuum lacking sufficient infrastructure and resources. Often, babies in California arrive at audiology offices without a translator, which can severely compromise obtaining an accurate case history and the transmission and reception of vital information about test findings and recommendations for necessary follow-up.

Earlier, Danhauer and Johnson (2006a, 2006b) described and assessed an emerging, community-based EHDIP in Santa Barbara, CA. Their retrospective chart review of 51 infants born between March 2000 and February 2003 revealed that while parental compliance for initial and follow-up rescreenings was excellent, that related to intervention services could be improved. A postal questionnaire revealed that 36 parents whose children received screenings had generally positive impressions of the program. The present status of this EHDIP can be considered maturing rather than emerging, and its stabilization in recent years has made it possible to investigate additional variables related to the demographics of the population it serves. Thus, the purpose of the present study was to update the description and evaluation of this community-based EHDIP by assessing parents’ compliance with professionals’ recommendations for their babies and their impressions of the program with a focus on the diversity of the population served.

METHODS

The EHDIP

California’s EHDIPs are overseen by three geographically delineated hearing coordination centers. The private practice, Hearing Consultants of California (HCC), and the EHDIP described in this study are located in Santa Barbara County, which is served by the Southern California Hearing Coordination Center (SCHCC) based in Long Beach. The 2000 census estimated the Santa Barbara County population to be 399,347 people with about 34% reported to be Hispanic or Latino (U.S. Census Bureau, 2000b).

Santa Barbara’s EHDIP continues to receive follow-up hearing screenings and audiologic services by HCC. Babies in this study were born at either Santa Barbara Cottage Hospital (SBCH) or Goleta Valley Cottage Hospital (GVCH), both owned and operated by the Cottage Health System. SBCH is an acute-care facility with over 2,400 births annually (Santa Barbara Cottage Hospital [SBCH], 2007). Its NHSP was initiated in 2000 and routinely provides automated auditory brainstem response screenings to infants

prior to discharge from its well-baby nursery (WBN) and neonatal intensive care unit (NICU). All babies who do not pass their initial inpatient screenings are primarily referred to HCC for further audiologic testing, but a few babies are also referred to other audiology groups.

GVCH is an acute-care facility having fewer than 400 births annually (Goleta Valley Cottage Hospital [GVCH], 2007), but no NICU or NHSP. All parents of babies born there are given a letter describing the concept of and need for newborn hearing screening and information about how to schedule an appointment for initial outpatient screenings at HCC, which is located across the street from the hospital. GVCH also relies on pediatricians encouraging parents to have their babies' hearing screened. Because GVCH had no system for tracking babies after they were discharged, it was difficult to determine how many parents actually followed through with hearing screenings for their babies.

Participants

This study was conducted in two parts. From May 2003 through November 2006, 150 babies (82 from SBCH and 68 from GVCH) were seen at HCC for outpatient services. Of those 150 babies, 116 passed their screenings at HCC and were not considered further here. This study focused on the 34 (22 male and 12 female) babies (and their parents) identified from HCC's Santa Barbara office's database as having been referred from either SBCH following inpatient screenings or from GVCH for initial screenings and seen during this period. Part 1 analyzed parents' compliance with professionals' recommendations for their infants, while Part 2 evaluated parents' impressions of the program. The babies in Part 1 and their parents in Part 2 were coded using the same numbers (as seen in Table 1 and Appendix 1) so that parents' compliance and perceptions could be tracked across both components of the study to gain a better understanding of issues that contributed to lack of follow-up. Of these 34 babies, 27 were referred from SBCH's WBN (10) or NICU (17). The remaining seven babies were referred from GVCH's WBN. The institutional review boards of the University of California Santa Barbara, the Cottage Health System, and the SBCH approved this study and rendered it "exempt" because it involved retrospective data collection from a statewide registry. The SCHCC also authorized use of its data in the study.

Part 1: Compliance Assessment

Procedures

Parental compliance was assessed using the five-level flowchart model developed by Danhauer and

Johnson (2006a, 2000b) for use in the evaluation of this and other EHDIPs. The model was published earlier in this journal (Danhauer and Johnson, 2006a, 2000b) and is not reproduced here. Briefly, the model evaluates EHDIPs at Level 1: initial inpatient screening conducted by nurses in the birth hospital; Level 2: outpatient rescreening performed by an audiologist in a private practice setting; Level 3: diagnostic testing performed by an audiologist; Level 4: medical/surgical evaluation/treatment at an otolaryngology office; and Level 5: follow-up and habilitative intervention by an audiologist. This study similarly defined compliance measured at each of the levels as whether parents followed through with professionals' recommendations and appointments, and if so, the time taken to comply. Compliance was evaluated by calculating the months elapsed from each infant's birth to the date of service at each level. The highest level reached and whether it should have been an appropriate stopping point for the child was also determined by the researchers' retrospective review of the 34 babies' charts.

Participants' compliance data were entered into a Microsoft Excel spreadsheet and included date of birth; birth hospital; WBN or NICU; home language (Spanish, English, other, or unknown); patient's insurance type; high-risk registry (HRR) factors (present in all NICU and some WBN babies); date(s) of outpatient rescreening and/or diagnostic testing; date(s) of hearing loss diagnosis; date(s) of referral to otolaryngologist if warranted; date(s) of hearing aid fittings if needed; and date(s) of subsequent follow-up testing and/or appointments.

Three of the authors independently assessed each chart and recorded the highest level of compliance reached and determined whether it was an appropriate stopping point for each baby on a form specifically designed for this study. The independent analyses from two of the evaluators were compared, and the third was used to resolve any discrepancies. Interjudge reliability agreement across all 34 files was 87.5% using the following formula: $(\text{agreements}/[\text{agreements} + \text{disagreements}]) \times 100$. The time taken for parents to comply was compared to JCIH benchmarks and the previous study's (Danhauer and Johnson, 2006b) findings.

Part 2: Parents' Perceptions

Instrument

Part 2 of this study employed the same 11-item *Probe of Parents' Perceptions (PPP): An Early Hearing Detection and Intervention Program (EHDIP) Outcome Measure* questionnaire created and used by Danhauer and Johnson (2006a) to evaluate parents' perceptions and opinions about their experiences with community-

Table 1. Results for Part 1

#	Gen	DOB	Lg	HRR	NICU	L2M	L3M	HL	L4M	L5M	F/U
1*	M	4/6/03	E	N	N	1.8		N			<u>N</u>
2*	M	6/3/03	E	Y	N	0.3	4.0	U,S	37.6	38.3	H
3*	M	8/7/03	E	Y	N	0.2	0.9	B,S	2.7	3.9	H
4*	M	8/19/03	S	N	N	0.3	1.0	B,S	2.5	11.5	H
5	F	10/21/03	?	Y	Y	2.6	3.5	U,S	6.8	10.3	H
6*	F	11/3/03	?	Y	Y	1.7	4.7	U,S	8.4	11.7	H
7	F	3/17/04	B	Y	N	1.1	1.1	B,S	3.2	7.4	H
8	F	3/30/04	E	N	N	0.7	1.2	B,C	16.1		R
9	F	2/20/04	?	Y	Y	2.3	2.9	B,C			R
10	F	4/23/04	S	Y	Y	0.6	1.3	U,C	11.3		O
11	M	4/28/04	S	Y	Y	1.8		B,C,a			R
12*	M	7/13/04	E	N	N	5.9	5.9	B,S			O
13	M	5/24/04	S	Y	Y	1.9	10.6	U,S,d			O
14	M	8/24/04	S	N	N	0.3	0.8	U,S	2.8	3.5	H
15	F	12/20/04	E	Y	Y	1.7	2.6	B,C, <u>N</u>	7.5		<u>N</u>
16	M	8/15/04	E	Y	Y	8.0	10.3	U,S			O
17	M	9/15/04	?	Y	Y	12.1	12.1	U,S			O
18*	M	2/25/04	E	Y	N	0.4	0.8	U,C, <u>N</u> ,p	2.2	7.4	<u>N</u>
19	F	3/17/04	E	N	N	0.4	1.1	B,S, <u>N</u>			<u>N</u>
20	F	9/19/04	S	N	N	0.5	5.4	B,S	12.3	24.5	R
21	M	1/31/05	S	Y	Y	0.7		U,C,a			R
22	M	1/10/05	S	Y	Y	1.6	3.4	B,C			R
23	M	6/23/05	?	Y	N	0.5	0.9	B,S			O
24	M	7/11/05	?	Y	Y	1.0	1.0	U,S	4.0		O
25	M	9/2/05	?	N	N	0.7	0.7	U,S, <u>N</u>			<u>N</u>
26	M	10/19/05	S	Y	N	0.9		B,C,a			R
27	M	2/24/05	S	Y	Y	0.6	14.7	B,C, <u>N</u> ,d			<u>N</u>
28	M	1/24/06	E	Y	Y	0.9	0.9	B,S			O
29	M	1/22/06	O	Y	Y	1.3	6.7	B,S	10.1		R
30	M	2/28/06	S	N	N	1.6	2.6	U,S			R
31	F	5/4/06	?	Y	Y	1.1	1.1	B,S	1.5	15.4	H
32	M	7/1/06	S	Y	Y	0.5	3.4	B,S, <u>N</u>			<u>N</u>
33	F	7/4/06	E	Y	Y	2.3		B,C			O
34	F	10/19/06	B	Y	N	0.6	3.7	B,S	3.7	4.8	H

Note: # = child; * = Goleta Valley Cottage Hospital; Gen = gender; DOB = date of birth; Lg = language spoken by parents (E = English, S = Spanish, B = bilingual, O = other, ? = unknown); HRR = high-risk register factors present; NICU = infant was in a neonatal intensive care unit; L2M = time in months to comply at Level 2 (outpatient rescreen by audiologist); L3M = time in months to comply at Level (diagnostic testing by audiologist); HL = type of hearing loss (N = normal hearing, S = sensorineural, C = conductive, U = unilateral, B = bilateral, N = normal at later testing, a = atresia, d = Down syndrome, p = cleft palate); L4 = time in months to comply at Level 4 (medical/surgical evaluation/treatment by otolaryngologist); L5 = time in months to comply at Level 5 (follow-up/habilitation intervention by audiologist); F/U = intervention with hearing aid(s) or other follow up (H = hearing aids, R = receiving medical treatment elsewhere, N = normal after later testing, O = out of compliance).

based EHDIPs. Both English and Spanish versions of the *PPP* were published earlier in this journal (Danahauer and Johnson, 2006a) and were not reproduced here. The *PPP* assesses four areas: “Demographics and Consent,” “Explanation of the Purpose of Screening,” “Explanation of Screening Results,” and the “Referral Process.” It requires parents to place an “X” by or circle their responses and provides space for them to elaborate and give opinions as to how aspects of the program can be improved. Danahauer and Johnson (2006a) found both versions of the *PPP* to be useful in eliciting parents’ impressions of this EHDIP.

Procedures

Information specific to the participants’ families (i.e., address, telephone number, insurance) was coded numerically onto a spreadsheet using Microsoft Excel. Three researchers made initial telephone calls to the babies’ parents prior to mailing the questionnaires. They informed parents about the purpose of the study and that the questionnaires would be arriving by mail. Each call used a script devised for this study and was conducted in the language expressed in the HCC charts as preferred by the parents (Spanish, English,

or both). An additional follow-up call was made if parents could not be reached or a message had been left during the first attempt. The *PPP* and a cover letter explaining its purpose was then mailed to the parents in the preferred language. The *PPP* and the stamped return envelopes provided were numerically coded using the same numbers assigned in Part 1. Parents were given ten days to complete and return the surveys.

Incoming surveys were analyzed, and the responses were entered onto a Microsoft Excel spreadsheet and rechecked for accuracy by the authors. *PPPs* not returned on time and those that came back "Return to Sender" were followed up with another telephone call in the preferred language allowing parents to provide their answers over the phone or be sent an additional copy of the *PPP*.

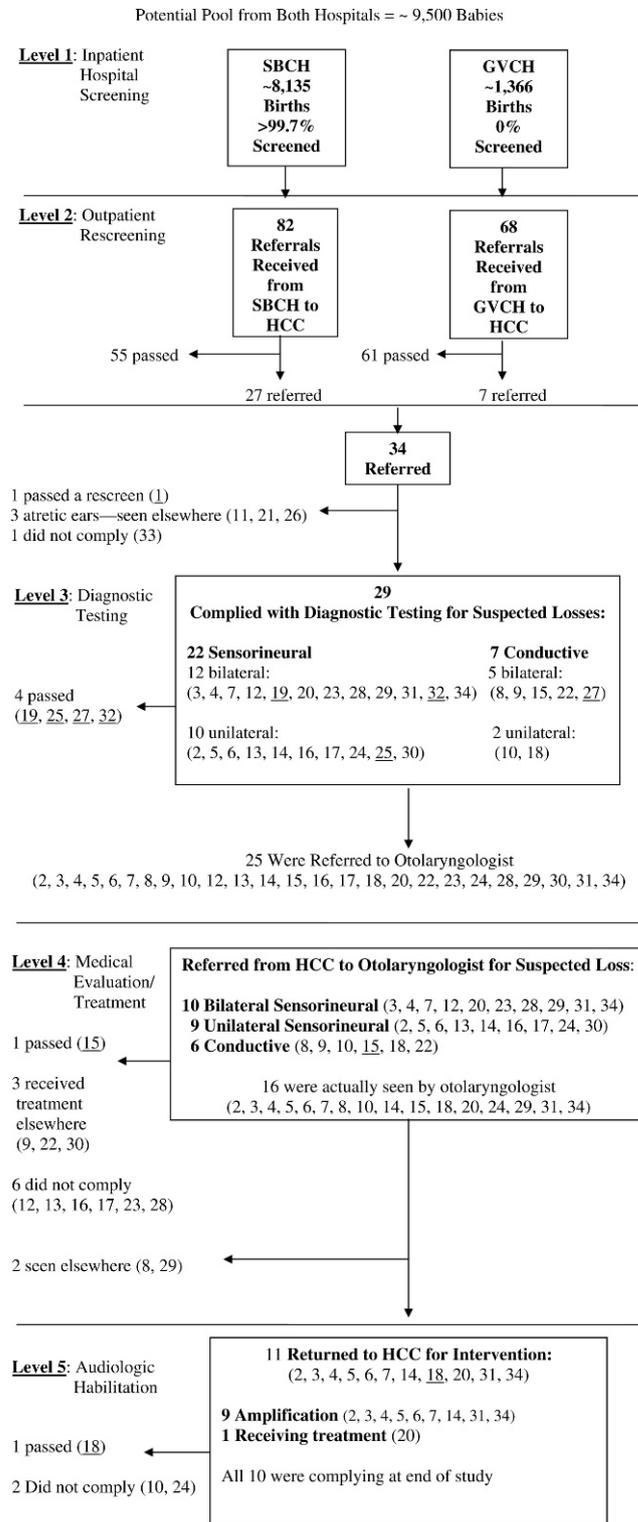
RESULTS AND DISCUSSION

Part 1: Compliance

Figure 1 summarizes the data collected and flow of individual babies through the five levels of compliance.

Level 1: Inpatient Initial Screening

Assessing compliance at Level 1 involved determining the number of infants born at SBCH and GVCH and how many of them received hearing screenings from April 2003 through November 2006. The SBCH reported having about 8,135 births (2,323, 1,209, 2,219, and 2,384 in 2003, 2004, 2005, and 2006, respectively) of which nearly 100% received screenings. No explanation was provided by SBCH or SCHCC as to why nearly 1,000 fewer babies were born in 2004 compared to the other years. Note that the total included infants born for all of 2003 when this study only covered those born from April through December of that year. Because SBCH and SCHCC records were not available for partial years, the actual number of births for this study would have been less than 8,135. Also, due to administrative changes, the SCHCC only had information available for SBCH covering the period from July 2004 through December 2006. The SCHCC's data for that period are summarized in Table 2. The SBCH and SCHCC databases covered slightly different time periods and reported numbers of births that varied by about 1,900 babies (8,135 for SBCH; 6,168 for SCHCC). A reason for this discrepancy was not provided and illustrated some of the difficulties that EHDIPs have in obtaining accurate and consistent reports for quality assessments. Interestingly, information calculated from Table 2 (i.e., refer rate for WBN at 1.1% plus that for NICU at 2.9% = 4% multiplied by the 1,900 discrepant births) showed that HCC should have had



Hearing Losses Identified from Pool:

Bilateral Sensorineural = ~10/9,500 or ~1/950

All Losses Including Unilateral Sensorineural and Conductive = ~27/9,500 or ~3.5/1,000

Figure 1. Flow of babies through the five levels evaluated for compliance in this study. SBCH = Santa Barbara Cottage Hospital; GVCH = Goleta Valley Cottage Hospital; HCC = Hearing Consultants of California; numbers in parentheses = babies' codes; underline = found to have normal hearing.

Table 2. Data Provided from the SCHCC for the SBCH NHSP covering the Period from July 2004 through November 2006 (which varied somewhat from the dates of this study)

	WBN	NICU	TOTAL
Number of infants screened	5449	719	6168
Screening rate	99.8%	99.7%	
Refer rate	1.1%	2.9%	
Missed rate	0.1%	0.3%	
Waived rate	0.1%	0%	
Number of hearing losses diagnosed	7	6	13
Hearing loss % of screened	0.1%	0.8%	
Hearing loss % of referred	12%	29%	

about 76 infants referred from SBCH for this period; in fact, 82 babies were seen. Table 2 shows that SBCH's NHSP compliance at Level 1 was nearly perfect and met or exceeded the recommended benchmarks for babies receiving initial screening by one month of age and for the percent of infants screened and referral rates.

The GVCH reported having about 1,366 births (340, 379, 348, and 299 for 2003, 2004, 2005, and 2006, respectively). Because none of these babies received inpatient screenings, computing compliance at Level 1 was impossible. Thus, nearly all of the babies born at SBCH received screenings, but most of the 1,366 infants born at GVCH did not. Clearly, having all babies receive initial screenings in a hospital NHSP is ideal, because, once discharged, it may take several days or weeks for parents to comply, if at all. Nance (2007) advocated hearing screening and immediate confirmation of results in the birth hospital and compared screening for hearing loss to that for other serious conditions that affect the heart, brain, and vital organs in which infants would not be discharged without appropriate diagnostic testing. He noted the relative ease and accuracy of testing infants' hearing in the hospital compared to when they are older as outpatients. Nance also stated that parents may be misled when they are told that their infants are "referred" for further testing when they actually have "failed" their screenings, which might dispose families to believe that screening and follow-up testing are not important.

Level 2: Outpatient Rescreening

Compliance at outpatient Levels 2 through 5 was assessed using the criteria described earlier, and the results are summarized in Figure 1 and Table 1. Results for Level 2 served as the first indicators of parental compliance with professionals' recommendations and the time taken to do so once infants left the birth hospital. Compliance at Level 2 and beyond

required considerably more effort and initiative from parents than at Level 1 because it often involved having to arrange time, childcare for siblings, and transportation to take their babies to a private practice location after they were settled in the home.

From May 2003 (which covered babies born in April) through November 2006, HCC saw 150 at Level 2 (82 SBCH + 68 GVCH). This number was reasonable for SBCH, which had a NHSP, but seeing only 68 of a potential 1,366 babies from GVCH for initial hearing screenings clearly showed the advantage of having all babies receive them within the hospital setting and the potential risks of them being lost to follow-up when they are discharged without it.

Figure 1 shows that of the 150 babies seen, 116 passed at Level 2 and were not considered further here. Of the 82 from SBCH, 55 passed and 27 progressed to Level 3. Of the 68 from GVCH, 61 passed and 7 went on to Level 3. Thus, the 34 infants considered in the remainder of this study failed at Level 2 and were referred for further testing at Level 3, and beyond if necessary. All of the 68 babies (including 5 of the 7 that failed) from GVCH received their initial screenings from HCC within slightly over the one-month after birth benchmark.

It was nearly impossible to calculate the true percent of compliance at Level 2 for all infants born in either hospital and referred to HCC during this period because of differences in record keeping and reporting, and difficulties in getting accurate referral numbers from the hospitals compared to those actually seen at HCC. The staff at SBCH verified that the numbers for their infants referred to HCC during this period were close to those actually seen. The previous study of this EHDIP (Danhauer and Johnson, 2006b) reported 100% compliance at this level and cited excellent communication between HCC and the SBCH nursing staff and the low ratio of hospitals to screeners as contributors to this success. The sustained high compliance rate at this level was also attributed to the continued development and refinement of this EHDIP.

Table 1 shows the number of months taken for these 34 parents to comply at Level 2. Just over half (18) of the babies complied and were rescreened within one month of age, meeting the JCIH (2000) benchmark. Of the remaining babies, 10 were rescreened between one and two months of age, and 5 by two or more months. Thus, although compliance at Level 2 was achieved for all 34 babies, it was not done so in a timely manner for 15 of them. Unfortunately, when parents were late in complying for whatever reasons early on in the process, achievement of subsequent benchmarks was impossible and required reconsideration of program expectations. For example, baby #17 was not rescreened until one year after birth. The chart notes failed to reveal the reason, but the HCC staff believed

that the family returned to Mexico during that period. This is often an issue that compromises compliance with EHDIPs in California due to the transient nature for segments of this population. The native language of the parents was not a major factor at this level because compliance was 100%. However, language/cultural barriers were still a concern considering that all but one of the babies taking longer than two months to comply had parents whose language was either bilingual or Spanish.

Level 2 was the highest level reached for five of the 34 babies. Although this was deemed an appropriate stopping point for baby #1, who passed a second rescreening at Level 2 and was considered to have normal hearing, three of the remaining four babies (all suspected of having conductive hearing losses in one or both ears) were referred to a medical facility for atretic ear canals and were receiving treatment elsewhere with no return contact at HCC, and one (# 33 also suspected of having a bilateral conductive hearing loss) did not comply due to failed correspondence with the family and difficulty obtaining referral authorization from her insurance company. Danhauer and colleagues (2006) surveyed pediatric otolaryngologists nationally and found that although most of them were aware of EHDIPs and said they referred babies back to audiologists following their medical management, the responses indicated that many seemed to be unaware of just how important their role was on EHDIP teams. These results show the importance of communication among EHDIP team members.

Although nearly all of the babies referred from SBCH should have been tested, seeing only 68 from GVCH did not come close to screening the nearly 400 babies born there during each year of this study. It can be assumed that the remaining babies never even received an initial newborn hearing screen, that they were at least temporarily outside of the entire EHDIP, and that it would be up to their pediatricians and parents to pursue testing if problems were noted. Demographic information was not available for the families that elected not to pursue testing and services in this study, which made it impossible to determine the reasons why they did not comply. However, based on the demographic census data cited earlier for California, it was unlikely that ethnic or racial minority issues were the reasons for most of those not seen. However, 117 of the 150 infants that were seen had Hispanic or other non-Anglo surnames, and 29 of the 34 babies that failed at Level 2 were indigent and covered by Medi-Cal and/or CCS. That was not surprising considering this was indeed the population that hospitals in California were mandated to serve. These factors and the migrant nature of a

portion of this population suggested that cultural barriers and socioeconomic factors likely played a role in this EHDIP's problems meeting benchmarks beyond Level 2. We believe that this is part of the reason why California's screening rates were among the poorest in the country and shows some of the obstacles that audiologists and other health-care professionals face in meeting the challenge of reaching national benchmarks.

Level 3: Diagnosis of Hearing Loss

The results for compliance at Level 3 are summarized in Figure 1 and Table 1, which also indicate the types of hearing losses suspected. Because five of the babies did not progress beyond Level 2, only 29 advanced to diagnostic testing at Level 3. Additional complications besides hearing loss that could have compromised compliance included: congenital atresia in one or both ears of three babies, Down syndrome in two, and cleft palate in another. The diagnoses of the 25 babies with hearing loss at Level 3 included ten bilateral sensorineural, nine unilateral sensorineural, four bilateral conductive, and two unilateral conductive. Some of those with suspected hearing loss at Level 2 were found to have normal hearing after passing diagnostic testing at Level 3 or having had conductive hearing loss in one or both ears, which (as seen below) resolved or was being treated by an otolaryngologist at Level 4.

Danhauer and Johnson (2006b) found only nine losses (three bilateral sensorineural, two unilateral sensorineural, three unilateral conductive, and one bilateral conductive) during the first three years (the emerging phase) of this EHDIP. The increase to 25 hearing losses identified in the subsequent three years of this program may have been due in part to more births, enhanced communication between the staffs at SBCH and HCC, and the overall maturation and refinement of this EHDIP, which lead to improved efficiency of initial inpatient screenings at SBCH. Danhauer and Johnson (2006b) reported that 12 of their 51 participants had "missed" their initial inpatient screenings at SBCH. All of the babies from SBCH in the present study had received inpatient screenings prior to being referred to HCC, which indicated that the inpatient NHSP had matured and met benchmarks. Morrow (2007) reported that approximately 2/1,000 babies in California are diagnosed with hearing loss annually. Thus, from this pool of approximately 9,500 babies, 27 hearing losses (including any type of loss at any of the levels) were identified, which was about 3.5/1,000. If only the ten bilateral sensorineural losses were included, then the number was close to the national average of about 1/1,000.

As Danhauer and Johnson (2006b) indicated, bilateral sensorineural losses pose the most concern for the development of children and warrant immediate intervention. The overall ramifications of and treatment options for dealing with unilateral sensorineural and conductive losses are somewhat less clear-cut or agreed upon by hearing professionals and parents (Bess, 1985; Bess, 1986; Tarpe, 2007). This often results in leaving the treatment for children with unilateral and/or minimal hearing loss up to the parents, which makes it all the more important that audiologists and physicians offer their best evidence-based recommendations to families in helping them make these important decisions for their babies. Moreover, the JCIH (2007) stated that children with any degree of bilateral or unilateral hearing loss and their families should be eligible for early intervention services.

The amount of time taken to comply at Level 3 ranged from 0.7 to 14.7 months. The chart review revealed that 14 of the 25 babies with hearing loss at Level 3 had received confirmation of their hearing status before the age of three months, indicating a compliance rate of 56% with the JCIH (2000) benchmark. The rest were diagnosed within six months or more. Although the 14 babies who complied within three months of age were from families speaking English, Spanish, or both, only one of the nine families of the babies whose diagnoses exceeded six months spoke English.

These results differ somewhat from those of Danhauer and Johnson (2006b), who found that nine of the ten babies in their study were diagnosed with hearing losses before 1.5 months of age, for nearly 100% compliance with the JCIH (2000) benchmark. Although the sample size of their study was considerably smaller than this one, it is interesting but unexplainable that the current compliance rates would be lower.

Level 3 was the highest level attained for 13 of these babies. Additional diagnostic testing revealed hearing within normal limits making Level 3 an appropriate stopping point for four of these babies. Several potential reasons for parents' noncompliance were uncovered from the chart notes. They included: ongoing treatments, cleft palate surgery with no follow-up date, parents' disagreement with the hearing loss diagnosis, insurance constraints, desire to give the child time to grow, and simply lack of follow-up.

Level 4: Treatment by Otolaryngologist

Of the 25 babies diagnosed with hearing losses at Level 3, 16 complied with recommended medical/surgical treatment at Level 4. Of these, seven had bilateral sensorineural hearing losses (Figure 1 and Table 1); the rest had unilateral or minimal losses.

Table 1 reveals that the time taken to comply at Level 4 ranged from 1.5 to 37.6 months. Compliance occurred by the six-month target for eight of these babies.

Level 4 was the highest level reached for five of these babies, but it was deemed to be an appropriate stopping point for only two of them. One (#15) of these infants received confirmation that hearing was within normal limits at the conclusion of treatment by the otolaryngologist; the other (#8) was still under medical care. Of the remaining three babies, #18 was still receiving treatment at the time of the study (pressure equalization [PE] tubes were in place), #25 had a suspected unilateral sensorineural loss, which was later found to be normal, and the parents elected not to follow-up, and #10 was a "no-show" for an appointment following a referral to an otolaryngologist.

As Danhauer and Johnson (2006b) described, once a hearing loss was diagnosed, treatment by an otolaryngologist at Level 4 potentially represented the third point in the process at which parents had encountered hearing-related professionals since their child's birth. Treatment by physicians was essential and critical for infant and pediatric hearing health care. However, the poor communication of their findings to HCC and the low number of babies that returned at Level 5 (as seen later) made it appear that some physicians were not tracked or held accountable to the same rigors that audiologists were. The staff at the SCHCC stated that they had extreme difficulty in getting some physicians to comply with reporting results of their contacts with babies in the EHDIP. The SCHCC staff also stated that they had tried meeting with physicians individually, using in-services and grand rounds, and educating them about the importance of their reporting to follow-up efforts, which were unsuccessful for many physicians. Thus, unfortunately, some physicians may not have known or seemed to believe that they were not required or simply did not want to follow through with local audiologists' recommendations or EHDIP timelines. This was discouraging considering that the JCIH has representatives and input from several physicians' groups, but was consistent with findings of Danhauer and colleagues (2006), who surveyed pediatricians and otolaryngologists in Santa Barbara and found that while they were knowledgeable about EHDI benchmarks, they could benefit from additional information on the importance of timely follow up and their role in EHDIPs.

Physicians played a critical role in and had powerful influence over parents' decisions about whether to pursue follow-up for their children's hearing losses, but the authors' review of the chart notes suggested that some physicians seemed to believe that infants and toddlers were too young to be tested, failed to see the immediacy of EHDI, were concerned about parental

anxiety and bonding issues caused by false positives or delayed diagnosis associated with NHSPs, among other reasons. These observations were consistent with those reported in a number of earlier investigations (Bess and Paradise, 1994; Paradise, 1999; Halloran et al, 2005; Danhauer and Johnson, 2006b; Danhauer et al, 2006; MacNeil et al, 2007; Serpanos and Jarmel, 2007). Although most of these concerns have been shown to be unfounded (Danhauer and Johnson, 2006b; Danhauer et al, 2006; MacNeil et al, 2007; Serpanos and Jarmel, 2007), many physicians may still need to be informed about the critical role they play in follow-up and the need for them to be persuasive and enthusiastic in counseling parents to comply with professionals' recommendations for their children (Danhauer and Johnson, 2006b; Danhauer et al, 2006). Thus, the fact that only 11 of the 25 (44%) babies referred to otolaryngologists in this study actually returned to HCC for follow-up services at Level 5 suggested that it may still be necessary to increase communication between these local audiologists and otolaryngologists in addition to promoting awareness of EHDIP goals.

Level 5: Follow-Up and Habilitative Intervention

After Level 4, 11 of the babies' chart notes at HCC contained information relevant to follow-up at Level 5, which is also summarized in Figure 1 and Table 1. Compliance at Level 5 could be in several forms. Some babies might simply need a recheck to confirm normal hearing following medical treatment for a conductive component, while others might require hearing aids or additional habilitation. One of these babies (#18) was suspected as having a unilateral conductive loss in 2004 but was found to have normal hearing after removal of PE tubes and follow-up audiologic testing, which indicated that the parents had complied appropriately. Meanwhile, hearing aids were recommended for one of the babies (#12) diagnosed with bilateral sensorineural hearing loss in 2005, but the child had not received them by the end of this study, which indicated that the parents had failed to comply. Comments made by the parent of this child in Part 2 suggested otherwise, but also showed the need for hearing health-care providers to share information to insure that babies are not lost to follow-up. Aside from the fact that the parents spoke Spanish, the chart notes did not indicate the reason for this lack of compliance, which suggested that the family needed outreach as soon as possible to insure that the child was not lost to follow-up. The remaining nine babies (four unilateral and five bilateral sensorineural hearing losses) had all received their recommended hearing aids by the end of this study and were considered to be in compliance.

Thus, intervention services were initiated within six months of birth for 10 of these 11 babies, yielding a compliance rate of 90.9%, which was better than that in the previous study (77.8%). Excluding the child for whom compliance was questionable, the age at which appropriate intervention/amplification was provided ranged from 3.5 to 38.3 months, with an average of 11.4 months. Although the final hearing aid fittings occurred later for some of these children, intervention services were initiated for all of them by the six-month benchmark. If child #2 with the unilateral sensorineural loss that took 38.3 months to comply was removed, then the average hearing aid fitting would improve to 8.4 months, closer to the JCIH (2000) benchmark of six months.

It is important to note that it is possible for a child to have a congenital sensorineural hearing loss that can be overlooked by physicians treating an overlying (and perhaps more apparent at that age) middle ear problem, and that even though the conductive component may be remedied, the sensorineural loss will still remain and warrant intervention. For example, HCC's chart notes for child #2 indicated that the mother stated that he had been seen by an otolaryngologist on October 1, 2003, and PE tubes were in place; on April 16, 2004, the mother was again contacted by HCC, and she reported that the same physician had told her that no follow-up was necessary; later, on July 7, 2006, the family returned and was consulted regarding hearing aids, which were subsequently fitted on July 26, 2006. This child emphasized the need for physicians to communicate their findings directly to the referring audiologists so that parents do not perceive and/or transmit incorrect information about their children. In this case, failed communication among the parents, audiologists, and otolaryngologists may have resulted in delayed intervention for the child. Thus, of the nine babies who complied with the recommendations for hearing aids, only three were fit before the age of 6 months and four by 12 months. Danhauer and Johnson (2006b) reported that the average of the four infants who were fit with hearing aids in their study was 7.3 months of age. Although slightly longer than the six-month benchmark, it was considerably better than in the present study. Thus, when parents delayed compliance at earlier levels or when conductive losses for atretic ears, middle ear problems, or other complications had to be dealt with first, the chance of meeting benchmarks for later levels decreased substantially.

An alternative method could have been used to analyze the data where compliance would be tracked at subsequent levels by how long it took parents to comply once professionals had made recommendations (i.e., from Levels 3 to 4, or 4 to 5). In that way, compliance might not have "looked" as poor as reported

here. However, we believe that method would have only artificially improved the situation by masking the true delays in compliance that are critical to having children receive needed intervention according to the 1-3-6 goals. Thus, although compliance was poorer as tracked here, it was more realistic than the alternative method. This is supported by recent studies by Moeller and colleagues (Moeller, Hoover, Putman, Arbataitis, Bohnenkamp, Peterson, Lewis, et al, 2007; Moeller, Hoover, Putman, Arbataitis, Bohnenkamp, Peterson, Wood, et al, 2007) that compared speech development in early-identified children having hearing loss and access to current hearing technologies and intervention to peers with normal hearing. The authors stated that the performance of these children with hearing loss was similar to that of peers with normal hearing and was better than that reported in earlier studies, but that they still demonstrated developmental speech delays up to 24 months of age. Those findings showed the importance of tracking compliance and performance by one method using the birth date as the anchor.

Table 1 showed that all but two (#2 and #3) of these children with hearing loss had parents who were Spanish or bilingual speakers, and the time for them to comply was generally longer than for families that spoke English. While hospitals such as SBCH are apt to have translators on staff and provide these services to patients, this is not always the case in private audiology practices that sometimes must rely on younger siblings or extended family members to convey screening results. Having to rely on nonprofessional translators is completely inappropriate but sometimes unavoidable when parents show up for appointments without assistance. Although Medi-Cal and CCS both provide translators, and the HCC office staff determines if this is required at the time the appointment is scheduled, too often, none is present. This means that either the child must be rescheduled for a time when a translator can be present, or the evaluation is conducted but the family is provided with inadequate descriptions of findings and recommendations, which can also produce negative outcomes. In trying to combat these problems, HCC hired a bilingual receptionist; provided intake, case history, and other forms and brochures in Spanish; and tried to determine if a translator was necessary at the time of scheduling appointments. Even so, it was difficult to know how much of an impact these accommodations had on compliance.

With two exceptions, the children taking six months or more to comply were indigent and all had Medi-Cal and/or CCS insurance coverage. Unfortunately, only the initial and secondary screenings were covered by the mothers' Medi-Cal insurance. Before any subsequent services (including diagnostic testing and hear-

ing aids) could be provided, the parents had to complete an application to be enrolled in CCS. This meant that HCC then had to perform a social services function and assist the families in completing these applications (often in Spanish), which caused further delays in the children receiving needed testing and intervention and was an inordinate drain on HCC's resources. The staffs at both HCC and SCHCC stated that they used the same policies for contacting noncompliant parents (i.e., making a minimum of at least three telephone calls and mailing letters twice) before considering the babies lost to follow-up. Again, this much effort from a small private practice is a huge drain on resources and is a constant source of frustration, which is why many private practitioners do not participate in EHDIPs, supporting Nance's (2007) recommendation that hearing screening and diagnosis be conducted within the hospital setting.

Part 2: Parents' Perceptions

In Part 2 of this study the *PPP* was retrospectively mailed to the parents of the same 34 babies presented in Part 1 inquiring about their involvement in this EHDIP. Of the 34 questionnaires mailed, seven were returned undeliverable by the postal system because of insufficient or inappropriate addresses. Only seven completed questionnaires were returned for a response rate of 25.9% compared to 34% in the earlier study (Danahauer and Johnson, 2006a). Factors possibly contributing to this response rate and difficulties in obtaining responses via mailed surveys are discussed below.

The results for each question on the *PPP* (English version shown here) are provided in Appendix 1. The numbers listed under "Parents" correspond to those of the "Children" in Part 1 (shown in Figure 1 and Table 1), enabling the tracking of responses.

Section 1: Demographics and Consent

The home languages of the 34 families were English (10), Spanish (11), bilingual (12), and "Other" (an Asian language) (1). The seven parents that returned the *PPP* represented a socioeconomically and culturally diverse group of babies (six male, one female) born between July 2004 and October 2006. The languages spoken in the homes were evenly distributed: three Spanish, three English, and one bilingual (Spanish/English). Six of the babies were born at SBCH (one in the WBN, five in the NICU), and one was born at GVCH.

Appendix 1 depicts information relating to the respondents' demographics and the informed consent process. Item 1 on the *PPP* revealed that the parents stated that two of the babies were born in the WBN,

three in the NICU, and two parents did not respond (their records showed that they were both from the NICU). Item 2(a) showed that four parents said they were informed that their babies would receive a hearing screening before it was actually performed, two were informed after the screening was performed, and one was not informed at all, but Item 2(b) showed that all seven had consented for their babies hearing to be screened.

Section 2: Explanation of Purpose of the Screening

Item 3(a) showed that five parents said they understood the explanation of the purpose of screening, one did not (#12), and one did not respond (#26). Item 3(b) revealed that parents' ratings of the explanation of the hearing-screening program were as follows: three positive, two negative, and two neutral. On Item 3(c) parents suggested that this aspect of the screening program could be improved by parents doing what they can to help make things more clear and having a person who spoke Spanish present. One parent believed that the baby had been "targeted" by the pediatrician for a hearing loss based upon his developmental delays, which implied the need for continued improvements in refining the explanation of the hearing-screening program to new parents.

Section 3: Explanation of Screening Results

Items 4(a) and (b) revealed that all but one of the parents said they were informed of the screening results prior to leaving the hospital and were satisfied with when they were told. Item 4(c) showed that only one parent was told that the baby passed the hearing screening; the rest received failed, did not pass, referred, or some other descriptor, which was to be expected from this sample considering that only babies seen for further testing at HCC were included. Child #21 was referred to HCC for unilateral congenital atresia, making it unlikely that the staff at SBCH would have informed the parents that he had passed the screening in the hospital. This emphasizes the point that parents may not always remember at a later date what they were told in the hospital, or that they might not always process it correctly. Further, the parents of child #21 were Spanish speakers, which suggested that the exact meaning of the results might have been lost in translation, again showing the need for this information to be presented to parents in their preferred language.

Danhauer and Johnson (2006b) stated that hospital staff untrained in counseling parents about hearing loss should avoid using words like "fail" and "deaf" when reporting screening results to parents because they

might contribute to undue anxiety. The responses to item 4(c) suggested that the staff at SBCH had received that message. However, Nance's (2007) position on this issue makes sense and warrants strong consideration as long as the diagnosis of the hearing loss could be confirmed before infants leave the hospital and audiologists, pediatricians, or nurses conveying the information are experienced in this type of counseling and culturally sensitive to families' needs. From our experience, we have observed that in many Hispanic households, the entire immediate family may accompany the baby for audiological appointments. They often share the information received as a family unit, which can be hindered if Spanish translation is not available. Frequently, these families are not in touch with resources that might be available to them and their children, and it is incumbent on audiologists and staff to make the connections for services.

Items 5(a) and (b) showed that the results of the hearing screening were typically provided to these parents by audiologists, nurses, or pediatricians, and that they were knowledgeable about the program. All but one of the parents (#12) indicated in Item 6(a) that they clearly understood the explanation of the results. These findings were interesting considering the less than perfect compliance data presented for these families in Part 1. Chart notes at HCC indicated that child #12 was suspected of having a bilateral sensorineural hearing loss, but his parents appeared to be in denial, and Table 1 revealed that they were noncompliant after Level 3. Thus, the collective results of Parts 1 and 2 stressed the importance of maintaining contact with and providing the support necessary for parents to come to grips with their children's diagnoses and assuring appropriate compliance so that they are not lost to follow-up.

Item 6(b) showed that these seven parents were pretty evenly divided in rating the explanation of the results positively and negatively. Suggestions offered in Item 6(c) for improving the way parents are provided the screening results centered on having them presented in the parents' preferred language and not immediately giving parents the impression that their child has a hearing problem if they fail the first time. Cultural differences may dictate the best ways to provide such information to families (e.g., with entire families and translators present if necessary).

Interestingly, the results of Item 7(a) were mixed regarding how these parents felt about NHSPs affecting their ability to bond with their babies. One parent said that it "helped me realized that he had hearing problems." Another parent commented that the "staff worked with a lot of attention and love of their job." Items 8(a) and (b) indicated that all but 2 (#12 and #21, both having issues with the program on other questions) of these parents felt that the hospital

staff was helpful in assisting them with obtaining further information by providing phone numbers, pamphlets, and reassurance/support.

Section 4: Referral Process

Items 9(a) and (b) demonstrated that five of these parents felt the hospital staff was sensitive to the needs of their baby and family (two did not respond) and were evenly split as to whether the parents clearly understood the need for hearing rescreening. Again, three of the four parents that either said no or did not respond were Spanish speaking, reiterating the need for critical information like this to be presented in the families' preferred languages. As shown in Part 1, most of these families complied with professionals' recommendations for their children, but two did not. This was especially a problem for the parents of child #12, because he was suspected of having a bilateral sensorineural hearing loss, and the chart notes suggested that he was lost to follow-up. Language/cultural barriers should not have been the reason because his family spoke English, but they may have been for child #13, who had Down syndrome and whose family spoke Spanish.

Item 9(c) showed that all of the parents but one that did not respond said they had kept their babies' hearing screening appointments within a few days to six months after leaving the hospital. This was a close match to what actually happened as seen in Table 1, which showed that their recollections of the screening process were generally accurate. However, some of the parents failed to comply according to timelines for the JCIH benchmarks, which again supported the concept of having diagnostic testing to confirm hearing loss done in the hospital before discharge (Nance, 2007).

Unfortunately, the notes in the charts at HCC indicated that although children #12 and #13 complied with testing at Levels 2 and 3, they did not comply at Levels 4 and/or 5. As noted earlier and on Table 1, child #21 had unilateral atresia, and he was receiving treatment elsewhere. This lack of contact and the parents' failure to respond to this question suggested that this Spanish-speaking family needed to be reached to determine that the child was not lost to follow-up. The responses to Item 9(d) seemed appropriate regarding the results of the hearing rescreenings indicating a need for further diagnostic testing for these children, as expected given the nature of this sample. The need for further testing was clear to all of the parents, except maybe for two who did not respond.

Item 9(f) showed a range of responses as to how these parents perceived the referral process. Two of the parents who rated the process negatively or not at all were Spanish speaking. Item 9(g) indicated that parents' suggestions for ways to improve the referral

process included making appointments more accommodating to people who come from long distances and having more choices of hearing testing facilities. Unfortunately, because only one or two providers participated in this community-based EHDIP, these suggestions could not be implemented. However, if more providers were willing to participate, and there was a strong infrastructure facilitating communication among participants, it would ease the burden on both parents and the private practices involved, which might lead to greater compliance and help keep children from being lost to follow-up. Item 10 revealed that all but one of these parents said they would recommend newborn hearing screening to others or would consent to have it done again on future pregnancies of their own. One wrote in that more education was needed if the babies are to be seen at another location after leaving the hospital, again supporting Nance's (2007) point about the need for testing to be conducted in the hospitals. Finally, two parents provided additional comments on Item 11. Parent #13, who was noncompliant at the end of Part 1, thanked us for conducting this survey. Another pointed out the fact that GVCH did not have a NHSP and encouraged us to help them obtain one, and indicated that their child hears fine and was tested when he was older (obviously elsewhere), which again demonstrated the need for consistent sharing of follow-up information among providers.

SUMMARY

Figure 1 and Table 1 showed that 27 of the 150 babies seen for follow-up services from the greater potential pool of about 9,500 births at the two hospitals during the period of this study were found to have hearing loss. Of those, ten were bilateral sensorineural; nine resulted in hearing aid fittings at Level 5. This number is close to the 1/1,000 expected from EHDIPs. If unilateral sensorineural and conductive losses were included, then the 27 total losses per about 9,500 babies (a little more than 3/1,000) were also close to expected benchmarks (NCHAM, 2006). Some of the babies suspected of having hearing loss were being seen elsewhere or had medical complications that delayed compliance across the five levels; others simply did not comply. If those having other complications were in fact receiving treatment and were still in the system, then they should catch up and comply, albeit at later times than would be desirable according to benchmarks. It can be assumed that those who did not comply were lost to follow-up. Reasons for loss to follow-up, including those related to this diverse population, need to be pursued so that these families can be contacted and that the babies receive services.

Benchmark 1-3-6 targets were met for many of the babies through HCC. However, those goals may be unrealistic for some community-based programs lacking necessary infrastructure and support from other EHDIP stakeholders. Some conscientious private practitioners may be overwhelmed in conducting NHSP follow-up and tracking without accurate statistics from hospitals and support from state coordination centers, which forces them to shoulder an extra burden of anxiety and costs to their practices. Nevertheless, this EHDIP met the JCIH (2000) goals of initiating intervention (rather than the actual fitting of hearing aids) within six months of birth and tracking follow-up at 70% or better, which were in effect at the time of this study. Future assessments of this and similar EHDIPs should use the updated targets (JCIH, 2007).

Although the SBCH program functioned adequately, met benchmark targets for most of the babies, and was generally received well by the parents, the results for GVCH were far less satisfactory. This study showed striking differences between a program having mandated hospital screening and one that did not. Considerable effort and resources (with little assistance from state or local agencies) were required for the private practice to maintain this program once babies left the hospital for outpatient services. The responsibility for insuring that babies are serviced and not lost to follow-up is disproportional to the time required and reimbursement received for a small practice serving a diverse patient population. Unfortunately, HCC expends considerable resources and audiologists' time working beyond their purviews to get indigent families to apply for and receive needed social services. This burden may be a reason why many small practices have elected not to participate in similar EHDIPs, which increases the load on those that do. Ideally, children's Medical Homes should share in facilitating families' access to timely hearing health care for their babies.

The nature of this EHDIP meant that many of these indigent families required special considerations. This segment of the population was notorious for missing multiple scheduled appointments without calling to cancel or reschedule. This meant that other patients could not be seen and that no income was produced from services that could have been provided in those time slots. This can be fatal to the success of small practices, let alone to EHDIPs. Testing a cooperative or sleeping infant can be accomplished within minutes, but this is usually not the case when babies are older and fussier, and when parents bring other children, family members, and friends along, which creates additional noise in the test environment. Often it is difficult for families to obtain child care for siblings, which means that audiologists must serve as babysitters while trying to keep background noise to a

minimum to complete testing. Fussy babies that require feeding or changing can prolong test time. These factors coupled with language restrictions can cause frustration for staff, audiologists, and families and reduce enthusiasm for involvement in EHDIPs. When questioned, the HCC staff all believed that participation in the EHDIP was necessary and "the right thing to do for the babies," but unanimously agreed that the practice's resources were stretched to accommodate the program and that they would opt out of it if there was any other way for babies to receive services.

Audiologists serving diverse populations must be prepared to work with members of ethnic groups having different cultural values (e.g., multiple family members present who wish to observe the entire evaluation, the need for translators, and missed appointments). For example, some Hispanic mothers are less inhibited about breastfeeding to calm their infants during testing than are women from other ethnic groups. This often facilitates recording otoacoustic emissions compared to when mothers need to be left alone with their babies in a separate room, preferably with a rocking chair, or when parents need to drive the baby around in the car until it goes to sleep, or worse, when the evaluation must be terminated and rescheduled due to a fussy baby producing too much movement and noise. Although breastfeeding can facilitate testing, it is not a situation that some audiologists, particularly males, might be experienced or comfortable in at first.

As a result of our efforts to develop this program over the past decade, we believe that many of the problems incurred in conducting and maintaining EHDIPs could be greatly alleviated and fewer babies would be lost to follow-up if Nance's (2007) recommendations for screening and diagnosis of hearing loss were conducted within the hospital environment or via hospital-based programs. The "captive audience" of infants within the birth hospital should greatly reduce the numbers of those who do not receive or pass screenings and that are lost to follow-up. Hospitals should also be better prepared to overcome linguistic and cultural barriers than are many small practices. Once hearing loss is diagnosed, then families could be referred to audiology practices for intervention services.

We assume that other community-based EHDIPs managed mainly by small private practices find themselves in similar dilemmas. Unfortunately, while Nance's (2007) recommendations have great merit, it is unlikely that smaller, regional hospitals will incur the costs of purchasing equipment and hiring audiologists to conduct inpatient EHDIPs. Thus, for the foreseeable future, it will be necessary for this and similar private practices to shoulder the burden. The models of assessing parental compliance and

opinions presented here were beneficial in evaluating the success of this EHDIP and should be helpful to similar programs.

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APPENDIX 1. Parents' Responses to the PPP (numbers correspond to parents of babies as listed on Figure 1; underlined numbers indicate use of the Spanish version of the PPP; write-in responses were translated to English here)

Item	Question/Responses	Parents
Check person completing this form?		
	Mother	12, <u>13</u> , 15, <u>21</u> , <u>22</u> , <u>26</u>
	Father	0
	Relative	0
	Friend	0
	Interpreter	<u>29</u>
Demographics and Consent		
1	Which nursery was your baby in?	
	Well-baby nursery	12, <u>26</u>
	Neonatal intensive care unit (NICU)	15, <u>22</u> , <u>29</u>
	Not applicable	0
	No response	<u>13</u> , <u>21</u>
	Not born in hospital	0
2(a)	When were you informed that your baby might receive a hearing screening before leaving the hospital?	
	Before the screening occurred	15, <u>21</u> , <u>22</u> , <u>26</u>
	After the screening occurred	<u>13</u> , <u>29</u>
	Was not informed	12*
	No response	0
	**"Was <u>not</u> told we'd have to go have it done later."	
2(b)	Did you give permission to have your baby's hearing screened?	
	Yes	12, <u>13</u> , 15, <u>21</u> , <u>22</u> , <u>26</u> , <u>29</u>
	No	0
	No response	0
Explanation of Purpose of the Screening		
3(a)	Did you understand the purpose of the screening?	
	Yes	<u>13</u> , 15, <u>21</u> , <u>22</u> , <u>29</u>
	No	12
	No response	<u>26</u>
3(b)	Overall, how do you rate the explanation of the purpose of the hearing screening program? (Circle a number)	
	1 Positively	<u>13</u> , <u>29</u>
	2	15
	3	<u>21</u> , <u>26</u>
	4	0
	5 Negatively	12, <u>22</u>
	No response	0
3(c)	Please list any suggestions you have for improving how parents are informed about this program.	
	<ul style="list-style-type: none"> • "Parents need to do what they can to help make things more clear and have a person who speaks Spanish present." • "Our pediatrician 'targeted' our son for some kind of hearing loss because of his delays developmentally, <u>Unfair.</u>" 	
Explanation of Screening Results		
4(a)	When were you told the results of the screening?	
	Right after it took place	12, <u>21</u> , <u>22</u>
	Before you left the hospital	<u>13</u> , 15, <u>26</u>
	After you left the hospital	<u>29</u>
	No response	0
4(b)	Would you have liked to have been told at a different time?	
	Yes	0
	No	12, <u>13</u> , 15, <u>21</u> , <u>22</u> , <u>26</u> , <u>29</u>
	No response	0

APPENDIX 1. Continued.

Item	Question/Responses	Parents
4(c)	What were the results of your baby's hearing screening? (Check all that apply)	
	Pass	<u>21</u>
	Fail	12, 15
	Did not pass	<u>13</u> , <u>22</u> , <u>29</u>
	Refer to diagnostic testing	12*, <u>13</u>
	Other	<u>21</u> ***, <u>22</u> ***, <u>26</u> ****
	No response	0
	* "On the same day, too <u>much</u> for our baby, be <u>REALISTIC</u> ."	
	** "One side was normal, but the right side was completely covered/sealed off."	
	*** "They did another test; everything was OK."	
	**** "One side passed and the other didn't."	
5(a)	How were you told of the results of the hearing screening? (Check all that apply)	
	Written message	0
	Nurse	15, <u>22</u>
	Audiologist	12, 13, 21, <u>29</u>
	Doctor	<u>13</u>
	Pediatrician	<u>22</u> , <u>26</u>
	Other	0
	No response	0
5(b)	If a person informed you about the screening results, was he/she knowledgeable about this program?	
	Yes	12, <u>21</u> , <u>22</u> , <u>29</u>
	No	<u>26</u>
	Does not apply	15
	Other	0
	No response	<u>13</u>
6(a)	Did you clearly understand the explanation of the results?	
	Yes	<u>13</u> , 15, <u>21</u> , <u>22</u> , <u>26</u> , <u>29</u>
	No	12
	No response	0
6(b)	How would you rate the explanation of the results of your baby's hearing screening? (Circle a number)	
	1 Positively	<u>29</u>
	2	<u>13</u> , 15
	3	0
	4	12, <u>26</u>
	5 Negatively	<u>22</u>
	No response	<u>21</u>
6(c)	Please list any suggestions you have for improving the way parents are given the screening results.	
	• "Have a person experienced with people not having much English."	
	• "Please do <u>not</u> immediately give parents the impression that your child has a hearing problem/definite if they <u>fail</u> the first time!"	
7(a)	Do you believe that the UNHS program had any effect on your ability to bond with your baby?	
	Yes	<u>13</u> , <u>26</u> , <u>29</u>
	No	12, 15, <u>21</u> , <u>22</u>
	No response	0
	If yes, please explain how:	
	• "I noticed that they work with a lot of attention and love of their job." (<u>13</u>)	
	• "Helped me realized that he had hearing problems." (<u>29</u>)	
8(a)	Was the hospital staff helpful in assisting you with obtaining further information about the program and follow-up?	
	Yes	<u>13</u> , 15, <u>22</u> , <u>26</u> , <u>29</u>
	No	12, <u>21</u>
	Does not apply	0
	No response	0

