

A National Survey of Pediatric Otolaryngologists and Early Hearing Detection and Intervention Programs

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Abstract

Follow-up rates for babies identified for hearing loss from early hearing detection and intervention programs (EHDIPs) and newborn hearing screening programs (NHSPs) in the United States do not meet the goals posited by the Centers for Disease Control. Pediatric otolaryngologists (PED-ENTs) play a vital role in EHDIPs and can positively influence parents' compliance with professionals' recommendations for their babies. This national study used a 19-item questionnaire and postal survey to assess PED-ENTs' knowledge about, experience with, and attitudes toward NHSPs. Of 565 surveys mailed (36 were undeliverable), 233 were returned for a 44% response rate. Most of these PED-ENTs had adequate knowledge about, participated in, and expressed positive attitudes toward NHSPs; however, some could benefit from additional information about national EHDIP benchmarks and poor follow-up rates. Audiologists should ally with PED-ENTs locally and nationally to strengthen EHDIPs and prevent loss of children with hearing impairment to follow-up.

Key Words: Early hearing detection and intervention programs, national survey, newborn hearing screening programs, pediatric otolaryngologist questionnaire

Abbreviations: DSHPSHWA = Directors of Speech and Hearing Programs of State Health and Welfare Agencies; EHDIPs = early hearing detection and intervention programs; ENTs = otolaryngologists; JCIH = Joint Committee on Infant Hearing; NHSPs = newborn hearing screening programs; NHSPQ = *Newborn Hearing Screening Program: Physicians' Questionnaire*; PEDs = pediatricians; PED-ENTs = pediatric otolaryngologists

Sumario

Las tasas de seguimiento para bebés identificados con trastornos auditivos a partir de programas de identificación e intervención auditiva temprana (EHDIP) y de programas de tamizaje auditivo neonatal (NHSP) en los Estados Unidos, no cumplen con las metas postuladas por los Centros de Control de Enfermedad. Los otolaringólogos pediátricos (PED-ENT) juegan un papel vital en los EHDIP y pueden influir positivamente en el cumplimiento de los padres con relación a las recomendaciones profesionales para sus bebés. Este

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estudio nacional utilizó un cuestionario de 19 ítems y una encuesta postal para evaluar el conocimiento, la experiencia y la actitud de los PED-ENT hacia los NHSP. De los 565 cuestionarios enviados por correo (36 no pudieron ser entregados), 233 fueron devueltos para un 44% de tasa de respuesta. La mayor parte de estos PED-ENT tuvieron un conocimiento adecuado y una participación previa, y expresaron actitudes positivas hacia los NHSP; sin embargo, algunos podrían beneficiarse de información adicional sobre los parámetros de referencia para los EHDI y sobre pobres tasas de seguimiento. Los audiólogos deberían aliarse con los PED-ENT, local y nacionalmente, para fortalecer los EHDIP y prevenir que niños con hipoacusias se pierdan para el seguimiento.

Palabras Clave: Programas de detección auditiva temprana y de intervención, encuesta nacional, programas de tamizaje auditivo neonatal, cuestionario otolaringológico pediátrico

Abreviaturas: DSHPHWA = Directores de Programas de Audición y Lenguaje de Agencias Estatales de Salud y Bienestar; EHDIPs = programas de detección e intervención auditiva temprana; ENTs = otolaringólogos; JCIH = Comité Conjunto sobre Audición Infantil; NHSPs = programas de tamizaje auditivo neonatal; NHSPQ = *Programa de Tamizaje Auditivo Neonatal*: Cuestionario para el Médico; PEDs = pediatras; PED-ENTs = otolaringólogos pediatras

Currently, early hearing detection and intervention programs (EHDIPs) and newborn hearing screening programs (NHSPs) across the United States are identifying infants with hearing loss at a very early age. However, in order to achieve the goals of these programs, once infants are identified, it is critical that they receive necessary intervention services in a timely fashion and that they are not lost to follow-up. Unfortunately, although over 90% of infants born in many states in this country receive newborn hearing screenings within the first month of life, follow-up rates for diagnosing hearing loss by three months and beginning intervention by six months of age in these programs do not meet Centers for Disease Control (CDC) goals (Directors of Speech and Hearing Programs of State Health and Welfare Agencies [DSHPHWA], 2005; Park et al, 2005). It is important to assess pediatric otolaryngologists' (PED-ENTs) involvement in EHDIPs and NHSPs, because physicians, especially PED-ENTs, can be particularly helpful in ensuring that parents comply with professionals' recommendations for their infants. This study reports the results of a national survey that was administered to PED-ENTs to document their knowledge of, participation in, and experiences with NHSPs.

The rapid development of EHDIPs in the United States has resulted in great variability among service-delivery models. However, whether programs are self-contained hospital-based or diffuse community-based offerings,

promoting parental compliance with professionals' recommendations and appointments for their infants who are identified by screenings and preventing them from being lost to follow-up is an issue of paramount importance (Danhauer and Johnson, 2006). One national system that measures quality assurance in NHSPs is managed through the DSHPHWA (2005), which receives and aggregates outcome data on infants and programs from 43 states.

States vary in their attainment of national benchmarks set for EHDIPs (Joint Committee on Infant Hearing [JCIH], 2000), and national aggregation of statistics shows better performance for initial inpatient-hospital screening than for later phases of diagnosis and intervention in the hearing health-care continuum. For example, as of October 2005, national statistics for report year 2003 indicated that 98.6% (43 states reporting) of all babies' hearing was screened prior to hospital discharge. However, only 40.1% of babies received an audiologic evaluation by three months of age after referral in 31 states, with an estimated 44.8% of infants lost to follow-up before diagnosis (DSHPHWA, 2005). Of 58 families in Utah responding to a recent survey of parents whose infants were identified with hearing loss (Park et al, 2005), 37% (21) required at least four audiologic test visits before reaching a diagnosis. Of those who did not pass their newborn hearing screenings, the age at diagnosis of hearing loss ranged from birth to 60 months, and age at hearing aid use

was 11.6 (± 14.4) months. The families cited several obstacles in obtaining a timely diagnosis and treatment of their infants' hearing loss, and the authors concluded that otolaryngologists should be more involved in the diagnosis and treatment of hearing loss. Clearly, these numbers exceeded the goals for NHSPs and support the conclusions of a systematic review by Thompson and colleagues (2002), which found that although NHSPs had resulted in efficient screening of infants' hearing, long-term gains in language development remained unclear.

A coordinated effort of health-care professionals is required to prevent loss to follow-up. Physicians, particularly pediatricians (PEDs), family physicians, and otolaryngologists (ENTs), are vital team members of successful NHSPs and EHDIPs (Heldrich, 1995; Bluestone, 1996; Doyle, 2000; Kim et al, 2002; Yoshinaga-Itano, 2004; Park et al, 2005). While PEDs and family physicians serve as medical homes for infants with hearing loss and their families (Buttross et al, 1995; Heldrich, 1995), NHSPs are increasing the number of very young children being identified with both conductive and sensorineural hearing losses that are seen by ENTs for medical diagnosis and treatment (Westerberg et al, 2005). For example, a retrospective chart review revealed that 76 babies, who were referred to a tertiary care institution for an otolaryngology evaluation after failing their newborn hearing screenings using otoacoustic emissions, received a diagnosis of conductive hearing loss resulting from otitis media with effusion (Boone et al, 2005). Similarly, Park and colleagues (2005) found that the reason for delay in diagnosis of hearing loss was due to middle ear infections in 20% of their sample. ENTs also provide medical clearance for further audiologic diagnostic and habilitative services including hearing aids and cochlear implants (Doyle, 2000; Kim et al, 2002). Although the treatment courses and ramifications of conductive problems are different from those for sensorineural losses, it is particularly important for ENTs to diagnose and treat them both, and to encourage parents to comply with professionals' recommendations for their babies. Unfortunately, recent evidence indicates that some ENTs may not be aware of just how important their roles in NHSPs and EHDIPs really are (Danahauer et al, 2006).

Recently, audiologists used the *Newborn*

Hearing Screening Program: Physicians' Questionnaire (NHSPQ) to partner with ENTs and PEDs in an emerging community-based EHDIP (Danahauer et al, 2006). The NHSPQ is a 19-item questionnaire that elicits information about respondents' demographic data and their knowledge about, experiences with, and perceptions of the service-delivery continuum of NHSPs. The survey results revealed that both the ENTs and PEDs in that local study had adequate knowledge and attitudes about EHDIPs. However, to date, no national survey has been conducted on ENTs, particularly those with a pediatric subspecialty (PED-ENTs), regarding their knowledge about, experiences with, and attitudes toward EHDIPs. The purpose of this study was to complete a national survey of PED-ENTs and EHDIPs using the NHSPQ.

METHOD

Participants

Potential participants in this national study were 565 physicians listed in the American Academy of Otolaryngology—Head and Neck Surgery's "Find an Otolaryngologist" database. These physicians reported that they had a pediatric subspecialty; thus, they are referred to here as "PED-ENTs." They had mailing addresses within the United States, and the list included physicians from all 50 states and the District of Columbia, except for Nevada, North Dakota, and Wyoming.

The Questionnaire

The survey instrument used in this study was the *Newborn Hearing Screening Program: Physicians' Questionnaire* (NHSPQ) (Danahauer et al, 2006), a 19-item questionnaire shown in Appendix A. The entire questionnaire was developed through an exhaustive iterative process using input from hospital staff, colleagues, and experts in the field. Earlier versions of the questionnaire were constructed and pilot tested on small focus groups of physicians, which resulted in the final 19-item form. Realizing that physicians' time is precious, the questionnaire

was designed to elicit their information in less than ten minutes in order to maximize the likelihood of having them return the survey. The NHSPQ was developed and found to be effective earlier (Danhauer et al, 2006) with ENTs and PEDs in a community-based EHDIP in Santa Barbara County, California.

The NHSPQ was designed to elicit information about respondents' demographic information and their knowledge about, experiences with, and perceptions of the service-delivery continuum of EHDIPs. After the section on demographics, respondents are asked about their knowledge of NHSPs. If they respond that they do not know what NHSPs are, then they are asked to stop and return the questionnaire. Similarly, item #9 asks respondents if they participate in NHSPs. If not, they are instructed to go on to item #13. The NHSPQ was designed using a format employed earlier in assessing related health-care professionals' knowledge and attitudes toward participating in audiologic service delivery (Johnson and Stein, 1992; Johnson et al, 1998). The questionnaire was designed to assess physicians' knowledge about and attitudes toward NHSPs in order to uncover any misconceptions or biases that could contribute to poor follow-up rates for infants identified as possibly having hearing loss in these programs. The questionnaire was also structured to highlight possible future outreach and continuing education activities that could be directed to physicians, if they expressed a need for them.

Each section of the questionnaire elicits critical information about physicians' preparedness to participate in an EHDIP. For example, the section on knowledge about NHSPs contains questions concerning critical benchmarks for follow-up. Participants were also asked about their current role in NHSPs, which provided a way to judge their responses on other sections of the questionnaire and to help determine if additional information about these programs should be provided to them. For example, if respondents reported that they were otolaryngologists on item # 10 but "strongly disagreed" about the importance of diagnosis and intervention of hearing loss by six months of age on item # 17, then informational outreach campaigns should be directed toward informing them about the importance of NHSPs and EHDIPs.

Procedure

The names of ENTs reporting themselves as having a pediatric subspecialty were obtained from the American Academy of Otolaryngology—Head and Neck Surgery's "Find an Otolaryngologist" online service that provides listings of member otolaryngologists practicing in the United States and abroad. Users of the service are welcome to print off individual members' listings. A search was conducted to find the names, cities, and states of all the PED-ENTs in the United States from that list, which resulted in 565 names that were used for possible participants in this study. Addresses were then obtained and/or verified for these 565 PED-ENTs from the WebMD Physician Directory (www.doctor.webmd.com/physician_finder). The NHSPQ, an instruction letter, and a pre-addressed and stamped envelope for returning the survey were sent to each of the 565 ENTs in May 2005. The Institutional Review Board at the University of California Santa Barbara approved the study as "exempt" from needing any informed consent from the participants due to the survey nature of the study.

Data Preparation and Analysis

Returned questionnaires were numbered and placed into a notebook, and the participants' data were entered onto a Microsoft Excel spreadsheet. The PED-ENTs' responses were tallied, and calculations were made of the percentages responding in each category for each question on the NHSPQ. Data entry and analysis were completed independently and then verified by two sets of reliability judges. That is, two judges double-checked the data that were transferred from the individual surveys to the spreadsheet. Similarly, two judges double-checked the tallying of responses on the spreadsheet for each item on the questionnaire to determine the numbers of respondents who responded to each category. These data were then used to calculate the numbers and percentages in the tables, which were also triple-checked for accuracy.

RESULTS AND DISCUSSION

The purpose of this study was to complete a national survey of PED-ENTs and EHDIPs using the NHSPQ. The questionnaire was mailed to 565 PED-ENTs (36 were undeliverable by the postal system), and 233 completed surveys were returned, producing a 44% response rate.

The participants' data are reported here according to the percents and numbers replying out of the total sample responding for each item on the questionnaire. The maximum possible number of responses was 233, but in some cases the number was smaller if participants failed to provide a response or wrote in "N/A" (Not Applicable) for certain items. The N/A responses (indicated by the numbers in the parentheses in the tables) were not used in calculating the totals or the percentages for those items. Further, items #6 and #11 through #18 provided the option for respondents to indicate if they were unfamiliar with the statement or the topic. Also, some participants provided additional comments in the margins of the questionnaire to expand upon their responses.

Demographics

As with most surveys, it was difficult to know exactly what kind of persons returned the questionnaires and whether they were those who were most interested in or knew something about the topic; however, the demographic data suggest representation from a fair cross-section of the PED-ENTs across the country. Table 1 displays these PED-ENTs' responses to items #1 through #4 of the questionnaire regarding their demographic information. Most of the sample, 80.8% (185/229), was male, and 19.2% (44/229) was female; four of the participants did not indicate their gender. Interestingly, the proportion of females in this sample was greater than the roughly 7% of ENTs practicing in the United States who are female (Grandis et al, 2004). Nearly all or 98.3% (229/233) of the sample said they were otolaryngologists with work settings being 55.2% (127/230) private practice, 33.9% (78/230) hospital, 4.3% (10/230) clinic, 2.2% (5/230) academic, and a few in more than one service-delivery site. The sample was

composed of experienced physicians with 55% (127/231) being in practice for more than 10 years, and 26% (60/231) and 19% (44/231) for 0 to 5 years and 6 to 10 years, respectively.

Knowledge about and Participation in EHDIPs

Table 2 summarizes these PED-ENTs' responses to items #5 through #10 on the questionnaire regarding their knowledge about and participation in NHSPs. The overwhelming majority or 98.7% (228/231) of these PED-ENTs knew what NHSPs were, which was not surprising because PED-ENTs play a major role in the diagnosis and management of hearing loss in infants referred from these programs. Similarly,

Table 1. PED-ENTs' Demographic Information

(1) What is your gender?		
Responses	N	%
Male	185	80.8
Female	44	19.2
N/A	(4)	
Total	229	100.0
(2) What type of physician are you?		
Responses	N	%
Otolaryngologist	229	98.3
Otolaryn./Other	1	0.4
Other	3	1.3
Total	233	100.0
(3) What is your practice setting?		
Responses	N	%
Academic	5	2.2
Clinic	10	4.3
Hospital	78	33.9
Hospital + Clinic	2	0.9
Hospital + Private	4	1.7
Other	3	1.3
Other: HWO	1	0.4
Private Practice	127	55.2
N/A	(3)	
Total	230	100.0
(4) How long have you been in practice?		
Responses	N	%
0-5 Years	60	26.0
6-10 Years	44	19.0
10+ Years	127	55.0
N/A	(2)	
Total	231	100.0

Table 2. PED-ENTs' Knowledge about and Participation in NHSPs

(5)	Do you know what universal newborn hearing screening programs (UNHSPs) are?		
	Responses	N	%
	Yes	228	98.7
	No	3	1.3
	N/A	(2)	
	Total	231	100.0
(6)	Do you agree with the Joint Committee on Infant Hearing Year 2000 Position Statement re: early hearing detection and intervention programs?		
	Responses	N	%
	Yes	188	83.9
	No	2	0.9
	Not Familiar	34	15.2
	N/A	(9)	
	Total	224	100.0
(7)	According to recommended practices, by what age should hearing loss be diagnosed in a child?		
	Responses	N	%
	3 Months	162	71.7
	3–6 Months	1	0.4
	6 Months	57	25.2
	9 Months	2	0.9
	1 Year	3	1.3
	2 Years	1	0.4
	N/A	(7)	
	Total	226	100.0
(8)	According to recommended practices, by what age should an intervention program be in place for a child with hearing impairment?		
	Responses	N	%
	3 Months	53	23.6
	6 Months	143	63.6
	9 Months	10	4.4
	1 Year	17	7.6
	2 Years	2	0.9
	N/A	(8)	0
	Total	225	100.0
(9)	Do you participate in a UNHSP?		
	Responses	N	%
	Yes	179	79.9
	No	45	20.1
	N/A	(9)	
	Total	224	100.0
(10)	What role do you play in UNHSPs?		
	Responses	N	%
	ENT (diagnosis/ treatment)	184	98.4
	Pediatrician (medical home)	0	0
	Family physician (family's doctor)	0	0
	Other	3	1.6
	N/A	(46)	
	Total	187	100.0

98.9% (188/190) of the PED-ENTs who were familiar with the *Joint Committee on Infant Hearing Year 2000 Position Statement* (JCIH, 2000) agreed with it. However, it is disturbing that 34 (15.2%) of these PED-ENTs said they were not familiar with this document. The *JCIH Year 2000 Position Statement* represents the best practices in EHDIPs in the United States and was developed by committee representatives from the American Speech-Language-Hearing Association, the American Academy of Audiology, the American Academy of Otolaryngology—Head and Neck Surgery, the American Academy of Pediatrics, the Council on Education of the Deaf, and DSHPSHWA.

The *JCIH Year 2000 Position Statement* established benchmarks and quality indicators for EHDIPs (e.g., all babies' hearing should be screened by one month of age). The NHSPQ probed the accuracy of these PED-ENTs' knowledge about these benchmarks, and 71.7% (162/226) of this sample knew that hearing loss should be diagnosed by three months of age. However, 25.2% (57/226) of these PED-ENTs answered incorrectly that hearing loss should be diagnosed by six months of age. Nearly two-thirds, or 63.6% (143/225), knew that intervention for children with hearing impairment should begin by six months of age. Although incorrect, nearly one-fourth, or 23.6% (53/225), said an intervention program should be in place by three months of age, which was earlier than recommended by the JCIH (2000). Nearly 13% (29/225) also incorrectly stated that an intervention program should be in place by nine months of age or later. Thus, the results of this survey revealed that even PED-ENTs could benefit from additional information about recommended outcomes from NHSPs, especially because the large majority of these respondents, or 79.9% (179/224), said they participated in NHSPs, and nearly all, or 98.4% (184/187), stated that they diagnosed and treated infants referred from those programs.

Attitudes toward NHSPs

Table 3 summarizes these PED-ENTs' responses to items #11 through #19 on the NHSPQ, which probed their attitudes

Table 3. PED-ENTs' Attitudes toward NHSPs

(11) My role in early hearing detection and intervention programs is an important one.				(16) Generally, audiologists adequately perform their role in UNHSPs.			
Responses	N	%		Responses	N	%	
Agree	186	80.9		Agree	190	86.8	
Strongly		145	63.0	Strongly		94	42.9
Moderately		41	17.8	Moderately		96	43.8
Neutral	4	1.7		Neutral	19	8.7	
Disagree	40	17.4		Disagree	10	4.6	
Moderately		0	0	Moderately		7	3.2
Strongly		40	17.4	Strongly		3	1.4
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Total	230	100.0		Total	219	100.0	
N/A	3			Not familiar	4		
(12) Current methods of educating parents about UNHSPs are adequate and effective.				(17) It is very important that infants' hearing losses be identified and interventions begun before they reach six months of age.			
Responses	N	%		Responses	N	%	
Agree	104	56.5		Agree	215	95.6	
Strongly		6	3.3	Strongly		172	76.4
Moderately		98	53.3	Moderately		43	19.1
Neutral	35	19.0		Neutral	1	0.4	
Disagree	45	24.5		Disagree	9	4.0	
Moderately		38	20.7	Moderately		6	2.7
Strongly		7	3.8	Strongly		3	1.3
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Total	184	100.0		Total	225	100.0	
Not familiar	9			N/A	8		
N/A	40			(18) Universal newborn hearing screening programs are deserving of the necessary health-care resource expenditure for their development and maintenance.			
Responses	N	%		Responses	N	%	
Agree	6	2.7		Agree	210	93.3	
Strongly		2	0.9	Strongly		177	78.7
Moderately		4	1.8	Moderately		33	14.7
Neutral	15	6.8		Neutral	11	4.9	
Disagree	198	90.4		Disagree	4	1.8	
Moderately		26	11.9	Moderately		3	1.3
Strongly		172	78.5	Strongly		1	0.4
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Total	219	100.0		Total	225	100.0	
Not familiar	0			N/A	8		
N/A	14			(19) Do you feel like you need more information about UNHSPs?			
Responses	N	%		Responses	N	%	
Agree	126	57.5		Yes	160	78.0	
Strongly		21	9.6	No	44	21.5	
Moderately		105	47.9	Yes/No	1	0.5	
Neutral	43	19.6		N/A	(28)		
Disagree	50	22.8		<hr/>			
Moderately		35	16.0	Total	205	100.0	
Strongly		15	6.8	If yes, in what format would you prefer to receive it?			
<hr/>				Responses	N	%	
Total	219	100.0		Email	12	31.6	
Not familiar	6			Email/Pamphlets	1	2.6	
N/A	8			Email/Internet	1	2.6	
(14) The referral and follow-up process for infants identified with hearing loss by UNHSPs is adequate and effective.				Internet	3	7.9	
Responses	N	%		Pamphlets	16	42.1	
Agree	212	95.1		Journal	1	2.6	
Strongly		167	74.9	Pamphlets/Videos	1	2.6	
Moderately		45	20.2	Videos	3	7.9	
Neutral	8	3.6		N/A	13		
Disagree	3	1.3		<hr/>			
Moderately		2	0.9	Total	38	100.0	
Strongly		1	0.4				
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Total	223	100.0					
Not familiar	2						
N/A	8						

toward NHSPs. Items #11 through #18 allowed respondents to indicate the strength of their responses on a scale from “strongly agree” to “strongly disagree.”

Role in NHSPs

Nearly four-fifths, or 80.9% (186/230), of these PED-ENTs believed that their role in NHSPs was important. Unfortunately, 17.4% (40/230) strongly disagreed that their role in these programs was important, contradicting findings that a large proportion of children who are referred require treatment from PED-ENTs for otitis media with effusion (Boone et al, 2005). Comments provided by a few of the respondents hinted at why they may perceive their role as being relatively unimportant. One PED-ENT stated, “We do not have a cohesive working group that brings healthcare personnel together.” Another said, “Our audiologist runs the programs and I see the problems.” Therefore, these results suggest that PED-ENTs need to be reminded of the important role that they play in diagnosing/treating hearing disorders in children and in preventing them and their families from getting lost in the referral and follow-up process. The results from this study, as well as those from another recent investigation using the NHSPQ (Danhauer et al, 2006) and our clinical experience, indicate that we cannot emphasize enough the invaluable role that PED-ENTs play in encouraging families to comply with professionals’ recommendations for their babies. These findings also show the need for having open lines of communication, establishing the roles of the stakeholders and participants in NHSPs, and sharing responsibilities and information among members of the team. This is especially important and can be problematic in states like California (Danhauer and Johnson, 2006; Danhauer et al, 2006), which relies on three regional hearing coordination centers to manage its NHSPs. These programs have large numbers of births, hospitals, providers, and stakeholders that generate huge amounts of NHSP information annually and need considerable coordination and data management to insure that infants and their families are not lost to follow-up.

Current Methods of Educating Parents

Parental education about NHSPs has a strong impact on preventing the loss of children to follow-up. Slightly more than half, or 56.5% (104/184), of these PED-ENTs who participate in NHSPs agreed with the statement “Current methods of educating parents about UNHSPs are adequate and effective,” whereas nearly one-fourth, or 24.5% (45/184), disagreed with this statement. Again, whether PED-ENTs agreed or disagreed with this statement, they all should be reminded of the important role that they serve in improving EHDIPs by educating parents about the importance of compliance regarding medical and audiologic recommendations.

Effect on Parent-Infant Bonding

The large majority, or 90.4% (198/219), of these respondents disagreed that infant hearing screening negatively affects the parent/infant “bonding” process. Generally, these physicians’ attitudes were consistent with findings from several other studies that have shown that bonding and parental anxiety are not affected by the NHSP process (Barringer et al, 1997; Watkin et al, 1998; Luterman and Kurtzer-White, 1999; Magnuson and Hergils, 1999; Hergils and Hergils, 2000; Stuart et al, 2000; Weichbold et al, 2001; English et al, 2004). Supportive PED-ENTs can have a positive impact on the referral and follow-up process and can calm anxious parents’ concerns about any fears regarding bonding issues with their babies. In responding to this question about infant/parent bonding, one respondent said, “The bonding process can be more affected by lack of response from an identified infant.” This comment seemed to summarize the beliefs of most EHDIP team members and parents, and suggested that parents may suffer more anxiety from lack of a definitive diagnosis of hearing loss than from the screening process itself. These findings and comments are in agreement with those from a study of 288 mothers in the United Kingdom (Watkin et al, 1998) whose infants had received newborn hearing screenings. Of those mothers, only 15% reported having some anxiety, and less than 1% said they were very worried, which caused the authors to conclude that newborn hearing screening

did not influence mothers' states of anxiety.

Referral and Follow-Up Process

Slightly more than half, or 57.5% (126/219), of these PED-ENTs agreed with the statement that "The referral and follow-up process for infants identified with hearing loss by NHSPs is adequate and effective." These PED-ENTs' relatively positive attitudes toward referral and follow-up in NHSPs can be both positive and negative for EHDIPs. For example, PED-ENTs' positive attitudes may reflect a willingness to work with audiologists and other stakeholders in preventing loss of babies to follow-up. However, PED-ENTs' positive attitudes may reflect complacency with the current system(s), which might hinder the development of further innovations in service delivery. All stakeholders (particularly physicians) must be reminded of the unacceptable 44.8% loss to follow-up rate in the United States (DSHPHWA, 2005), which severely lessens the effectiveness of NHSPs.

Additionally, one respondent commented that rapid discharge rates in hospitals have a negative impact on the referral and follow-up process. This comment agrees with the findings of a report from the United Kingdom (Watkin et al, 1998) where about 70% of infants born in one hospital were discharged before they were 48 hours old, which prompted the use of a two-staged screening process that is being implemented in many EHDIPs to help with the follow-up process. Clearly, NHSPs must devise ways of making appropriate referrals and ensuring follow-up with families in a very timely manner before they leave the hospital. Another respondent commented that "Pediatricians seem to be the missing link in encouraging posthospital follow up." These comments implied that PED-ENTs must take on responsibilities for follow-up services since they will likely see infants identified with hearing loss once they leave the hospital. Another respondent commented that local and state referral and follow-up rates are poor and that there is a need for a federal program for informing families about their infants' hearing losses and stressing their compliance for follow-up. Again, the California NHSP, which has three regional Hearing Coordination Centers and the highest number of births but some of the poorest screening and follow-up rates in the country, may be an

example of the difficulties these programs can have at the state and local levels. However, it is unclear as to whether a federal program would fair any better than the current system. Clearly, this is an issue that warrants attention from EHDIP team members at local, state, and national levels.

Importance of Audiologic Reevaluation

Both parents' and physicians' complacency about audiologic reevaluations or poor attitudes toward audiologists and their role in NHSPs could contribute to high rates of loss of infants and their families to follow-up. Fortunately, the large majority, or 95.1% (212/223), of these PED-ENTs agreed that it was very important to have infants' hearing reevaluated after their medical evaluation and treatment. Interestingly, one respondent stated that audiologic reevaluations after medical treatment are not necessary if the infants pass their initial newborn screenings. This comment seems to miss the point that a pass on an initial newborn screening only indicates the infant's status at or near birth and that hearing losses can occur after that time. Parents (and perhaps some physicians) need to be informed that a pass on a newborn hearing screen is like a snapshot in time and does not inoculate a child from hearing loss forever. This is sometimes a difficult concept to convey to parents but is one of which physicians should be well aware. It makes sense that, in most cases, infants' hearing status should be confirmed after medical diagnosis and treatment (Boone et al, 2005). However, parents should be educated to be on the alert for behaviors in their children that might indicate hearing loss as they get older so they can be seen by their PED-ENTs and proper referrals can be made in a timely manner. Another respondent stated, "Some audiologists feel they can make a decision that MDs (ENTs) should make." This statement points to the need for team members to adhere to their scopes of practice and that the roles of each stakeholder are established at the outset of developing EHDIPs. These issues are important and should be discussed and agreed upon by the EHDIP team members in order to avoid any misconceptions and misunderstandings that could hinder effective functioning of the program.

Adequacy of Audiologists' Role

Most, or 86.8% (190/219), of these PED-ENTs agreed that audiologists adequately perform their roles in NHSPs. However, as was seen for the previous question, some of the comments provided by a few of the respondents suggested that they were not all completely pleased with the way audiologists performed their roles in their respective EHDIPs. The following statements were made in reference to some audiologists: "They overdo"; "They don't send typed reports to all MDs involved"; "Many audiologists don't need ENTs"; "There are many audiologists in practice who do not know how to evaluate babies"; "Depends on the audiologist"; "Our audiologists own the program and reluctantly refer to ENTs." Although several other very complimentary comments were provided about audiologists by some of these PED-ENTs, the few statements above show the need for all members of the team to respect each other's contributions and to communicate with each other in order to avoid "turf battles" that could have negative effects on the program.

Another finding that bodes well for EHDIPs is that nearly all of these PED-ENTs, or 95.6% (215/225), agreed that infants' hearing losses should be identified and intervention begun before they reach six months of age. Further, nearly all, or 93.3% (210/225), of these respondents agreed that NHSPs were deserving of the necessary health-care resource expenditure for their development and maintenance. The results of this study would suggest that if additional funding should become available for NHSPs and EHDIPs, it should be put toward fostering increased awareness for and education of parents (and perhaps some physicians) that would lead to better follow-up rates.

Desire for Additional Information

An important finding from this survey was that 78.0% (160/205) of these physicians indicated that they would like additional information about NHSPs. Preferred methods of receiving educational materials were through pamphlets and e-mails. Surprisingly, few of these physicians indicated that they would like to have access to informational

materials via the Internet or in video formats. This is in contrast to the findings of a large-scale survey of 1000 general practitioners (524 respondents) conducted in the United Kingdom, who preferred to access Internet sites that had downloadable articles for information about NHSPs (Moorjani and Fortnum, 2004).

Qualitative Responses

Some of the comments provided in the margins to this question about what information they want included the following: "2006 position statement"; "Hard facts showing efficiency of early detection"; "Updates on latest trends"; "Correct answers to questions with references"; "Position statement and parent education"; "Journal articles on your results in ENT journals." The respondents' desires for increased continuing education about EHDIPs and NHSPs are encouraging, if their requests are to maintain currency with information about these programs. However, this finding could cause more concern if these PED-ENTs' requests were to obtain basic information about benchmarks for EHDIPs and NHSPs (as some of them clearly were).

Often, both parents and allied medical stakeholders in NHSPs assume that physicians are knowledgeable about everything related to medicine, including these programs. In some cases this may be an inaccurate or unfair assumption, because physicians may not have all the answers or be current about the latest information relating to the newborn hearing screening and follow-up process. It is worth restating that audiologists should supply PED-ENTs with current information as rapidly as possible and in the formats they desire because of the importance of the role that they play in EHDIPs and the influence they can exert on parents to comply with professionals' recommendations for accessing follow-up services for their infants with hearing loss.

A major finding of this study was that these PED-ENTs desired additional information about EHDIPs. Interestingly, this is in close agreement with a recent report from the American Academy of Audiology's Marketing Committee regarding its presence at the American Academy of Pediatrics and the American Academy of Family Physicians

meetings this year (Borton et al, 2005) where some of the most requested types of information pertained to newborn hearing screening, tracking, and follow-up. Several of the physician attendees were interested in knowing how their programs compared to those of other hospitals or states, the numbers of infants that should be identified with significant hearing loss, and how many would be missed in these programs, and they wanted follow-up information from the American Academy of Audiology by e-mail or regular mail. These encounters provide opportunities for audiologists to communicate and build bridges with the pediatrics profession as a whole, which is a major resource for audiologists.

Interestingly, several of the respondents in this study also wanted to know how their EHDIPs compared with those in other states and the nation. The NHSPQ can be useful in making such comparisons. For example, we (Danhauer et al, 2006) recently used the NHSPQ to evaluate the local NHSP in Santa Barbara County, California. Although those results were for a very small program and number of participating ENTs and PEDs, there were some similarities and differences to the findings in this national study. The physicians in that study were also generally knowledgeable about and had positive attitudes toward NHSPs, and they too did not view their role in the program as being very important. However, unlike the respondents in this national study, the physicians in that local study did not believe that they needed additional information about EHDIPs. Thus, the NHSPQ can be used to assess EHDIPs both locally and nationally to evaluate programs and provide useful information to stakeholders. Audiologists, who are often also the managers of EHDIPs, should act on these findings and create ways of making necessary educational materials available in several formats and in a timely manner for our physician colleagues. Inclusion of and support from physicians are critical to the success of any EHDIP.

SUMMARY AND CONCLUSIONS

The purpose of this study was to complete a national postal survey of PED-ENTs and EHDIPs using the NHSPQ. The results of this survey indicate that even PED-ENTs

would benefit from information on EHDIP guidelines, important benchmarks, and high rates of infants and their families who are lost to follow-up. Audiologists who participate in EHDIPs should partner with ENTs and other physicians to create strong networks so that no infant is lost “between the cracks.” Earlier, we (Danhauer et al, 2006) showed how the NHSPQ could be used at a local level as an icebreaker for proactively establishing relationships with physicians in community-based EHDIPs. On a national level, the American Academy of Audiology should continue its role in reaching out to physicians’ professional organizations such as the American Academy of Otolaryngology—Head and Neck Surgery; American Academy of Pediatrics; and American Academy of Family Physicians. Strong partnerships between audiologists and ENTs locally and nationally can improve the outcomes for young children diagnosed with hearing loss and their families.

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Appendix 1. Newborn Hearing Screening Program Physicians' Survey (NHSPQ)

**UNIVERSAL NEWBORN HEARING SCREENING PROGRAM:
PHYSICIANS' QUESTIONNAIRE**

Universal Newborn Hearing Screening Programs (UNHSPs) exist in about 40 states. Please take a few minutes to answer the following questions surveying physicians' knowledge, participation, and opinions of UNHSPs. As a physician, your responses are valuable in monitoring the outcomes of UNHSPs.

DEMOGRAPHICS

INSTRUCTIONS: Please circle the item that best reflects your response to each question.

- (1) What is your gender? Male Female
- (2) What type of physician are you? Otolaryngologist Pediatrician Family Physician
Other _____
- (3) What is your practice setting? Hospital Private Practice Clinic
Other _____
- (4) How long have you been in practice? 0 to 5 years 6 to 10 years over 10 years

KNOWLEDGE OF UNHSPs

- (5) Do you know what Universal Newborn Hearing Screening Programs (UNHSPs) are? Yes No
**IF NO, STOP HERE AND RETURN THIS SURVEY IN THE ENCLOSED ENVELOPE.
THANK YOU!**
- (6) Do you agree with the Joint Committee on Infant Hearing Year 2000 Position Statement re: early hearing detection and intervention programs?
Yes No Not familiar with the Position Statement
- (7) According to recommended practices, by what age should hearing loss be diagnosed in a child?
3 months 6 months 9 months 1 year 2 years 3 years
- (8) According to recommended practices, by what age should an intervention program be in place for a child with hearing impairment?
3 months 6 months 9 months 1 year 2 years 3 years
- (9) Do you participate in a UNHSP?
Yes No **IF NO, PLEASE GO ON TO QUESTION 13**

PARTICIPATION IN UNHSPs

- (10) What role do you play in UNHSPs?
- a. As an otolaryngologist, I receive referrals to determine type/degree of hearing loss and provide treatment
 - b. As a pediatrician, I serve as the baby's doctor and "Medical Home"
 - c. As a family physician, I serve as the family's doctor
 - d. Other: I am a _____ and I serve as _____.

FOR ITEMS 11-18, PLEASE CIRCLE THE RESPONSE THAT BEST REFLECTS YOUR AGREEMENT WITH EACH STATEMENT. IF YOU ARE NOT FAMILIAR WITH THE TOPIC, CIRCLE THE CHOICE AT THE FAR RIGHT.

(11) My role in early hearing detection and intervention programs is an important one.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

(12) Current methods of educating parents about UNHSPs are adequate and effective.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

(13) Infant hearing screening negatively affects the parent/infant “bonding” process.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

(14) The referral and follow-up process for infants identified with hearing loss by UNHSPs is adequate and effective.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

(15) It is very important to have infants’ hearing re-evaluated after your medical evaluation/treatment.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

(16) Generally, audiologists adequately perform their role in UNHSPs.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

GENERAL OPINIONS REGARDING UNHSPs

(17) It is very important that infants’ hearing losses be identified and interventions begun before they reach six months of age.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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(18) Universal newborn hearing screening programs are deserving of the necessary health-care resource expenditure for their development and maintenance.

Strongly Agree	Moderately Agree	Neutral	Moderately Disagree	Strongly Disagree	Not Familiar with the Topic
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Comments: _____

(19) Do you feel like you need more information about UNHSPs?

No Yes, regarding _____

If yes, in what format would you prefer to receive it?

Email Pamphlets Videotapes Internet Other _____

THANK YOU FOR YOUR PARTICIPATION. PLEASE ADD ANY COMMENTS BELOW AND RETURN THIS SURVEY IN THE ENCLOSED ENVELOPE.