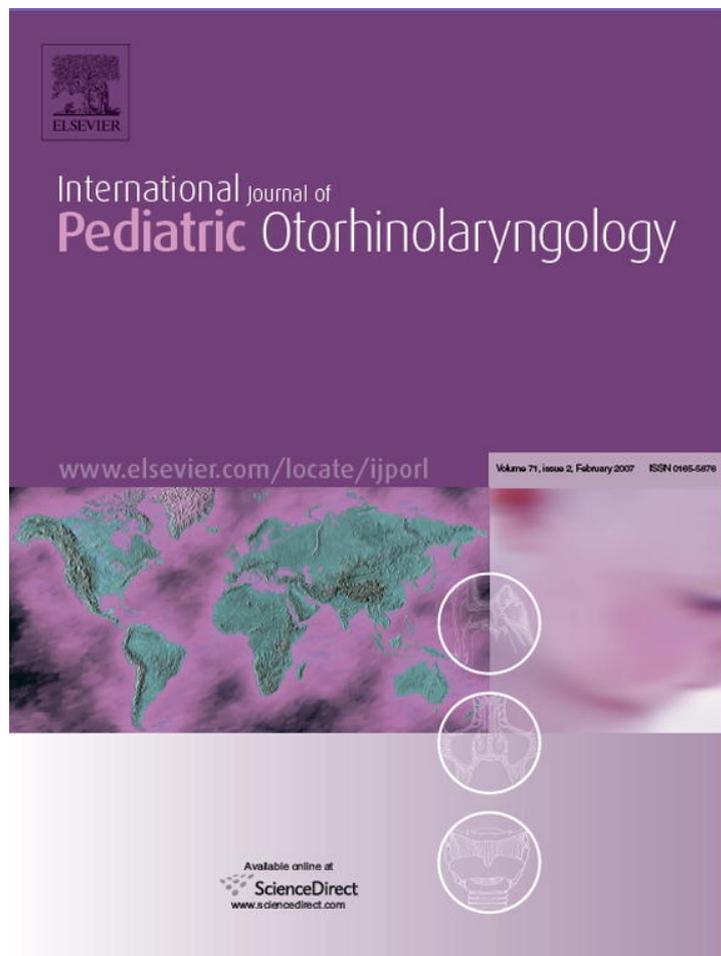


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Comparison of universal newborn hearing screening programs in Illinois hospitals

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Summary

Summary/objectives: In accordance with the Joint Committee on Infant Hearing's (JCIH, 2000) position statement regarding Universal Newborn Hearing Screenings (UNHS), the state of Illinois enacted legislation requiring all birthing hospitals to conduct UNHS by 31 December 2002. Currently 100% of birthing facilities in the state of Illinois perform newborn infant hearing screenings using otoacoustic emissions (OAEs) and/or automated auditory brainstem response (AABR) measures. This study is an attempt to document current practices in hospital-based UNHS programs, as reported by program personnel, in the state of Illinois. The goal is to compare these reported practices to the recommended standards and identify factors that could lead to further refinement of the process.

Methods: A modified version of the Newborn Hearing Screening Survey from the Marion Downs National Center for Infant Hearing was used to gather practice- and protocol-related data for the 2004 calendar year via the World Wide Web. Data presented here are extracted from the online survey *as reported by hospital staff* presumably associated with the UNHS program.

Results: Fifty-nine of the 140 hospitals with UNHS programs responded to the Web-based survey. Nursing staff, followed by technicians, were most commonly reported to perform initial hearing screenings in both the well-baby nursery (WBN) and the neonatal intensive care unit (NICU). Audiologists appeared to participate in re-screenings at a greater number of the facilities. Automated ABR was the most common

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screening tool (80%) followed by Distortion Product OAEs (32%) and Transient Evoked OAEs (5%). Eighty-six percent reported referral rates that were less than 5%, with 32% reporting a referral rate less than 1%.

Conclusions: At the beginning of 2004, 99% of all infants born in Illinois were being screened for hearing loss. Personnel involvement and screening measures employed were comparable to the few reports available from other states. The audiologist's role was found to be fairly limited in screening, re-screening, or managing UNHS programs. Referral rates were consistent with national standards (~1%). Management of UNHS programs in small, rural facilities, tracking/monitoring high-risk infants, and other services provided to families emerged as areas with room for improvement.

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1. Introduction

Approximately 33 babies are born in the United States with a hearing loss every day [1,2]. Another three of every 1000 children born with normal hearing acquire a hearing loss during childhood or have an undiagnosed progressive hearing loss [1,3]. The goal of Universal Newborn Hearing Screening (UNHS) programs is to identify hearing loss as early in life as possible allowing the initiation of appropriate treatment and/or rehabilitation, thereby preventing the demonstrated educational, social, emotional and communicative consequences [4–7] of hearing loss. Prior to the inception of UNHS programs, the national average age of identification of childhood hearing loss was between 14 months and 2.5 years [8]. Such delays in diagnosis have been linked to irreversible delays and/or deficits in speech and language development [7,9] possibly leading to negative effects on literacy, academic ability, and social/emotional development [4]. Evidentiary support of the success of UNHS programs and appropriate early intervention comes from improved language abilities of children with hearing impairments [6,10] which are expected to translate into improved academic outcomes [4,6]; reduction in special education and training costs [6,10]; and ultimately to fulfilling employment and contributions to society [6,10,11].

The Joint Committee on Infant Hearing (JCIH) recommends a “1–3–6” plan: all infants, including those born in alternative birthing facilities, should be screened prior to 1 month of age, preferably before discharge [5,8]; diagnostics should be completed by 3 months of age for those referred after a re-screening [5,8]; and, for those with confirmed hearing loss, intervention should be initiated by 6 months of age [5,8]. Screenings need to be performed using objective physiologic measures that detect the presence of “permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30–40 dB or more in the frequency region important for speech recognition (approximately

500–4000 Hz)” [5, p. 800]. The JCIH also outlines suitable UNHS program personnel. An audiologist should be designated as manager of the program, with supervisory responsibilities for hearing screening as well as the design, implementation and evaluation of the program [5]. Personnel other than the audiologist performing the screenings may include nurses, speech-language pathologists, and others trained by an audiologist [5].

The above-mentioned initiatives at the national level have rapidly percolated to state level efforts. Currently in the United States, 38 states have some form of legislation that mandates UNHS. Cost effectiveness and efficacy of UNHS programs were questioned initially [7,12]. Although opponents were in favor of early identification, they argued for selective screening using a high-risk register, citing limitations of available equipment and program practices. It is important to acknowledge that high-risk infants represent only about 50% of infants with congenital hearing loss [7,13]. However, the cost of implementing and maintaining UNHS programs, the inability to detect atypical or progressive hearing loss, and noncompliance of families are pitfalls in UNHS that programs need to address [7].

Current universal screening practices are, indeed, ineffective in the identification of atypical hearing loss configurations and/or mild degrees of hearing loss. Automated auditory brainstem response (AABR) and otoacoustic emissions (OAE), used in current screening protocols, have the potential to miss low frequency hearing loss in infants with normal/near normal mid- to high-frequency hearing [12,14–16]. Borderline or mild hearing losses (thresholds between 15 and 25/30 dB) also may go undetected using current screening tools. Neonates often have vernix in their ear canals or transient fluid in the middle ear compromising the results of screenings and increasing false positive rates, particularly when using OAEs [14,15,17]. Those infants who may have progressive or late onset hearing loss would not be identified through newborn hearing

screening, which makes diagnostic protocols and high-risk registries still necessary [17].

Outside of medical and/or audiological factors, the efficiency of UNHS is also compromised by compliance and logistic factors [18]. The JCIH encourages state departments of health to develop centralized systems for monitoring hearing screening programs to ensure follow-up, tracking of referrals, and missed outcomes [7]. National estimates of infants lost to follow-up after the initial screening range from 25% to 80% despite recruiting efforts by state programs [18]. This systemic “leak” lends ammunition to those opposed to UNHS, who argue that the loss to follow-up is due to the lack of resources, inadequate data management systems, inconsistent reporting requirements, and lack of communication with medical professionals regarding follow-up testing [12,19]. Often, lack of follow-up is deemed the fault of the family and considered noncompliance, overlooking causal flaws in the system or relationships with professionals [20]. Sass-Lehrer argues that the success of Early Hearing Detection and Intervention (EHDI) programs are dependent on the relationships developed between the professional and paraprofessionals with families and their effectiveness in communicating respect and sensitivity regarding issues of importance to the family [20]. Although the relationship between professionals and family members and communication between these two groups should not be neglected, these efforts may be handicapped by lack of resources and efficient reporting and monitoring protocols.

1.1. The UNHS program in Illinois

In the state of Illinois, an estimated 500 infants are born with hearing loss each year [21]. In order to identify these infants, the state of Illinois enacted legislation requiring all birthing hospitals to conduct UNHS with full implementation by 31 December 2002 [22]. The Illinois Department of Public Health (IDPH), with the guidance of the Newborn Hearing Screening Advisory Committee and in cooperation with the Illinois Department of Human Services (DHS) and the Division of Specialized Care for Children (DSCC), has published guidelines developed in accordance with the JCIH 2000 statement for hospital screening programs. Similar to the JCIH recommendations, Illinois’ rules for administration of the Hearing Screening for Newborns Act provide information regarding who should be screened, when to screen, measures to use, pass/fail criteria, methodology, expected false-positive rate, documentation, reporting, follow-up, and intervention practices [22].

Currently, 100% of birthing hospitals in Illinois perform newborn infant hearing screenings using OAEs and/or AABR. To reduce false-positive rates, Illinois’ legislation requires a two-stage screening process in the event that a newborn does not pass the initial hearing screening. That is, a re-screening is performed on all such newborns during their birth admission prior to any diagnostic referrals [22]. Hospitals then report all data regarding UNHS activities to IDPH using the electronic data system. Data reporting and management is done using a central database with local installations of the Hi*Track Data Management System. This software system was created by the National Center for Hearing Assessment and Management (NCHAM), Utah State University, exclusively for newborn hearing screening data management and tracking. Following training from IDPH staff, hospitals are required to send their screening data to IDPH weekly by encrypted e-mail attachment. This allows for the timely submission of screening and follow-up data and a means of centralized monitoring of receipt of data by the state authority. State guidelines require that all infants, whether they were screened or not, be entered into the Hi*Track system in order to effectively and completely track hearing screening outcomes of 100% of infants born in Illinois. IDPH has worked closely with the developers of the Hi*Track system and the birthing facilities in Illinois to ensure that all data regarding infants and their families are encrypted in transmission to IDPH and protected while in storage.

Despite these efforts and investment in infrastructure, reporting and tracking have continued to be areas of difficulty for UNHS programs in general. The state of Illinois has witnessed tremendous growth in facility reporting since the inception of the legislation. In 2004, hearing screening information of an estimated 98% of infants born in the state were reported to IDPH compared to an estimated 90% in 2003 [21].

The state of Illinois follows up on all infants referred or missed in the time window for initial screening during their birth admission. IDPH has developed a newborn hearing screening monitoring timeline that commences with an informative letter reporting the results of the screening to both the infant’s parents and the physician within 5 days of receiving the report from the birthing facility. In these letters, parents are encouraged to obtain follow-up hearing screenings or diagnostic evaluations in a timely fashion to ensure early identification and intervention. IDPH makes *five* additional attempts to locate children and obtain follow-up information if the Department has not received documentation of follow-up. At 3 months, if IDPH

has not received verification that an infant has received a re-screening or diagnostic evaluation or that he/she is scheduled for testing, IDPH contacts local health departments to establish contact with families and assist them in obtaining follow-up. DSCC can provide financial assistance and help in locating appropriate professionals for families who have not obtained follow-up evaluations.

Although we have described the specific efforts in the state of Illinois to follow-up and track infants suspected of having impaired hearing, such significant investments are commonplace where UNHS is practiced. Monitoring the efficacy of programs such as UNHS and ensuring the maximum return on such societal investments are of utmost importance. Our study is an attempt to monitor the current practices of the hospital-based UNHS programs in the state of Illinois—as perceived and reported by the hospitals. Our goal is to compare these *self-reported* practices to the recommended standards and informally compare the trends in the data to those reported to the IDPH, particularly in the case of outliers. In the process, we hope to identify factors that could result in non-compliance. With this knowledge, audiologists, physicians, parents, administrators of the newborn hearing screening program, and legislators may gain a greater understanding of how these programs work at the local level and what improvements, if any, are needed.

2. Methods

The Newborn Hearing Screening Survey from the Marion Downs National Center for Infant Hearing (MDNC) was modified for online use by participating hospitals in the state of Illinois. The original MDNC survey was used in 1996–1997 as part of a battery of surveys to collect baseline data on the status of UNHS, audiological assessment, and intervention in states participating in the Maternal Child Health grant at the Marion Downs National Center [23]. The modified version of the MDNC screening survey included questions regarding UNHS personnel, testing protocol, testing criteria, test equipment, parental information, tracking, and monitoring procedures (see [Appendix A](#) for complete questionnaire). Questions regarding identification of personnel, hospital funding, and hospital payment procedures were excluded from the survey, as they were unrelated to the purpose of this study. To ensure context validity, the revised survey was reviewed by several clinical and research audiologists, including two audiologists involved with UNHS at IDPH. The survey was presented in electronic

Table 1 General information from the 59 responding facilities

Number of facilities contacted	140
Number of facilities responded	59 (42.5%)
Number of usable responses	59 (100%)
Setting of facilities	
Urban (population served >100,000)	30 (51%)
Rural (population served <100,000)	29 (49%)
Facilities that employ an audiologist	
Urban	13 of 30 (43%)
Rural	7 of 29 (24%)
Facilities that have a NICU	
Level 2	31 (52%)
Level 3	10 (17%)
Method of data interpretation	
Automated	51 (87%)
Automated and audiologist	5 (8%)
Audiologist	2 (3%)
Re-screening procedures	
Re-screen as inpatients only	18 (31%)
Re-screen as outpatient only	19 (33%)
Re-screened as both inpatient and outpatient	21 (36%)
Facilities that screen outpatients	26 (44%)
Average duration of programs	
Rural	5.5 years (range 2–11 years)
Urban	5.24 years (range 1–14 years)
Average number of infants screened in 2004	
Rural	565.8 (range 30–2000)
Urban	1771 (range 273–3895)

These data are limited to calendar year 2004.

form via a Website hosted by Northwestern University.

Every hospital in the state, participating in UNHS (140), was contacted with a request for participation in this study. IDPH provided the list of Illinois hospitals along with contact name(s) for each hospital's UNHS program. Over a period of 6 weeks, two contact letters providing basic information regarding the survey were sent to the person or persons listed. An additional contact requesting participation was sent by e-mail to facilities that were unresponsive to the initial contact letters. Those who expressed interest were provided individual usernames and passwords to access the survey online. Responses to the survey were gathered electronically and stored in a password-protected database. Participating facilities were not identified by name ensuring hospital anonymity.

We sought data pertaining to the calendar year 2004 from the responding facilities. Data were analyzed using descriptive statistical procedures to order and group the data into distributions. Group tendencies including mean, standard deviation, and variance were included in the analyses. Trend analyses also were performed to identify any patterns in the data. Hospital contact, data gathering, storage, and handling were performed in accordance with the standards of the Institutional Review Board (IRB) at Northwestern University.

3. Results

Fifty-nine of the 140 hospitals with UNHS programs in the state of Illinois responded to our survey; all of these surveys were deemed to be complete and are included in the analyses. One hospital had ceased to be a birthing facility and, hence, could not respond, giving us a response rate of 42.5% (59/139). Descriptive and classification data are presented in Table 1. Based on the size of the population served by the hospital, the responding facilities were divided into two approximately equal rural and urban groups. On average, the urban facilities screened three times as many infants as their rural counterparts, and were more likely to employ an audiologist. Irrespective of their population size, the responding UNHS programs had been functional for an average of 5 years. Automated data interpretation was reported in our survey to be the sole method of choice in 87% of the facilities. Cross verification with data routinely submitted to IDPH revealed that 100% of the facilities use automated methods of data interpretation for the initial screening.

Nursing staff (93% of facilities) followed by technicians (40% of facilities) were most commonly reported to perform hearing screenings in the well-baby nursery (WBN). Note that the sum total of facilities exceeds 100% as several reported using multiple types of personnel for UNHS. The totals for

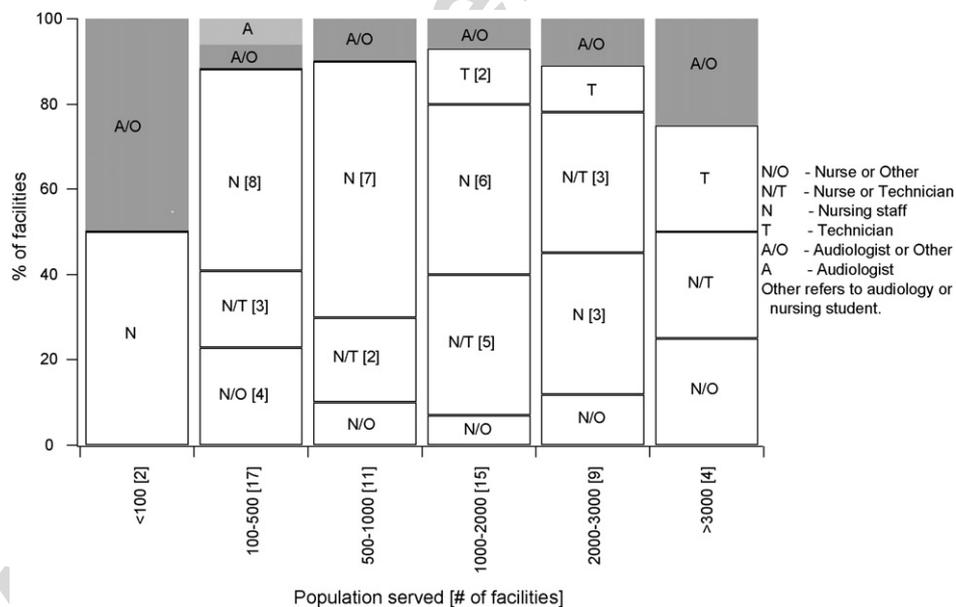


Fig. 1 Personnel performing screenings at the responding facilities categorized by the number of infants screened. Different categories of facilities are presented along the abscissa with the number of responding facilities in that particular category indicated in square brackets. Column-segments displaying the proportion of different personnel types active at each type of facility are presented with numbers in square brackets indicating the actual number of facilities. The column-segments with no numbers in them represent one facility. The representation of audiologists is highlighted by the use of shading. N/O: nurse or other; N/T: nurse or technician; N: nursing staff; T: technician; A/O: audiologist or other; A: audiologist; other refers to audiology or nursing student.

Table 2 Tabulation of the number (and percentage) of facilities where different types of personnel are responsible for referral, tracking, and re-screening of infants that fail the UNHS

Personnel	No. (%) of facilities			
	Referral	Tracking	Re-screen ^a	Manager
Physicians	25 (42%)	37 (63%)		
Nursing staff	8 (14%)	6 (10%)	19 (33%)	30 (51%)
Audiologist	6 (10%)	7 (12%)	18 (31%)	11 (18%)
Technicians			10 (17%)	
Physician or audiologist	5 (8%)			
Audiologist or other			2 (3%)	
Physician or other	11 (19%)			
Manager of hearing screening program	3 (5%)	2 (3%)		
Illinois Department of Public Health		4 (7%)		
Other	1 (2%)	1 (2%)		18 (31%)
Outside agencies			14 (24%)	
Unknown		2 (3%)		

The personnel types designated as the manager of the UNHS programs at the responding facilities are also presented.

^a The total number of facilities in the "re-screen" column exceed 100% or the number of responding facilities (59) as multiple personnel-types were reported to be performing re-screenings at some facilities.

several other indices reported here also exceed 100% for the same reason. A combination of audiologists and other personnel were involved in performing screenings in 10% of the WBNs. Forty-one responding hospitals reported having a neonatal intensive care unit (NICU). Hearing screening personnel in the NICU were similar to that of the WBN, with 87% of screenings performed by nurses and 25% performed by technicians. Of these 41 facilities, the audiologist was solely responsible for hearing screenings in the NICU in one facility. Another 8% of the responding facilities indicated that a combination of audiologists and other hospital staff were performing screenings in the NICU. Given this similarity in screening personnel in the NICU and the WBN, we present a general analysis of personnel involved as a function of facility size in Fig. 1. Although the dominance of involvement of the nursing staff is evident in this figure, the diversity of personnel also appears to increase with the size of the facility. Some facilities reported the involvement of nursing and audiology students as well as certified nursing assistants in the screening process; these reports are documented under the "other" category.

The value of these data are perhaps maximized when examined concurrently with information regarding personnel involved in decision making regarding referrals, follow-up testing, and administrative roles (see Table 2). Managers of UNHS programs also are presented in the same table. Note the increased involvement of physicians in referral and tracking of infants who fail the UNHS compared to physician involvement in the initial screening process. Audiologists also appear to participate in re-screening at a greater number of

institutions as compared to their involvement in the initial screening. This number (31%) has to be examined in light of the fact that approximately half of the responding facilities actually employ audiologists. Thus, these data can also be interpreted to show that audiologists were *not* involved in re-screening in 38% of the responding facilities where an audiologist was on staff. The survey instrument used did not distinguish between inpatient and outpatient re-screening. Thus, the above results related to re-screening are combined for both types of re-screenings. When asked about the manager designate, UNHS programs were managed by a member of the nursing staff in approximately half of the responding facilities. Again, the limited involvement of audiologists as managers of UNHS programs is evident; only 36% of the facilities where audiologists were employed used them to manage UNHS programs. Upon initial examination, it may appear interesting or even alarming that the person responsible for tracking infants who failed the UNHS was *unknown* in 3% of the responding facilities (Table 2). However, tracking infants who fail UNHS is the responsibility of IDPH in the state of Illinois. Some facilities do track these infants concurrently with IDPH.

Related to the general issue of personnel involved in UNHS programs, we inquired about the responsibility of informing parents of the screening outcome. Nursing staff was trusted with this responsibility in 91% of the responding facilities, with audiologists, physicians, and technicians informing parents in the remainder of the reporting facilities. Finally, a few facilities reported that a letter was typically left bedside informing parents of the outcome of the screening process.

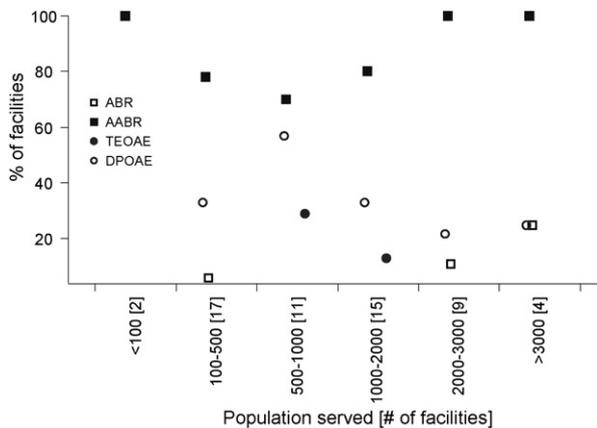


Fig. 2 Illustration of the relationship between the number of infants screened in 2004 and the physiologic measure used in hearing screening programs. Totals exceed 100% because some facilities use a combination of measures in screening programs. Of the 59 responding facilities, 48, 7, and 4 used 1, 2, or 3 measures, respectively.

The choice of physiologic screening measure used at reporting facilities of various sizes are displayed in Fig. 2. The abscissa of this figure is formatted identically to that of Fig. 1, with the data categorized according to the size of the population served and the number of facilities in each category reported in square brackets. Automated auditory brain stem response (AABR) was, by far, the most common choice of screening tool at approximately 80% of the reporting facilities. Distortion product OAEs (32%) and transient evoked OAEs (5%) were used less frequently. Forty-eight of the 59 responding facilities used a single measure for the initial inpatient screening; two and three measures were reported to be used in seven and four facilities, respectively. The choices of screening measure at facilities that employ an audiologist versus those that do not are displayed in Fig. 3. The category labels along with the number of facilities in square brackets using a particular screening tool or tool-combination are presented in the body of the figure. The choice of screening measure does not appear to be influenced by the presence of an audiologist on staff. These data may be interpreted in light of the limited role of audiologists in screening and re-screening seen in Fig. 1 and Table 2. However, staff at IDPH report that hospital staff frequently consult with the audiologists at IDPH, DSCC, NCHAM, and other hospitals regarding electrophysiological measures to be employed in their screening programs. Most devices used in UNHS today have built in interpretation paradigms with preset pass/fail criteria for automatic decision-making. Ninety percent of the responding facilities reported using the device-provided interpretation as the outcome of

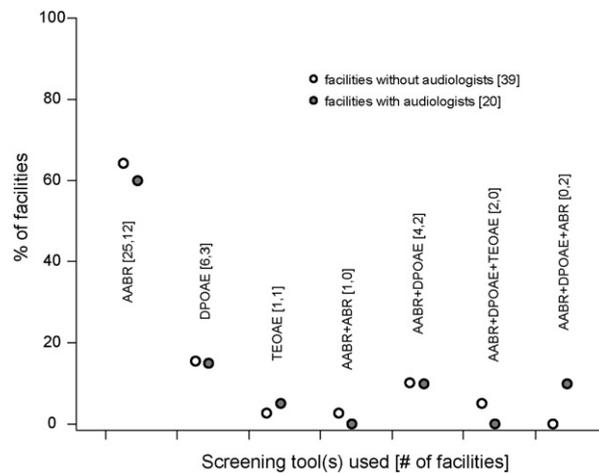


Fig. 3 Screening tools used in different facilities with and without audiologists. The open symbols represent the percentage of facilities without audiologists (out of 39) using a particular screening tool. The filled symbols represent the same percentage of facilities with audiologists (out of 20). The numbers in square brackets associated with each screening tool depict the actual number of facilities (with and without audiologists) using that particular tool. Note the similarity in choice of screening tools irrespective of the presence of an audiologist at the facility. Also note that one facility without an audiologist reported using non-automated ABR. Upon crosschecking with IDPH it was verified that non-automated ABRs were indeed used at this facility by a technician under the supervision of a neurologist.

the screening. The audiologist was reported to review the outcome determined by the screening device or directly interpret the results of the inpatient procedures in 35% of the 20 responding facilities where audiologists were employed.

The choice of physiologic measures used in re-screenings was comparable to the method used for initial screening. The proportion of facilities using AABR, DPOAEs, and TEOAEs for re-screenings remained approximately unchanged (82%, 32%, and 5%, respectively). However, 12% of the facilities reported using ABR for the re-screenings as opposed to less than 1% where ABR was used as a tool for the initial screening. As before, the data for re-screening cannot be parsed into those relevant to inpatient versus outpatient re-screening protocols due to the design of the survey.

Referral rates of less than 5% were reported by 86% of the responding facilities. Further, the referral rate was reported to be less than 1% at 32% of the facilities. The effect of the type of physiological measure used and/or personnel-type was not evaluated statistically due to the small spread in the data. However, no trends indicating either of these factors affect referral rate were observable. Four

Table 3 Operational details of the four facilities that reported referral rates greater than 5%

Facility	Referral rate (%)	No. of births	Measure	Screeener	Audiologist on staff	Interpretation	Manager	Program experience (years)
I	15–22	2,106	DPOAE, AABR	Nurse, technician	Y	Machine	Audiologist	>5
II	7.8	600	AABR	Nurse	N	Machine	Not reported	>5
III	10	1,200	DPOAE, AABR	Nurse	N	Machine	Nurse	>5
IV	10–15	12,000	DPOAE, AABR	Nurse, audiologist	Y	Machine	Audiologist	>5

Note the diversity in the number of births between the facilities. Also note the similarity in the screening measure and personnel used, the method of interpretation, and the experience of the facility in performing UNHS.

facilities reported referral rates greater than 5%, with the rate being greater than 10% at two of these institutions. Operational details of these four facilities are provided in Table 3. Note the wide range in the number of births among these facilities. This parameter appears to be the only notable difference among them. The methods used to screen, the personnel performing the screening, the method of data interpretation, as well as the facility's experience with UNHS are remarkably similar across institutions. An audiologist was on staff at two of the four institutions and was involved in program management at both facilities.

Seventy-three percent of respondents indicated that their facility reports to the IDPH using the Hi*Track computerized system, as mandated by the state guidelines. Twenty-four percent of these facilities indicated reporting to IDPH using Hi*Track and an internal hospital-based system to document and track screening results. Twenty-two percent of facilities reported the use of a hospital-based system to document hearing-screening data; however, these facilities did not provide any information regarding the protocol followed to report information to the IDPH. Finally, as seen in Table 2, the respondents from two facilities were unaware of any method of tracking or reporting results from the UNHS program. The reader is reminded that these data are reflective of the knowledge of the individual responding to the survey. Per Illinois' regulation, every UNHS facility reports to IDPH using the Hi*Track system.

An oft-cited limitation of UNHS programs is the inability to detect those infants who may have a progressive or late onset hearing loss [17]. Thirty-two percent of responding facilities in our survey reported using a set of high-risk indicators to identify infants at risk for hearing loss in addition to the electrophysiological screening methods. Fifty-three percent of facilities reported referring at risk infants to a licensed audiologist for monitoring. It was reported that parents are provided information

regarding progressive/late onset hearing loss at 26% of facilities, and physicians are solely responsible for monitoring these infants at 18% of facilities. Approximately 5% of responding facilities reported not identifying or monitoring infants at risk for progressive or late onset hearing loss.

4. Discussion

Universal newborn hearing screening programs were advocated and then initiated on the basis of a few powerful arguments, principal among which were the facts that hearing loss can be reliably diagnosed using physiologic means, but not by others, and that early intervention is significantly effective in reducing the impact of hearing loss on linguistic, social, and educational development. These programs are fast becoming truly universal, not only in the United States [24] but also internationally [25–27]. Every birthing facility in the state of Illinois has been mandated to have a fully implemented UNHS program since the end of the calendar year 2002. At the beginning of 2004, 98% of all infants born in the state were being screened for hearing loss—a screening rate well above the national average of approximately 93% [24].

Ours was a retrospective examination of the *hospitals' perception* of principles and practices being followed by the UNHS programs in the state of Illinois. We sought information limited to the calendar year 2004 from all birthing facilities in the state. Our choice of this time window was motivated by our desire to capture a current picture of practice during that year, as perceived and reported by the hospital staff. Collecting data over a longer time window, extending into years prior to 2004, would have biased the results by the influence of practices and procedures that may have evolved since or may even have fallen out of favor. Note that the average duration of UNHS programs sampled in our results was approximately 5 years, putting their

initiation well before the state-mandated date of 31 December 2002.

We have reported results based on responses from 59 of the 139 active UNHS programs in the state of Illinois. Thus, these results represent the information and perception of approximately 42% of the programs in the state. A cursory examination of the non-responding institutions did not reveal any trends as far as geographic location or size of population served leading us to believe that the results reported here are generally representative of the entire state. However, the response rate of 42% has to be recognized in the interpretation of the data. We used a cross-sectional approach in our study, seeking information through a Web-based questionnaire (Appendix A). Our survey queried the facility or the institution in general, without stipulation to the responder's specific involvement with the UNHS program. The letter announcing the survey and all other communication was directed to the contact person listed with IDPH. However, this does not guarantee that the same individual answered our survey questions. It would have been preferable to impose a control on who responded. However, such a requirement was incompatible with the chosen method (Internet) of the survey and the requirement of anonymity as per our agreement with the IRB at Northwestern University. Thus, the results reported here are reflective of the responding individuals' level of understanding and knowledge about the implementation of UNHS at the facility and the general areas of referral, tracking, and follow up. In interpreting our results, the reader should consider this lack of control in addition to the usual caveat of self-report bias in survey research.

Convention would be to compare our results to those of similar reports in the literature. However, there is a paucity of reports that simply document UNHS practice in other states. The National Center for Hearing Assessment and Management offers guidelines for the evaluation of statewide UNHS programs and evaluation reports of the programs in two states (Ohio and Utah) are available on their Web site (as of 8 February 2006). The evaluation report for the state of Ohio could not be used for comparison with our results as those data are from 1996 to 1997 and is limited to a risk-factor-based screening program. We also found a report very similar to ours, documenting UNHS practice between the years 1997 and 2001 in the state of Wisconsin [28]. The crucial difference between the Wisconsin report and ours is the fact that UNHS was voluntary and not mandatory in that state at the time of the Kerschner et al. survey [28]. Thus, the results could be biased to the extent that interested and resourceful facilities are more likely to have

voluntarily initiated a UNHS program. Several other peer-reviewed reports prepared prior to the year 2000 are incompatible for comparison with our results as the "U" was yet to be added to "NHS" at that time. The lack of peer-reviewed reports on UNHS programs nationally is partially compensated by the information easily accessible on the World Wide Web.

Current practices in the state of Illinois appear to follow empirical evidence in the use of screening tools. Automated ABR has been demonstrated repeatedly to be the screening method of choice (e.g. [29]) in terms of accuracy, training needs, as well as cost. Referral rates are consistently lower when ABR, as opposed to any type of OAE, is used in UNHS programs; the referral rate is lower at program initiation and quickly drops to below 4% or 5%—the accepted benchmark for UNHS programs. In contrast, initial referral rates have been shown to be approximately twice as high for DPOAEs with little evidence of a training effect, i.e., the referral rates do not drop significantly with time as the personnel get more accustomed to the protocol or receive training. Our results show that the vast majority of facilities in Illinois do indeed use the ABR, albeit in conjunction with other measures, such as OAEs, in some cases.

The involvement of different professionals in UNHS programs in Illinois is also similar to reports from Wisconsin [28] and Utah [24]. Members of the nursing staff appear to be most involved in the screening programs. The involvement of audiologists was found to be fairly limited in screening, re-screening, or managing the UNHS programs. Audiologists are more likely to be employed in the larger facilities. When on staff, audiologists were mostly involved in managerial roles in UNHS programs. The variety of personnel actually performing the screenings increased with the size of the facility. Use of nursing staff not dedicated solely to the UNHS program for the initial inpatient screening and, if necessary, re-screening appears to be supported by the minimal delay between birth and the first hearing screening [29] and a higher proportion of infants being screened before discharge. It seems logical that the time between birth and screening is increased when the performance of the test is the responsibility of dedicated program staff that has limited and fixed work schedules. It is noteworthy that the use of non-dedicated personnel does not increase referral rate or cost of the program (e.g. [29]).

Overall referral rates in the state of Illinois are well within the accepted standard of 4% or 5% [5,8]. This is perhaps a direct consequence of the education and awareness campaigns, along with

mandated reporting, coordinated, administered, and monitored by IDPH. Additionally, IDPH is vigilant in monitoring referral rates as well as delays in reporting, notifying facilities when there is a lag of even a few days between the screening date and the date data are uploaded in the Hi*Track system. Within the larger group of facilities, where the referral rate was reported to be less than 5%, choice of the physiologic measure or the number of physiologic measures used did not influence the referral rate. Four of the facilities reported referral rates greater than 5% (see Table 3). These numbers were verified to be correct with the IDPH staff. Informal conversations with the IDPH staff intimately familiar with these institutions revealed that these “spikes” in referral rates were related to change in personnel or management practices at these four institutions.

If there is one area of concern, it would relate to the few cases where there appeared to be improper management of the UNHS program. For example, 3% of the reporting facilities claimed no knowledge of the person responsible for tracking infants who failed screening. As pointed out before, the mandate in the state of Illinois puts the onus of tracking infants on IDPH and not on the UNHS facility. We point to this statistic as an indicator of lack of awareness in a minority of facilities, not as a systemic weakness at the state level. Similarly, 5% of the facilities did not attempt to identify infants at risk for late-onset hearing loss and did not inform the parents of this possibility. It is understandable that the cost per infant screened is considerably higher for smaller facilities, making it more difficult to employ managers dedicated to the UNHS program. Perhaps a single manager for multiple facilities could be a cost-efficient solution to the problem. Our suggestion, of course, is tempered by the usual geographical disparity between such small, usually rural, facilities. Increased use of the Internet leading to remote management of programs may be worth exploring to solve this shortcoming.

Some information obtained from our survey was not quantifiable and, hence, not easily presentable in our results. However, this information may be useful and informative to program managers and policy makers. Several responders appeared to be unable to distinguish between ABR and AABR, skewing the results presented here. Many failed to distinguish between an automated and manual decision of screening outcome. These findings point to limited knowledge of the respondent on issues important to UNHS programs. This perhaps is the drawback of the otherwise cost-effective solution of using non-dedicated personnel for screening. Another source of this finding could be the lack of control regarding the respondent to the survey.

However, we have no reason to believe that individuals completely dissociated with the UNHS program at a certain facility completed the survey. In general, the reported data match what is reported to IDPH, leading us to believe that the respondents were involved in some capacity with the UNHS program. In a majority of responses where the responder was an audiologist, they expressed a desire to play a more active role in tracking and following up with infants who fail the initial inpatient screening. Our data indicate that this is the responsibility of the physician in a majority of the facilities. Although we did not seek information about the level of awareness of physicians related to UNHS, data from the state of Utah suggest that physicians in general think approximately 60% of infants are screened for hearing loss [24]. Given the education and long-term interest in hearing loss that audiologists bring to the health-care arena, exploring possibilities of making audiologists more responsible for referral and tracking may be beneficial to the UNHS movement. This role would augment the stellar effort of the departments of Public Health. It is commendable that UNHS programs are in place in 100% of the birthing facilities in the state of Illinois and approximately 98% of all infants born in the state are being screened [21]. The “soft spots” that remain will certainly be solved over time as UNHS is still a relatively new and growing program and all parties involved strive to find better and more complete solutions.

The focus of this survey was on the operational and audiological aspects of UNHS programs, *as understood and perceived by the hospital staff*. Although these do not complete the entire UNHS landscape, they are important aspects. This, the first statewide survey of UNHS practices for Illinois, should definitely be followed by more encompassing and comprehensive evaluations in Illinois as well as other states. The inclusion of financial information as well as information and reaction from parents and physicians would lend a more complete picture in the future. Monitoring the success and outcome of outpatient screening programs also will be important, albeit more difficult to accomplish. UNHS in the state of Illinois has made remarkable strides in a short period of time. Continued monitoring of screening practices will assure the efficacy of services provided to families throughout the state.

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Appendix A. Newborn hearing screening practices and protocols survey

Newborn Hearing Screening Practices and Protocols Survey

- 1) What is the location of your hospital?
 - Rural (population of less than 100,000)
 - Urban (population of more than 100,000)
 - Military base
 - Country (population of less than 6 people/square mile)
 - Other, please describe _____
- 2) Approximately how many newborns had their hearing screened in 2004?
- 3) How long has your facility had a newborn hearing screening program?
- 4) Who developed the plan/protocol for your hearing screening program?
- 5) Does your hospital have a staff audiologist?
 - Yes
 - No
- 6) Does your hospital have a Neonatal Intensive Care Unit (NICU)?
 - Yes, what level(s): Level II Level III
 - No
- 7) What is the title of the manager of your hearing screening program?

Title: _____
- 8) What physiologic measures are used on all babies you screen? Check all that apply:
 - DPOAE
 - TEOAE
 - AABR
 - ABR
 - Other, please specify _____
- 9) What testing equipment/system(s) do you use?
- 10) Who performs the hearing screening? Check all that apply.

	Well Baby Nursery	NICU
Nurses	_____	_____
Technicians	_____	_____
Audiologist	_____	_____
Volunteers	_____	_____
Other, please specify	_____	
- 11) If someone other than an Audiologist performs hearing screenings, who trains them?

Approximately how many hours of training do they receive?
- 12) How/Who interprets the hearing screening results?
- 13) On average how long after birth is hearing screening performed?

Minimum: _____

Maximum: _____

14) What criteria do you use to determine that an infant should be re-screened. Check all that apply.

- Evidence of high risk factors
- Absent DPOAE
- Absent TEOAE
- Abnormal ABR
- Abnormal AABR

15) Who informs parents of the results of their baby's hearing screening?

	Infants Who Pass	Infants Who Are Referred
Nurses	<input type="checkbox"/>	<input type="checkbox"/>
Technicians	<input type="checkbox"/>	<input type="checkbox"/>
Audiologist	<input type="checkbox"/>	<input type="checkbox"/>
Volunteer	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify _____	<input type="checkbox"/>	<input type="checkbox"/>

16) Are infants re-screened as inpatients or outpatients?

- Inpatient.
- Outpatient.

17) What technology is used to re-screen? Check all that apply.

- DPOAE
- TEOAE
- ABR
- AABR

18) Does your nursery perform outpatient hearing screening on any infants after they leave the hospital?

- Yes, please describe _____
- No.

19) Who performs the outpatient re-screen? Check all that apply.

- Nurses
- Technicians
- Audiologists
- Volunteer
- Other, please describe _____

20) Who refers the family for a diagnostic evaluation following the hearing screening process?

Check all that apply.

- Physician
- Nursery Staff
- Audiologist
- Manager of Newborn Hearing Screening Program
- Other, please describe _____

21) Who is responsible for confirming that an infant who is referred after a hearing screening receives a diagnostic evaluation?

- Physician
- Nursery Staff
- Audiologist
- Manager of Newborn Hearing Screening Program
- Other, please describe _____

- 23) What type of hospital-based data management system(s) do you use to document hearing screening? Please describe.
- 23) How do you identify and/or monitor infants at risk for progressive hearing loss. Check all that apply.
- No identification of infants at risk for progressive hearing loss.
 - High risk indicators established by Joint Committee on Infant Hearing.
 - Provide parents with information regarding progressive hearing loss.
 - Refer for audiological monitoring.
 - Other, please describe _____
- 24) What information regarding diagnostic audiologic services is made available to parents of those infants who are referred from the screening?
- No specific information is provided.
 - Information provide about hospital audiologic services.
 - Referral list consisting of audiologists in the community.
 - Referral list consisting of subset of audiologists in the community.
 - Information about Public Health/State supported audiology services.
 - Other, please describe _____
- 25) Who monitors outcomes of diagnostic referrals? Check all that apply.
- Outcomes are not monitored at this time.
 - Outcomes are monitored by a State Health Department tracking system.
 - Outcomes are monitored by a hospital-based system.
 - Outcomes are monitored by a community/regional tracking system.
 - Outcomes are monitored by an audiologist.
- 26) Please provide an estimate of what percentage of infants are referred for further audiologic testing at the time they are discharged from the hospital.*
- | | | | | | |
|--------|--------|--------|---------|--------|--------|
| 1-10% | 11-20% | 21-30% | 31-40% | 41-50% | 51-60% |
| 61-70% | 71-80% | 81-90% | 91-100% | | |

* Question #26 was modified to ask the exact referral rate.

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