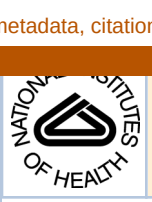

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Factors Influencing Follow-up to Newborn Hearing Screening for Infants who are Hard-of-Hearing

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Abstract

Purpose—To document the epidemiological characteristics of a group of hard-of-hearing children, to identify individual predictor variables for timely follow-up after a failed newborn hearing screen, and to identify barriers to follow-up encountered by families.

Method—An accelerated longitudinal design was used to investigate outcomes for children who are hard-of-hearing in a large multicenter study. The current study involves a subgroup of 193 of children with hearing loss who did not pass the newborn hearing screen. Available records were used to capture ages of confirmation of hearing loss, hearing aid fitting and entry into early intervention. Linear regression models were used to investigate relationships among individual predictor variables and age at each follow-up benchmark.

Results—Of several predictor variables, only higher levels of maternal education were significantly associated with earlier confirmation of hearing loss and fitting of hearing aids. Severity of hearing loss was not. No variables were significantly associated with age of entry into early intervention. Each recommended benchmark was met by a majority of children, but only one-third met all of the benchmarks within the recommended time frame.

Conclusions—Results suggest that underserved communities need extra support in navigating steps that follow failed newborn hearing screening.

Keywords

hearing loss; universal newborn hearing screening

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INTRODUCTION

Delayed identification of permanent childhood hearing loss (HL), which occurs in 1 to 3 per thousand live births (Finitzo, Albright, & O'Neal, 1998; Van Naarden, Decoufle, & Caldwell, 1999), is regarded as a major public health concern. Children with mild-to-severe HL (i.e., hard of hearing; HH) represent a unique and historically underserved group (Davis, 1977; Davis, Elfenbein, Schum, & Bentler, 1986; Davis, Shepard, Stelmachowicz, & Gorga, 1981; Elfenbein, Hardin-Jones, & Davis, 1994; Mace, Wallace, Whan, & Stelmachowicz, 1991; Moeller, Donaghy, Beauchaine, Lewis, & Stelmachowicz, 1996; Moeller, McCleary, Putman, Tyler-Krings, Hoover, & Stelmachowicz, 2010; Moeller, Tomblin, Yoshinaga-Itano, Connor, & Jerger, 2007). Prior to Universal Newborn Hearing Screening (UNHS), it was rare for these children to be identified before 2 years of age, and many were identified even later (Halpin, Smith, Widen, & Chertoff, 2010; Ruben, 1997; Sininger, Martinez, Eisenberg, Christensen, Grimes, & Hu, 2009; Spivak, Sokol, Auerbach, & Gershkovich, 2009; Stein, Jabaley, Spitz, Stoakley, & McGee, 1990; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

Early intervention is effective in preventing or minimizing the negative impact of HL on speech and language development (Calderon & Naidu, 1999; Kennedy et al., 2006; Moeller, 2000). However, it is likely that early identification will result in developmental advantages for children only if the process is linked to timely and effective interventions. The American Academy of Pediatrics (AAP, 2010) and the Joint Committee on Infant Hearing (JCIH, 2007) have recommended "1-3-6" benchmarks for follow up: (1) complete newborn hearing screening (NHS) before 1 month of age, (2) diagnose HL before 3 months, and (3) enroll those identified with HL in early intervention before 6 months. According to the Centers for Disease Control and Prevention (CDC) in 2006, 91.2% of newborns were screened for hearing loss and 2.1 % did not pass that screen. Of those who did not pass the screen, 29.9% were found to have normal hearing and 5.8% were found to have hearing loss, but no diagnosis could be documented in 64.2% of the babies who did not pass the newborn hearing screen (Gaffney, Green, & Gaffney, 2010). By 2009, the latest year for which data are available (U.S. Centers for Disease Control, 2011), national statistics improved: Ninety-eight percent of eligible newborns were screened and 1.6% did not pass. Of those who did not pass the screen, 39.0% were found to have normal hearing, 8.9% were diagnosed with hearing loss and 45.1% were lost to follow up or documentation. Advances in consistent data tracking and surveillance systems are partially responsible for these improvements. Even when progress through the EHDI process is timely, there exist wide variations among service providers in pediatric audiologic test batteries and appointment wait times (Munoz, Nelson, Goldgewicht, & Odell, 2011). This discouraging rate of loss to follow-up or documentation, along with variability in service provision, indicates that despite widespread UNHS, challenges remain to ensure that all children with prelingual HL can take advantage of the benefits of timely diagnosis, hearing aid fitting and entry into early intervention.

Unfortunately, challenges remain for many families in accomplishing recommended follow-up steps. Identified barriers to follow-up include: 1) limited access to audiologists with pediatric expertise, 2) appointment wait times, 3) the presence of medical co-morbidities, and 4) the presence of unilateral or mild HL (Coplan, 1987; Dalzell et al., 2000; Folsom, Widen, Vohr, Cone-Wesson, Gorga, Sininger, & Norton, 2000; Harrison & Roush, 1996; Moeller, Eiten, White, & Shisler, 2006; Moeller, White, & Shisler, 2006). Additionally, families of HH infants may have difficulty understanding the need to follow-up on a failed screening, given that they may observe the baby responding to loud sounds in the environment.

Several investigations have addressed factors related to loss to follow-up or delays in follow up. These include the presence of other medical conditions and the presence of unilateral or mild HL (Folsom et al., 2000; Dalzell et al., 2000). Severity of hearing loss can impact timeliness of follow-up: Prior to the era of universal newborn hearing screening, the age at which congenital HL was diagnosed and intervention was begun was often inversely related to the severity of HL (Coplan, 1987; Mace et al., 1991; Harrison & Roush, 1996). It is unknown whether this is still true. A recent survey study of state EHDI programs indicated the primary barriers to linking families to follow-up included lack of service-system capacity, lack of provider knowledge, challenges in obtaining services and information gaps (Shulman, Besculides, Saltzman, Ireys, White, & Forsman, 2010). Difficulties in system capacity included unreliable screening equipment, a shortage of sufficiently trained pediatric audiologists, inadequate early intervention services and lack of family support programs. Although providers have been found to be generally very supportive of NHS and follow-up (Goedert, Moeller, & White, 2011; Moeller, Eiten, et al., 2006; Moeller, White, et al., 2006), Shulman et al. found that many screening programs do not have standardized protocols, that some physicians take a “wait-and-see” attitude toward follow-up and that many providers lack specific knowledge about early intervention or family supports in the local area. In addition, families face challenges with respect to transportation for specialized services and third party payment for professional services, hearing aids and other amplification (Limb, McManus, Fox, White, & Forsman, 2010). Finally, information gaps exist when data management and tracking systems are not accessible to providers or when there exists poor communication among providers. Results of surveys of state EHDI coordinators and service providers are useful, but little data exist regarding families’ perceptions of barriers in the process.

There is a need to determine if prompt follow-up occurs after a failed NHS and if advancements in early identification result in the expected developmental advantages for HH children. To address these needs, the National Institutes of Health (NIH) funded a collaborative research team to investigate the speech, language, academic, psychosocial and family outcomes of HH children. The Outcomes of Children with Hearing Loss (OCHL) study is a five-year, multi-center investigation designed to characterize the developmental, behavioral and familial outcomes of HH children and to explore how variations in child and family factors and intervention characteristics relate to functional outcomes.

The present paper provides a general description of the design and methods of the OCHL study and the demographic characteristics of the study population. A primary goal of the current study is to document timeliness of follow-up steps for a subgroup of children who did not pass newborn hearing screening. Specifically, the study was designed to address the following questions:

1. How do family and child-specific factors such as socio-economic status (SES) and severity of HL affect timely diagnosis and follow-up?
2. How consistently are HH children receiving appropriate care and follow-up within the best-practice 1-3-6 timeline?
3. What reasons are given by families for delays between various steps in the EHDI process?

METHODS

OCHL Study Methods

Test batteries were developed to examine: 1) family and community factors (e.g., SES, race, ethnicity, service access, parental education), 2) child factors (e.g., gender, severity and type

of HL, etiology), 3) child outcomes (e.g., receptive and expressive language, speech perception and production, psychosocial development, academic abilities), and 4) intervention characteristics (e.g., audiological, therapeutic and educational). Developmentally-appropriate test batteries included normative-based tests, speech and language elicitation tasks, language sampling, and parent and service provider questionnaires. At each visit, children completed a comprehensive pediatric audiological evaluation. Specific measures and age intervals employed in the OCHL study are listed in Appendix A. This overall approach supports the goal of determining how family and child factors interact with intervention features to influence outcomes.

An accelerated longitudinal design (see Fig 1) maximized the amount of developmental and cross-sectional data that could be collected in a relatively short period of time. Children ranging in age from 6 months to 6 years 11 months were enrolled and followed prospectively on an annual basis for at least three visits from the age at entry. Those enrolled as infants or toddlers were seen every six months until 24 months of age and annually thereafter. Retrospective historical, medical, audiological, and educational data were collected to supplement the prospective data. Children were recruited and seen in the home states of the three research teams (Iowa, Nebraska, North Carolina), as well as in cooperative neighboring states (Kansas, Minnesota, Illinois, Missouri, and Virginia). State EHDI coordinators, audiologists, early intervention specialists, and educators assisted with recruiting HH children. Children with normal hearing (NH) were recruited from databases of past research participants, fliers in community centers and daycares or advertisements in newsletters, and word of mouth. A screening interview was conducted over the telephone to ensure basic criteria for candidacy were met. Approval for the study was obtained by the Institution Review Boards of each participating research site.

Inclusion criteria for the HH group included: a) permanent bilateral HL of any type (sensorineural, mixed, conductive), b) better ear pure tone average (PTA) (500, 1000500, 2000, and 4000 Hz) between 25 and 75 dB HL, c) entry ages between 6 months and 6 years, 11 months of age, d) no known significant sensory or developmental disorders, and e) at least one primary caregiver who speaks English in the home. Recruited participants in the OCHL study to date include 292 HH children and 115 NH peers who were matched on age and home background.

At the initial visit, parents completed an intake interview that documented several benchmark steps toward the diagnosis of HL and the receipt of early intervention including age at a) first diagnostic audiologic evaluation, 2) confirmation of HL, 3) hearing aid fitting, and 4) entry into early intervention. Parents also provided an explanation for any delays that occurred between steps.

At the initial visit and each subsequent visit, the HH child received an on-site comprehensive audiologic evaluation and the child's hearing aids were evaluated. When possible, the device use time was captured as a digital measure from the hearing aids. If audiometric results were not obtained due to child behavior or time constraints, a recent audiogram from the child's audiologist was obtained with parental permission. A receptive and expressive speech and language evaluation was also performed and measures of academic skills and psychosocial behavior were obtained, if age-appropriate. Parents completed questionnaires regarding their child's development, behavior and temperament, and hearing aid use.

Current Study Methods

The current statistical analyses focused on a subgroup of 193 HH participants with congenital hearing loss who did not pass the NHS. The 99 HH children who were excluded

from these analyses did not have a documented NHS or passed the screen and thus likely had delayed onset hearing loss. For the subgroup of children who did not pass NHS (n = 193), we explored the potential effects of child and family variables on timeliness of follow-up steps. Linear regression models investigated the relationships among the independent predictor variables (gender, site of testing, SES, and severity of HL) and each of the dependent variables (ages at each follow-up benchmark). Because none of the dependent variables were normally distributed, they were normalized by modeling the natural log of each of these variables.

RESULTS

The demographic characteristics of all HH participants recruited to date in the OCHL study are presented in Table 1. The distribution of better ear PTA for all participants is presented in Figure 2. The highest percentage of participants fell in the range of moderate HL. Eighteen participants had permanent conductive HL and the remainder had sensorineural HL. Table 1 also includes the demographic characteristics of the 193 children who are the primary focus of the current study.

For participants with congenital HL, the wide ranges of values of the dependent variables in this group who failed the newborn screen were striking: Ages of first diagnostic evaluation ranged from 0.25 to 60 months, ages of confirmation of HL ranged from 0.5 to 70 months, ages of entry into early intervention ranged from 0.25 to 57 months (some with long delays did not have age of entry into intervention reported) and ages of hearing aid fitting ranged from 1.5 to 72 months. Biological mother's education was significantly correlated with biological father's education and income group ($p < 0.0001$). To avoid the problem of multicollinearity between predictor variables and because more data were available for mother's education level than the other two SES variables, only biological mothers' education was used in the regression model as an indicator of SES. Of the independent variables, only mother's education was found to be significantly related to the ages of first diagnostic audiologic evaluation ($p = 0.0123$), HL confirmation ($p = 0.0013$) and hearing aid fit ($p = 0.0445$). None of the predictor variables were significantly related to the age at which the child entered early intervention. Similarly, none were significantly related to the time that elapsed between the EHDI milestones of HL confirmation, HA fitting, and entry into early intervention.

Figure 3 shows the average ages (in months) of first diagnostic evaluation, confirmation of HL, hearing aid fit, and entry into early intervention by mother's educational level. One difference is worth noting: The mean age of confirmation of HL for infants whose mothers had graduate degrees was more than seven months earlier than for those whose mothers had a high school diploma or less. Although all of these children were screened by 1 month of age, infants of mothers with the least education were later to receive follow up at every stage.

The proportion of children who met the national 1-3-6 goals, as outlined in the latest JCIH (2007) statement, is shown in Figure 4. Despite the fact that all of these participants failed a physiological hearing screen in the first month of life, only 83% had a diagnostic Auditory Brainstem Response (ABR) test by 3 months of age and only 64% had a confirmed diagnosis by 3 months of age. Hearing aids were fit on 66% of these children within one month of confirmation of HL and 75% were enrolled in early intervention by 6 months of age. Only 32% of these participants met all three of the JCIH benchmarks on time.

Parent interviews provided explanations for delays between steps in the EHDI process; these are summarized in Table 2. The first analysis examined delays between a failed NHS and

the first diagnostic evaluation. Seventy-three participants (38%) had a delay of more than 2 months and 67 of these provided a reason. The most common reason was multiple rescreens, which ranged in number from 2 to 10 following the referred newborn screen and accounted for delays up to 9 months in getting a diagnostic ABR. Other families experienced delays because of transient middle ear problems and some of these were reportedly told by physicians there was no need to get a diagnostic ABR. Six families could not get a timely appointment for a diagnostic ABR. Three families were reportedly told the ABR could not be completed until the baby was old enough to be sedated. Several others were delayed because of additional health conditions and appointments following a complicated newborn admission.

Next, delays between the first diagnostic audiologic evaluation and confirmation of HL were explored. One hundred nine (56%) children had HL confirmed at the first diagnostic ABR evaluation. Thirty-two (17%), however, had a delay of more than 2 months and 24 of these had a delay of more than 3 months between the first diagnostic audiologic evaluation and confirmation of HL. Twenty-three provided reasons. Fifteen infants underwent multiple ABR evaluations before a diagnosis was confirmed. Reasons for multiple ABRs included lack of sleep by the infant, equipment problems experienced by the audiologist, or multiple re-testing to confirm that the HL was not conductive and temporary. These are certainly valid reasons for multiple ABR tests, but they can lead to delays in confirmation of HL and HA fitting. Five families reported that the initial ABR was normal or near normal and a subsequent ABR indicated HL.

We also examined delays between HL confirmation and hearing aid fitting. The JCIH (2007) goals recommend no more than a month between confirmation of HL and hearing aid fitting. Sixty-six participants (34%) had a delay of more than 1 month to hearing aid fitting and 62 of these provided a reason. Eleven of these children did not have hearing aids recommended initially and some of these recommendations were justified: Two had mild HL which progressed in degree and 4 had unaidable unilateral HL which later progressed to bilateral. Two were told to wait until 6 months of age for amplification even though the HL was confirmed much earlier. In 12 other cases, families made the decision not to pursue amplification because their child was responding to sound and it was difficult for them to believe the diagnosis of HL. Four other families had delays due to difficulty obtaining funding and 10 had difficulty obtaining an appointment for hearing aid fitting. Other delays were caused by the misperception of physicians that a behavioral audiogram was necessary before diagnosis was reliable and hearing aids could be fit.

Finally, we examined delays between confirmation of HL and entry into early intervention services. Twenty-one children (11%) had delays of more than 3 months between confirmation of HL and the initiation of early intervention services; nine of these reported a reason. Three families chose not to start intervention until the child was older (10, 13 and 15 months respectively). In two other cases, HL started out as unilateral and early intervention was not provided until bilateral HL developed. Two families reported that it took an extended period of time for service providers to schedule a visit. In another case the family had difficulty believing there was a HL, while another experienced delays due to multiple medical appointments.

DISCUSSION

In an effort to determine the timeliness of diagnosis and intervention for a cohort of 193 HH children, we studied family and child-specific factors and their impact on age of diagnosis and intervention. We also examined specific reasons cited by families for delays in

diagnosis and intervention. Finally, we compared the age of diagnosis and intervention for the study cohort to the 1-3-6 benchmarks recommended by AAP (2010) and JCIH (2007).

For the first question, family and child-specific factors, we found that higher SES, as measured by mothers' educational level, was associated with earlier ages of first diagnostic evaluation, HL confirmation, and hearing aid fitting. The mean age of confirmation of HL for infants whose mothers had graduate degrees was more than seven months earlier than for mothers whose highest level of education was at or below high school, despite the fact that NHS is provided as a public health initiative and all infants in this subgroup were screened for HL by one month of age. Mother's education was not, however, related to age of enrollment in early intervention (EI) services. This may be a consequence of federal legislation that requires prompt referral following diagnosis of HL to determine eligibility for early intervention services.

A factor that could limit the generalizability of the present results is the representativeness of the educational level of mothers in our study sample. According to the 2010 United States Census, 44% of the population has a high school degree or less, 28% have attended some college, 18% have a college degree and 10% have graduate or professional degrees. The OCHL sample of children who did not pass the newborn hearing screen comes from families with higher educational degrees than the general population where 18%, 34%, 26%, and 22% of children come from households where the mother's education level are in the above categories, respectively. Given the importance of this variable as a predictor of timely follow-up, it is likely that compliance with benchmarks in our more highly educated group is an overestimate of compliance in the general population.

A child-specific factor of interest was degree of HL and whether it was associated with age of diagnosis and intervention. Our findings, which did not show a relationship between degree of HL and age of diagnosis and intervention, were similar to those of a recent study (Spivak, et al., 2009) and are in contrast to earlier studies prior to the implementation of UNHS that found later identification of infants with milder degrees of HL (Coplan, 1987; Harrison & Roush, 1996; Mace, et al., 1991). This newer evidence implies that UNHS ensures timely follow-up even for milder degrees of HL.

Another aim was to study the specific reasons cited by families for delays in diagnosis and intervention. The reasons included variability in audiological test protocols, excessive wait times for appointments, delays associated with medical co-morbidities, and presence of mild or unilateral HL. These findings were similar to earlier reports (Coplan, 1987; Harrison & Roush, 1996; Mace, et al., 1991; Prieve et al., 2000). The most frequently cited reason for delay in diagnosis of HL in the current study was multiple rescreenings and diagnostic tests by physicians and audiologists. Reports of multiple rescreenings are of particular concern considering that JCIH as well as EHDI guidelines in most states recommend referral for a comprehensive diagnostic evaluation with ABR following only one additional screening failure. Although repeated ABRs are sometimes necessary for a firm diagnosis, several families reported that incomplete ABR studies were conducted at one center before a comprehensive study was eventually completed at another center. This necessitated the use of sedation or general anesthesia due to the older age of the child, further delaying the diagnosis. Because there is variability between ABR thresholds and behavioral hearing thresholds, the diagnostic ABR represents the first step in an ongoing process to quantify the HL for hearing aid fitting. Hearing aid selection for infants below a developmental age of 6 months should rely on physiologic measures (JCIH, 2007), but behavioral follow-up testing when a child is older remains essential in optimizing audibility of speech.

Two additional issues resulted in delays in diagnosis and interventions in the current study group: 1) otitis media at the time of follow-up and 2) subjective observations of the child responding to sound. Parents reported delays in every step of the EHDI process when a healthcare professional attributed a failed screen or diagnosed HL to temporary middle ear effusion, without acknowledging that an underlying sensorineural HL may be present. Additionally, both professionals and parents delayed follow-up in some cases because a child responded to sound in the environment. Many parents with HH infants require additional counseling in order to appreciate the importance of proactive steps to encourage the child's communicative development.

These reported obstacles provide unique insights into opportunities for improvement in EHDI system capacity, public awareness, professional continuing education, and clinical practices. To avoid multiple rescreenings and multiple diagnostic tests, there is a need for knowledgeable pediatric audiologists to partner with primary care providers to provide definitive diagnostic care. There is also a need for greater access to audiological services, because difficulty obtaining an appointment was a recurring theme among those who experienced delays along the 1-3-6 timeline. Priority scheduling should be allotted to children who are HH for these benchmark appointments.

Educational materials about the NHS and follow-up process should be designed for, and distributed to, parents of children who do not pass the newborn hearing screening so that implications of HL are demonstrated clearly and are easily understood. These materials should cater to principles of healthcare literacy and family-centered care and emphasize early signs of HL and the impact of even mild degrees of HL on future developmental outcomes. Beyond public awareness, parents with less formal education (lower SES) may need further support in navigating the EHDI system – ensuring quick linkages with Early Intervention Coordinators and provision of family-to-family supports may help.

Fortunately, many of the children received timely diagnosis and follow-up care consistent with the 1-3-6 benchmark goals; however, approximately two-thirds of children referred from screening did not achieve all three goals by 6 months of age. Families reported a variety of factors related to the child, family, physician, or intervention program that created delays or obstacles to timely and appropriate diagnosis and intervention. Children enrolled in the OCHL study are a diverse group and efforts are made to ensure that families can participate despite apparent barriers. Research studies will carry some bias toward inclusion of children whose families have the resources and inclination to participate, thus the cohort described in this study may not include those who are at risk for the greatest delays in diagnosis and intervention. It is important for EHDI programs to develop materials and methods for public awareness campaigns that will be effective in communicating to the most vulnerable populations. The present findings regarding reasons for delays in the EHDI process also indicate that continuing professional education is needed for audiologists and physicians.

In conclusion, results of the present study indicate the following:

1. Many families in the current study accessed care following NHS within recommended time frames. Specific barriers were identified, and these appear to be addressable through improved systems, services and educational efforts.
2. In a group of children who are HH, higher maternal educational levels were significantly associated with earlier confirmation of HL and fitting of amplification. Severity of HL was not.

3. Public awareness campaigns about NHS and the importance of good hearing for speech and language development must continue to be developed, with particular emphasis on underserved communities.

4. There remains confusion on the part of providers and families about the possibility of HL in infants and toddlers who display awareness of sound. Educational resources and training should address this specific gap in understanding.

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Appendix

DOMAINS ASSESSED:	MEASUREMENT INSTRUMENTS:	AGE AT TEST (months)
Presymbolic Communication	Communication and Symbolic Behavior Scales: Temptations	18
	Communication and Symbolic Behavior Scales Caregiver Questionnaire	18
Vocal Development Landmarks	Vocal Development Landmarks (created for study)	6, 12, 18
LANGUAGE MEASURES		
	Spontaneous Language Sample	36, 72, 96
Vocabulary (receptive & expressive)	MacArthur Bates Communicative Development Inventory (MBCDI) Words & Gestures (8 to 18 mos)	12, 18
	MBCDI Words & Sentences (19 to 30 mos)	24
	MBCDI Upper Extension (31 mos and up)	36
	Peabody Picture Vocabulary Test-4	60, 84, 108
	Weschler Abbreviated Scale of Intelligence (WASI) vocabulary	72, 84, 96, 108
Verbal Reasoning	Preschool Language Assessment Instrument-2	60
Global Rec-Exp Measure	Mullen Scales of Early Learning	12, 24
	Comprehensive Assessment of Spoken Language 3–4 Core	36, 48
	Comprehensive Assessment of Spoken Language 5–6 Core	72
	Comprehensive Assess. of Spoken Language 7–10 Core	96
Narrative	Candy Stealing Story	84, 108
Elicitation of mental state stories	Explanation of Action Movies	84, 108
	Theory of Mind measures (Standard False Belief Tasks)	60, 72
Morphology	Clinical Evaluation of Language Fundamentals-4 Word Structure	60, 84
	Morphological Elicitation Procedure (created for study)	36, 48
SPEECH PRODUCTION MEASURES		
Speech Production	Goldman-Fristoe Test of Articulation	36, 60, 84, 108
	Open & Closed Set Test (D. Ertmer)	24
	Conditioned Assessment of Speech Perception and Production P (Ertmer & Stoel-Gammon, 2003)	24
Speech Intelligibility	Beginner's Intelligibility Test	60,84

DOMAINS ASSESSED:	MEASUREMENT INSTRUMENTS:	AGE AT TEST (months)
ACADEMIC MEASURES		
Phonological Processing & Memory	Comprehensive Test of Phonological Processing (CTOPP)	60, 84, 108
Phonological Awareness & Print Knowledge	Test of Preschool Early Literacy (TOPEL)	48
Print Knowledge	TOPEL	60
Word Attack	Woodcock Reading Mastery Test-R (WRMT-R) Word Attack	72, 96
Word Recognition	WRMT-R Word Identification	72, 96
Reading Comprehension	WRMT-R Reading Comprehension	72, 96
Spelling	Weschler Individual Achievement Test (WIAT)-II-A	84, 108
Math Reasoning	WIAT-II-A	84, 108
HEARING FUNCTION, AUDIBIITY & SPEECH PERCEPTION		
Audiologic Evaluation	History, Audiogram (VRA) + Tymps	Every visit
	History, Audiogram (CPA) + Tymps	Every visit
	History, Audiogram (Conventional) + Tymps	Every visit
	Electroacoustic Analysis 60/90 Curves	Every visit
Hearing Aid Function	Aided Speech Intelligibility Index (Verifit SII)	Every visit
Audibility	Hearing Aid Checklist	Every visit
Hearing Aid Use	Little Ears Questionnaire	12, 18, 24
Speech Perception	Parent's Evaluation of Aural/Oral Performance of Children (PEACH)	18, 24 (depending on Little Ears score)
	Early Speech Perception (ESP) lo-verbal	24
	ESP	24, 36
	Phonetically Balanced Kindergarten (PBK)	60, 72
	Computer-Assisted Speech Perception Assessment (CASPA)	84,96, 108
	Multisyllable Lexical Neighborhood Test (MLNT) & Lexical Neighborhood Test (LNT)	48
	Speech Spatial Qualities (SSQ) - revised	48, 72, 96
PSYCHOSOCIAL, BEHAVIORAL & FAMILY MEASURES		
Cognitive Skills	Weschler Preschool & Primary Scale of Intelligence (WPPSI)	48
	Weschler Abbreviated Scale of Intelligence (WASI)	72, 96
	Head to Toes Task	72
	Vineland Adaptive Behavior Scales	12,24,36,48
	Friendship Interview	72, 96
Social Skills	Child Behavior Checklists (CBCL)	24, 48, 72, 96
Behavior	Teacher Report Forms (TRF)	48,72,96,108
	Adult Perceptions II	60

DOMAINS ASSESSED:	MEASUREMENT INSTRUMENTS:	AGE AT TEST (months)
Parenting and Discipline	Family Activities Checklist & Parent Issues Checklist	48,72, 96
Family Activities	Infant Behavior Questionnaire	12
Child Temperament Early	Childhood Behavior Questionnaire	36
	Children's Behavior Questionnaire - short version	48,72
	Social Competence & Behavior Evaluation Scale	60, 84, 108
School Behaviors (teacher report)	Teacher Predictions of Peer Nominations	84, 108
	Direct and Indirect Aggression Scale - Teacher	84, 108
	Direct and Indirect Aggression Scale - Parent	84, 108
	Screening Identification For Targeting Educational Risk (SIFTER – preschool & school age)	36,48,60,72,84,96
FAMILY BACKGROUND & INTERVENTION MEASURES		
Intervention Program Measures	OCHL Service Provider Survey (SPS)-Audiology	Every visit
	OCHL SPS 0 to 3 years	Each visit 6–35 m
	OCHL SPS Preschool	Each visit 35–59 m
	OCHL SPS School-Age	Each visit 60m +
Family Background & Satisfaction	OCHL Family Interview	6 months after every visit
Family Quality of Life	Beach Center Family Survey	24,48,72, 96

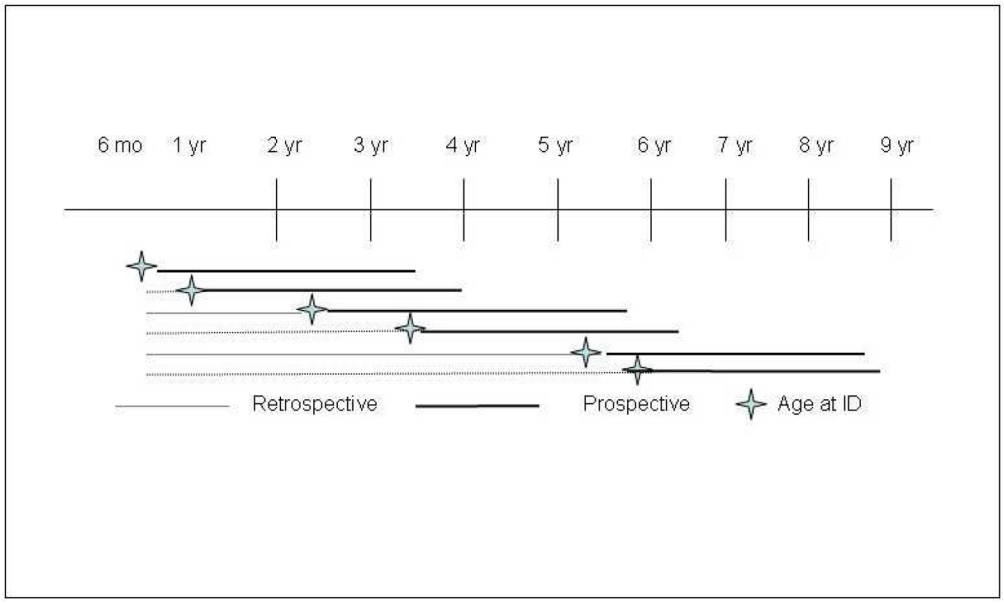

Figure 1.
Model of the accelerated longitudinal design used in the OCHL study. Vertical bars represent the age points at which data are obtained; stars indicate the age at which children are entered into the study (regardless of age at identification).

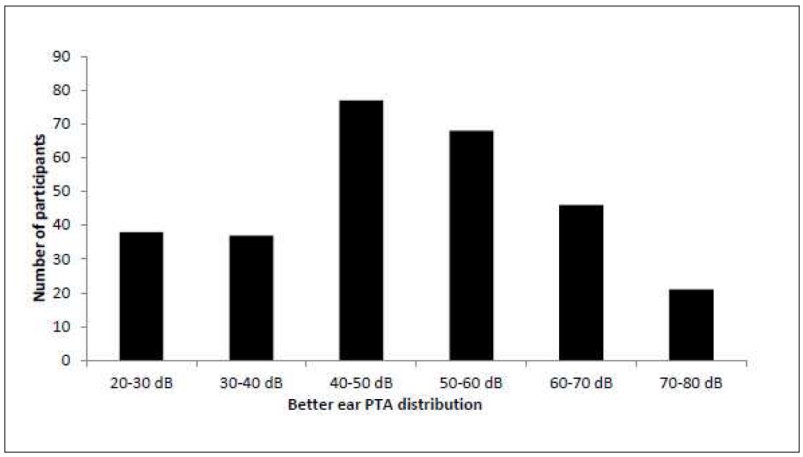

Figure 2.
Distribution of severity of hearing loss (better-ear pure tone average in dB HL) for all OCHL participants recruited to date

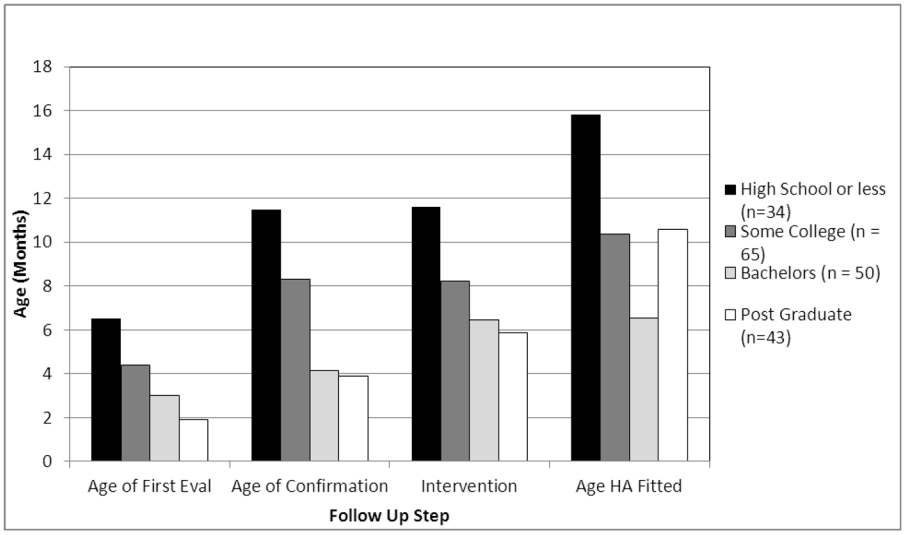

Figure 3.

Mean ages of first diagnostic audiologic evaluation (p = 0.0123), confirmation of hearing loss (p = 0.0013), hearing aid (HA) fit (p = 0.0445) and entry into early intervention (EI) (NS) by mother's education for 193 children who did not pass the newborn hearing screen.

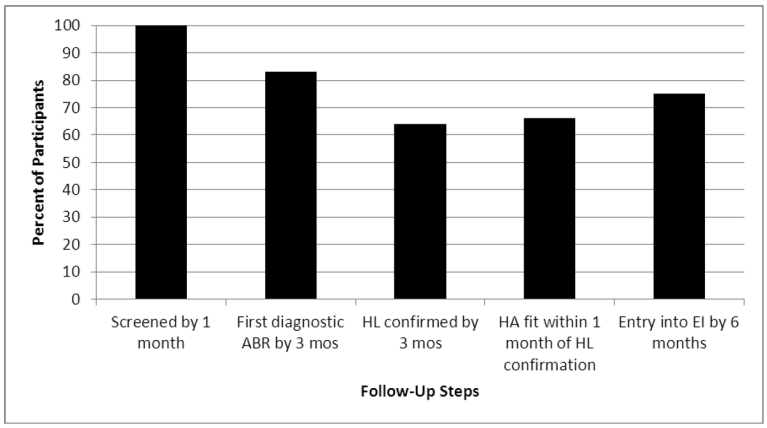

Figure 4.
Percentage of subjects meeting 1-3-6 goals for 193 children who did not pass newborn hearing screen (NHS).

Table 1

Demographic characteristics of all OCHL participants with HL and mean and range of ages (in months) of JCIH benchmarks for subgroup who did not pass the NHS

		Full OCHL group (n=292)	Subgroup (n=193)
Gender	F	134 (45.9%)	90 (45.0%)
	M	158 (54.1%)	103 (53.4%)
Research Site	Iowa	86 (29.5%)	57 (29.5%)
	Nebraska	107 (36.6%)	68 (35.2%)
	North Carolina	99 (33.9%)	68 (35.2%)
Self-identified Race	White	223 (76.4%)	151 (78.2%)
	Black	19 (6.5%)	12 (6.2%)
	Hispanic	10 (3.4%)	5 (2.6%)
	Indian	1 (.3%)	1 (.5%)
	Asian	5 (1.7%)	4 (2.1%)
	Pacific	1 (.34%)	1 (.5%)
	Multi-racial	14 (4.8%)	11 (5.7%)
	Other	5 (1.7%)	5 (2.6%)
	Refused	2 (.7%)	1 (.5%)
	Blank	12 (4.1%)	2 (1.0%)
JCIH benchmarks	Mean age of HL confirmation (range)		6.78 (0.5–70)
	Mean age of HA fit in months (range)		10.33 (1.5–72)
	Mean age of entry into EI (range)		7.74 (0–57) Not reported for all

Table 2

Reasons provided by parents for delays in confirmation of HL and follow-up in children who did not pass the NHS

Reasons for delay of more than 2 months between identification of HL (failed NHS) and first dx ABR	**N**
Multiple re-screenings	33
Family chose to wait before scheduling diagnostic test	4
Delayed because family was assured that the failed screening was likely caused by something other than permanent hearing loss (e.g. middle ear fluid after c-section delivery).	2
Delayed due to treatment of middle ear problems	4
Family was not told to get a diagnostic ABR	3
Difficulty getting an appointment quickly	6
Other	15
Reasons for delays of more than 3 months between first diagnostic test and confirmation of hearing loss	
Multiple retesting	15
Recurrent middle ear infections	1
Other:	
Initial ABR was normal or near normal	5
Fluctuating hearing loss due to Enlarged Vestibular Aqueduct	1
Unclear about reason	1
Reasons for delay of more than 1 month between confirmation and hearing aid fitting	
Delay in obtaining appointment for medical clearance for hearing aids	2
Delay in obtaining approval for insurance or other 3rd party funding for hearing aids	4
Hearing aids were not initially recommended	11
Difficulty obtaining clinic appointment for hearing aid fitting	10
Family decided not to proceed with hearing aid fitting right away	12
Child had other medical conditions that prevented follow up for hearing aid fitting	2
Child had recurrent ear infections or other middle ear problems	2
Other	19
Reasons for delay between confirmation of hearing loss and entry into early intervention	N
Family believed infant was too young for intervention	3
Delay by service provider in starting services	2
Family did not believe there was a hearing loss	1
Unilateral hearing loss progressed to bilateral and then services started	2
Delayed due to testing for other medical issues	1