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We hope you find this journal both informative and challenging. EHDl is a field that encompasses multiple disciplines, each of which contributes to helping everyone reach our goals for every child and their family. The National Center for Hearing Assessment and Management (NCHAM) is dedicated to being a resource for everyone in the EHDl community. As part of that commitment, NCHAM publishes both this journal and the EHDl E-Book.

The E-Book provides information and resources to those new to the EHDl community as well as families and students in training. It is revised and updated annually. Each chapter reflects the expertise of its author(s) written in an informal, understandable manner. The E-Book is intended to be viewed and shared openly and may be accessed on the NCHAM website: www.infanthearing.org

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As Editor-In-Chief, I get to see the results of the hard work and dedication of a LOT of people who contribute to making both these publications successful. The NCHAM team, especially Karl White, Karen Munoz, Diane Behl, Becca Tippets and Derek Saunders have devoted countless hours to making sure this journal was successfully launched. There would be nothing to read without the outstanding cooperation of the bePress team, our contributing authors, and reviewers.

We are delighted to present this, our first of many issues. We encourage your participation:

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Les R. Schmeltz, Au.D.
Editor-In-Chief

Effective And Efficient Pre-School Hearing Screening: Essential For Successful Early Hearing Detection And Intervention (EHDI)

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Abstract

An unacceptable number of infants failing newborn hearing screening do not receive necessary follow-up services in a timely fashion as a result of loss to follow-up problems. In addition, a high proportion of children who pass newborn hearing screening later acquire hearing loss during the preschool years. Systematic pre-school hearing screening offers a logical strategy for detection of hearing loss among these children.

Pure tone hearing screening of older preschool children has questionable test performance and validity. And, there is consensus that a behavioral technique is not feasible for routine hearing screening of younger preschool children. Otoacoustic emissions (OAEs) offer the most promising option for systematic hearing screening of the preschool population. Multiple advantages of OAEs are cited in support of their role in preschool hearing screening. This paper summarizes a new evidence-based and clinically feasible strategy for effective and efficient preschool hearing screening that relies on objective auditory tests.

Acronyms: AAA = American Academy of Audiology; ABR = auditory brainstem response; AABR = automated auditory brainstem response; ASHA = American Speech-Language-Hearing Association; ANSD = auditory neuropathy spectrum disorder; BBN = broadband noise; CDC = Centers for Disease Control and Prevention; DHH = deaf or hard of hearing; DP = distortion product; DPOAE = distortion product otoacoustic emissions; EHDI = Early Hearing Loss Detection and Intervention; HL = hearing level; LTFU = loss to follow-up; NIH = National Institutes of Health; OAE = otoacoustic emissions; SPL = sound pressure level; UNHS = universal newborn hearing screening

Rationale For Pre-School Hearing Screening

In the United States, universal newborn hearing screening (UNHS) has been a reality for more than a decade (White, 2014). The emergence of UNHS can be traced back to a convergence in the 1990s of multiple distinct developments. First, advances in hearing screening technology led to clinical trials of automated auditory brainstem response (ABR) and otoacoustic emissions (OAE) devices (Hall, Kileny & Ruth, 1987; Stewart et al., 2000; Vohr, Carty, Moore, & Letourneau, 1998; Vohr et al., 2001). Second, several multidisciplinary groups such as the National Institutes of Health (NIH; Consensus Conference on Early Identification of Hearing Impairment in Infants and Young Children, 1993) and the Joint Committee on Infant Hearing (1994) began to support UNHS. Third, systematic investigations provided unequivocal evidence of the benefits of early intervention for children who are deaf or hard of hearing (DHH; e.g., Moeller, 2000; White, 2006; Yoshinago-Itano, Sedley, Coulter, & Mehl, 1998). These developments in the late 1990s contributed to the American Academy of Pediatrics endorsing UNHS and establishing benchmarks for UNHS programs (American Academy of Pediatrics, 1999). During the same time period, EHDI (Early Hearing Loss Detection and Intervention) grants were first authorized in the Newborn and Infant Hearing Screening and Intervention Act of 1999 and reauthorized through the Children's Health Act of 2000.

Serious Loss to Follow-Up Problems

Unfortunately, the era of UNHS in the United States has not yet led to universal diagnosis of and early intervention for children who are DHH. In other words, early intervention does not occur for many young children who are DHH. When infants and young children who are DHH are not diagnosed or do not receive early intervention services it is often referred to as a loss to follow-up (LTFU) problem.

There are at least three general explanations for LTFU. First, a small proportion of infants (~3% nationwide) are not screened at birth. Prominent reasons for missed hearing screenings are listed in Table 1. Although the percentage of babies who miss the birth screening is small, the actual number of babies is substantial. In 2013 more than 134,000 babies began their preschool years with unknown hearing status (Centers for Disease Control and Prevention [CDC], 2013), just like infants did before the era of UNHS. Among these children there were likely 400 or more who were DHH.

A second and equally serious problem is the substantial number of newborns who have a refer outcome at the time they leave the hospital, but never complete the diagnostic assessment process. There are a variety of reasons for why infants are lost to follow-up after a refer outcome on newborn hearing screening. Some of the important factors are listed in Table 1.

Table 1. Two General categories of factors contributing to loss to follow-up rates for infants born in the United States

<p>Missed Newborn Hearing Screening</p> <ul style="list-style-type: none"> • Parent refusal of newborn hearing screening • Hospital discharge before hearing screening can be completed • Transfer to another hospital before hearing screening can be completed. • Infant does not undergo scheduled re-screening following initial refer outcome <p>Loss to Follow-Up: Undocumented Diagnosis or Intervention of Hearing Loss</p> <ul style="list-style-type: none"> • Inappropriately high newborn hearing screening failure rate • Infants are screened in one state who live in another state • Parent misunderstanding or lack of commitment about the need for follow-up testing following a refer hearing screening outcome • Physician misunderstanding about the need for follow-up testing following a refer hearing screening outcome • Information about newborn hearing screening results is not shared with proper persons, including medical home, audiologists, hospitals and/or state EHDI program • Inadequate number and geographical distribution of audiologists skilled, experienced, and equipped for diagnosis of and intervention of infant hearing loss • Parent problems with transportation to diagnostic assessment • Infants with no primary care physician who are essentially medically homeless • Infants whose families lack health insurance and who cannot afford diagnostic services • Parent refusal to consent to the diagnostic evaluation • The diagnostic assessment cannot be completed due to technical issues that are encountered during the assessment or due to infant non-compliance when ABR testing under sedation is not an option • Diagnostic assessment is not documented • A report of diagnostic test results is not distributed to medical home, audiologists, state EHDI program, and/or those responsible for intervention
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Note. ABR = auditory brainstem response; EHDI = Early Hearing Detection and Intervention.

As a result of these varied factors, an unknown number of children with hearing loss do not receive timely intervention services for lack of diagnostic information on hearing status. The CDC (2013) estimated that the nationwide LTFU rate in 2013 was 32.1% for diagnostic assessment and 25.8% for early intervention. These percentages may not accurately reflect the true status of the problem given concerns about the methods used to calculate loss to follow-up statistics.

Despite the uncertainty about the precise extent of the loss to follow-up problem, there is no question that an unacceptable number of infants do not receive necessary follow-up services in a timely fashion. Systematic programs for preschool hearing screening can play an important part in promoting early intervention for childhood hearing loss and minimizing the negative consequences for children who are lost to follow-up at some stage in the EHDI process.

Late Onset Hearing Loss

Another reason for expanding hearing screening programs for preschool-aged children is the surprisingly high proportion of children who pass newborn hearing screening but acquire hearing loss during the preschool years. For example, Fortnum, Summerfield, Marshall, Davis, & Bamford (2001) described a significant increase in prevalence of hearing loss from birth to school age. Up to 50% of children with hearing loss at age 9 passed newborn hearing screening. Bamford and colleagues (2007) and White (2014) also noted greater prevalence of hearing loss in the range of 6 to 10 per 1000 for school-age children versus 2-3 per 1000 for infants. And, according to Grote (2000), UNHS programs do not detect 10 to 20% of children with permanent hearing loss. Clearly, a substantial proportion of children who are DHH would be missed even if EHDI programs did not have any problems with LTFU.

There are a number of risk indicators for late-onset permanent hearing loss in the preschool years as delineated in the 2007 Joint Committee on Infant Hearing statement (JCIH). The term *delayed or late onset hearing*

loss implies normal auditory function at birth with the rather abrupt onset of auditory dysfunction and associated hearing loss sometime during infancy or early childhood. Depending on the etiology, hearing loss may begin in one ear or both ears and may affect any frequency. Hearing loss often gradually progresses from slight to more serious during early childhood, and sometimes even into school age years.

Screening Protocol and Equipment Considerations

A pass outcome for screening with OAEs or automated auditory brainstem response (AABR) technology depends mostly on hearing status for a high frequency region. Distortion product (DP) or transient OAE screening is usually limited to measurement of cochlear activity within the range of about 2000 to 4000 Hz. Screening outcome for click-evoked AABR also is most closely correlated with auditory status within a similar frequency range. It's likely that a proportion of children with the diagnosis of late-onset hearing loss actually had undetected auditory dysfunction as newborn infants.

Factors putting children at risk for late-onset hearing loss are summarized in Table 2. Documentation of these risk factors is essential for prompt identification of hearing loss in young children, even in the era of UNHS. To summarize, a substantial number of infants with apparently normal hearing at birth will acquire hearing loss before they enter school. It's also likely that some infants with certain patterns of hearing loss in the perinatal period will pass newborn hearing screening with existing techniques. In any event, a remarkably high proportion of children passing hearing screening as newborn infants have hearing loss at school age. Systematic pre-school hearing screening offers a logical strategy for detection of hearing loss among these children.

Historical Review of Pre-School Hearing Screening

Early Recommendations

Multi-disciplinary support and general recommendations for hearing screening of preschool children date back to the 1980s. In 1989 the United States Department of Health and Human Services suggested a protocol for screening and assessment of speech, language, and hearing in preschool children that included a risk register, parental questions about their child's response to sound, and formal middle ear screening and hearing screening with pure tone audiometry. A 1984 American Academy of Pediatrics Policy Statement included endorsement of screening for middle ear disease and language development. The American Public Health Association in 1989 also supported preschool hearing screening.

In 1985 the American Speech-Language-Hearing Association (ASHA) released guidelines for identification audiometry that contained detailed recommendations

about screening technique, personnel, and environment. The guidelines, limited to identification of hearing loss in children 3 years and older, specified that an audiologist must conduct pure tone hearing screening under earphones at an intensity level of 20 dB HL for frequencies of 1000, 2000, and 4000 Hz in an environment with maximum ambient noise levels of < 49.5 dB sound pressure level (SPL) at 1000 Hz.

1997 ASHA Guidelines for Audiologic Screening

Updating and extending the 1985 guidelines, ASHA published a 64-page document in 1997 that is the most comprehensive and, until recently, the most widely used set of guidelines for childhood hearing screening. The guidelines begin with an in-depth description of screening for outer and middle ear disorders for children birth through 18 years of age. It then includes sections devoted to hearing screening of children within four age groups: (a) newborn babies and infants from birth to 6 months, (b) infants and toddlers age 7 months through 2 years, (c) children age 3 to 5 years, and (d) school age children age 5 through 18 years. This article focuses on recommendations for children within the preschool age range of 6 months to 5 years—specifically who should conduct the screening, the technique recommended for screening, and the test environment.

The 1997 ASHA guidelines unequivocally state that, "Screening infants and children for hearing disorder and hearing impairment requires considerable professional expertise and technological sophistication. The Panel recommends that the screening process be designed, implemented, and supervised by an audiologist with the Certificate of Clinical Competence (CCC-A) from ASHA, and state licensure where applicable" (ASHA, 1997, p. 9). The guidelines emphasize repeatedly that it is "appropriate and necessary" that only certified audiologists conduct preschool hearing screening, particularly for younger children. Three categories of personnel are allowed for hearing screening of children within the age range of 3 to 5 years, including certified audiologists, certified speech pathologists, or "support personnel under supervision of a certified audiologist."

Consistent with earlier ASHA recommendations, the 1997 guidelines call for pure tone hearing screening with conditioned play audiometry at 20 dB HL for test frequencies of 1000, 2000, and 4000 Hz. Detailed instructions are offered in the guidelines for performing conditioned play audiometry. Criteria for a refer outcome are the absence of a reliable response for at least 2 out of 3 signal presentations at 20 dB HL for any frequency in either ear or inability to condition the child to the task. The 1997 guidelines refer to insert earphones as well as conventional supra-aural earphones for presentation of pure tone signals, although children who can be conditioned for visual reinforcement audiometry should be screened at 30 dB HL. Pass criteria are "... clinically reliable responses" at each

Table 2. Factors Associated with Delayed Diagnosis of Hearing Loss and Contributing to Late Intervention for Infants who Pass Newborn Hearing Screening

Caregiver concern regarding

- Hearing
- Speech and language
- Developmental delay

Family history of permanent hearing loss

Intensive care nursery stay of > 5 days and/or

- Extra-corporeal membrane oxygenation (ECMO)
- Assistive ventilation
- Exposure to ototoxic medicines
- Hyperbilirubinemia requiring exchange transfusion

In utero infections, e.g.,

- Cytomegalovirus (CMV)
- Herpes
- Rubella
- Syphilis
- Toxoplasmosis

Craniofacial anomalies involving

- Pinna
- Ear canals
- Ear tags and pits
- Temporal bone

Neurodegenerative disorders, e.g.,

- Hunter syndrome
- Sensory motor neuropathies such as Friedrich ataxia and Charcot-Marie-Tooth syndrome

Culture positive post-natal infections associated with sensorineural hearing loss, such as bacterial meningitis

Head trauma requiring hospitalization

Chemotherapy with potentially ototoxic drugs

Physical findings associated with syndrome

Syndromes associated with hearing loss, e.g.,

- Neurofibromatosis
- Osteopetrosis
- Usher
- Waardenburg
- Pendred
- Alport
- Jervell
- Lange-Nielson

Note. Adapted from Joint Committee on Infant Hearing (2007).

frequency in each ear (ASHA, 1997, p. 39). The guidelines also recommend screening in a calibrated sound field for children who do not comply with earphone placement. The 1997 guidelines specify that hearing screening must be done with calibrated audiometers, in an environment with sufficiently low ambient noise (< 49.5 dB SPL), and minimal visual and auditory distractions.

2011 American Academy of Audiology Childhood Hearing Loss Guidelines

The most recent document with recommendations relevant to preschool hearing screening is the 2011 American Academy of Audiology (AAA) Clinical Practice Guidelines on Childhood Hearing Screening. The 62-page AAA guidelines include detailed discussions of methods and techniques for childhood hearing screening, among them pure tone hearing screening, aural immittance measures

(tympanometry and acoustic reflexes), and both distortion product and transient evoked otoacoustic emissions.

The 2011 AAA guidelines provide a very detailed section on pure tone hearing screening that begins with the statement, “Historically, the most widely preferred hearing screening procedure and the one that has been considered the gold standard is the pure tone audiometric sweep test ...” Expectedly, the AAA guidelines concur with earlier ASHA recommendations that children “chronologically and developmentally” age 3 or older undergo pure tone screening at 20 dB HL for test frequencies of 1000, 2000, and 4000 Hz. Response criteria and requirements for the test environment are similar to those stated in the ASHA guidelines. Tympanometry is recommended as a second-stage screening method for children who do not pass pure tone hearing screening. The 2011 AAA guidelines do not specifically provide recommendations for personnel involved in preschool hearing screening but they do acknowledge that non-audiologists often manage hearing screening programs.

Otoacoustic emissions are discussed in considerable detail in the 2011 AAA document with the recommendation that they should be used “... only for preschool and school age children for whom pure tone screening is not developmentally appropriate (ability levels < 3 years). That is, OAEs are offered as an alternative for pure tone screening for young children” (p. 28). Also, follow-up screening with tympanometry is recommended for children who do not pass OAE screening.

The 2011 AAA guidelines cite limitations of OAE screening including the insensitivity of OAEs in ears with mild-to-moderate hearing loss (hearing sensitivity within the range of 20 to 50 dB HL), the difficulty of recording OAEs for test frequencies below 2000 Hz due to excessive ambient noise, and the possibility that children with auditory neuropathy spectrum disorder (ANSD) are missed with an OAE screening program. These alleged limitations of OAEs as a preschool hearing screening technique are addressed below in a discussion of new screening strategies.

Clinical Experience with Existing Guidelines

Published studies of preschool hearing screening highlight challenges in the application of existing guidelines. There is general acknowledgment in the guidelines that hearing screening of children younger than 3 years is not feasible with behavioral techniques. Representative studies in older preschool children are cited briefly here. Krishnamurti, Hawks, & Gerling (1999) described findings for 100 preschool children within the age range of 3 to 5 years. In some respects, the study reflects a “best case scenario” for preschool hearing screening with a pure tone technique. An experienced audiologist performed the screening according to ASHA guidelines in day care centers. Still, screening was unsuccessful for 3 children. Initial pure tone hearing screening refer rate was 24% and average hearing screening test times were 45 seconds for instruction prior to

pure tone screening and another 60 seconds for the actual screening.

Allen, Stuart, Everett, & Elangovan (2004) reported hearing screening data for 1,462 children age 3 and 4 years old. Audiology or speech pathology graduate students performed hearing screening under the supervision of an audiologist in public preschool, day care, or Head Start centers following 1997 ASHA guidelines. An audiology supervisor performed tympanometry following pure tone hearing screening of each child. The supervising audiologist also performed pure tone screening of “difficult-to-test” children. Refer rates for this older preschool sample were 10% for otoscopy, 29% for pure tone screening, and 29% for tympanometry.

In one of the largest studies of preschool hearing screening, Serpanos and Jarmel (2007) reported data for 34,979 children age 3 to 5 years screened “on site in private, non-profit, or public preschools, day care centers, or Head Start programs” (p. 5). Graduate level audiology or speech pathology students conducted the screening under the supervision of a state licensed and ASHA-certified audiologist. The overall refer rate for pure tone and/or tympanometry screening was 18%, whereas 7% of the children did not pass both tympanometry and pure tone screening. In this study 2% of the children did not pass the pure tone hearing screening and an additional 3% could not be tested.

Halloran, Wall, Evans, Hardin, & Woolley (2005) described perhaps the most real world experience with hearing screening of older preschool children. Indeed, the study design purposefully did not require “standardization of screening techniques” because “screening in primary care settings is highly dependent on operator techniques and practice characteristics” (Halloran et al., 2005, p. 954). Data were reported for 1,061 children age 3 to up to 19 years who underwent pure tone hearing screening in 8 pediatric practices in Alabama, including 5 non-academic private practices and 3 that were within an academic setting. A trained research assistant conducted the screening with a calibrated audiometer coupled to supra-aural earphones pure tone hearing screening at 20 dB hearing level (HL; 1000, 2000, and 4000 Hz) in an examination room. Most (95%) of the children were screened with conventional technique whereas conditioned play audiometry was required for 5%. Neither gender nor race (African American versus white) was a factor in the likelihood that hearing screening was completed, but older children were more likely to complete screening. The rates for successful completion of hearing screening as a function of age were: ≥ 6 years = 100%; 5 years = 97%; 4 years = 93%; 3 years = 55%. That 45% of the younger children did not complete the hearing screening is quite discouraging. Of the total population, 67 children (7%) could not complete the screening procedure.

Interestingly, pass versus refer rates among children with normal development who could be successfully screened

were consistently $\geq 90\%$ and unaffected by gender, race, or chronological age. Halloran et al. (2005), however, report a pass rate of only 67% for 21 developmentally delayed children. The overall failure rate was 10%, but a total of 162 children or 15% of the population either failed hearing screening or could not be tested. One of the rather surprising findings was the reluctance of pediatricians to refer children for further evaluation. As Halloran et al. (2005) noted: "The findings from this study are worrisome because physicians took no further action in more than 50% of the children who failed the hearing screening and more than 70% of the children who could not be tested" (p. 954).

Halloran et al. (2005) offered several possible explanations for the low follow-up rates, explanations that are relevant in any discussion of preschool hearing screening. Financial constraints presumably did not play a role in the decision against further testing because only infants with Medicaid or private health care insurance were enrolled in the study. However, some pediatricians may have elected to retest later as part of their typical follow-up. Also, physicians in private practice who have long-standing relations with families are presumably comfortable with continued monitoring for signs and symptoms of hearing loss. Additionally, physicians may believe that infants in generally good health and with higher socioeconomic status are at lower risk for hearing loss. Halloran et al. (2005) stated: "Lastly, little is known of the accuracy of conventional audiometry in the primary care setting; therefore, pediatricians may distrust their screening results and rely primarily on the history and physical examination or may seek stronger evidence of hearing loss in the form of a second failed screening prior to referral" (p. 953). Primary care physician attitudes about screening programs in general are explored in more detail in the next section.

Four years after the 2005 paper, Dr. Halloran and two of the authors published a follow-up article entitled: "The validity of pure-tone hearing screening at well-child visits" (Halloran, Hardin, & Wall, 2009). The authors raised serious questions about the value of pure tone hearing screening during well-child visits because of poor sensitivity (50%) and only fair specificity (78%), plus a high no-show rate for children referred for complete hearing evaluation by their primary care physician. Based on their data, Halloran et al. (2009) concluded, "Given the poor validity of pure tone audiometry, other methods of hearing screening should be considered for the primary care setting. One such option that practices and schools are increasingly using is otoacoustic emissions" (p. 161).

A New Strategy For Preschool Hearing Screening

Rationale for a New Strategy for Preschool Hearing Screening

Several strategies often used for preschool "hearing screening" in physician offices are not evidence-based options for accurate identification of hearing loss in young

children (Eiserman, Shisler, et al., 2008). They include parent questionnaire and behavioral observation of responses to hand clapping, bell ringing, and other noise-making devices. Otoscopy is an important part of the physical examination of young children but it clearly is not a measure of auditory function. Likewise, tympanometry is a useful measure of middle ear function, but it provides no information on hearing status. There is a role for tympanometry in conjunction with other hearing screening techniques in follow-up testing of children who yield a refer outcome with the primary hearing screening technique.

The collective experience from published studies (e.g., Brooks, 1971; FitzZaland & Zink, 1984; Fonesca, Forsyth, & Neary, 2005; Halloran et al., 2009) highlight at least five oft-cited serious challenges associated with reliance on the existing guidelines that recommend pure tone hearing screening for the preschool population.

- Audiologists are required for preschool hearing screening. However, audiologists are rarely available at sites where preschool hearing screening is conducted, such as day care centers, Head Start centers, or physician's offices. This challenge is significant, especially given the increasing demand for audiology services coupled with a stable or even declining supply of practicing audiologists (Windmill & Freeman, 2013).
- Acceptable ambient sound levels for pure tone screening are not always achievable in typical preschool hearing screening settings.
- When pure tone screening is done, the time for each child, including instructions and data collection, may be 4 to 5 minutes or longer.
- Pure tone hearing screening doesn't consistently identify middle ear disorders, a common problem in the preschool population (Roush & Tait, 1985).
- A child's age, cognitive level, and language skills are significant factors in pure tone hearing screening. Because of these factors, hearing screening cannot be successfully completed for at least 3 to 5% of older preschool populations and can-not-test rates for chronologically or developmentally younger children are unacceptably high, even when an audiologist performs the screening.

Preschool hearing screening must be quick and simple for children age 3 years and younger (Northern & Downs, 1991). According to a national survey of pediatricians, guidelines are most likely to be adhered to if they are simple, feasible, and lead to proven improved outcomes (Flores, Leo, Bauchner, & Kastner, 2000). Halloran et al. (2005) reported the discouraging finding that pediatricians did not refer 59% of the children who failed the screening and 73% of the children who could not be tested. These statistics may reflect primary care physician distrust with screening outcome. Unfortunately, behavioral pure tone screening does not consistently meet minimal screening criteria even for older preschool children. There is consensus that a behavioral technique is not feasible for routine hearing screening of children in the range age 6 months to 3 years. However, a simple and fast technique

for hearing screening of younger preschool children is essential for systematic early identification of hearing loss.

Rationale for OAEs

OAEs offer the most promising option for systematic hearing screening of the preschool population from age 6 months to 5 years. Multiple advantages of OAEs can be cited in support of their role in preschool hearing screening. As an objective technique, OAE findings are not influenced by the many listener variables that confound hearing screening with a behavioral technique such as pure tone measurement. Listener variables include chronological or developmental age, cognitive level, language skills, motor abilities, and the combination of visual and auditory distractions in the environment. Sensitivity to the types of auditory problems commonly encountered in preschool children is a major advantage of OAEs. Abnormal OAE findings are very likely in children with middle ear dysfunction and/or with cochlear hearing loss involving outer hair cell dysfunction (American Academy of Audiology, 2011; Dhar & Hall, 2012; Hall, 2014). Many studies confirm the sensitivity of OAEs to even subtle outer hair cell dysfunction or damage (see Dhar & Hall, 2012 for review). Most etiologies for childhood hearing loss affect outer hair cell function.

Recording OAEs in young children is feasible and technically simple as evidenced by widespread application of OAEs in newborn infants undergoing hearing screening. Many hundreds of peer-reviewed research publications confirm that assorted personnel including volunteers, technicians, and nurses can successfully complete newborn hearing screenings using OAEs (Dhar & Hall, 2012). An audiologist is not required for OAE-based hearing screening. OAE screening test time is quick, often less than 30 seconds per ear. The signal averaging process employed during OAE measurement, in combination with a properly fitted probe, permits screening in test environments with substantial levels of ambient noise (American Academy of Audiology, 2011). OAE devices are easily portable and often hand-held. Also, OAE test outcome is documented with a display that can be stored electronically, interfaced with data management systems, and printed immediately.

Dozens of articles describe the application of OAEs in preschool hearing screening. Transiently evoked OAEs were recorded in most of the earlier studies published in years up to about 2001. More recently distortion product otoacoustic emissions (DPOAEs) have emerged as the technique of choice for preschool hearing screening (e.g., Bhattia, Mintz, Hecht, Deavenport, & Kuo, 2013; Dille, Glatke, & Earl, 2007; Eiserman, Hartell, et al, 2008; Foust, Eiserman, Shisler, & Geroso, 2013; Hunter, Davey, Kohtz, & Daly, 2007; Janssen, 2013; Kreisman, Bevilacqua, Day, Kriesman, & Hall, 2013; Lyons, Kei, & Driscoll, 2004). Collectively these papers confirm the feasibility and usefulness of DPOAEs for hearing screening in the preschool population.

Two representative studies in different preschool populations are cited here. Kreisman and colleagues (2013) performed hearing screening of 198 children (mean age 4.5 years) in 8 different facilities using pure tones with a conditioned play technique and also with a DPOAE protocol. Several findings of this study highlight the advantages of DPOAEs compared to pure tone hearing screening. In addition to the subjects for whom data were reported, two children successfully screened with DPOAEs could not be tested with pure tones. A total of 57 children failed DPOAE screening whereas only 21 children failed pure tone hearing screening, but none of the children who failed pure tone screening passed DPOAE screening. Sensitivity to hearing loss appeared greater for DPOAEs than for pure tones. Also, average hearing screening time for both ears was less than 1 minute for DPOAEs but over 3 minutes for the pure tone technique.

Foust et al., (2013) reported findings for DPOAE hearing screening in primary care medical settings. Subjects included 848 children (842 in the target population of < 5 years of age and four older siblings) primarily from families whose incomes were at or below the federal poverty level. Audiologist-trained technical staff conducted DPOAE screenings at well-child visits, illness visits, or ear/hearing visits to the primary care physician. As expected, failure rates varied depending on the reason for the physician visit—10% for well-child visits, 13% for illness visits, and 85% for ear/hearing visits. Children who did not pass the initial screening received follow-up screening. Five percent of all children did not pass the final screening. Three children were identified with permanent hearing loss (one was < 5 years of age and two were 5 years old). The study provides further evidence that OAEs offer a feasible approach for hearing screening of young preschool children.

An OAE Protocol for Efficient and Effective Preschool Hearing Screening

Acknowledging the challenges of pure tone screening in young children and those with special needs, the 2011 AAA Clinical Practice Guidelines for Childhood Hearing Screening cited the need for an alternative technique such as OAEs. The AAA guidelines reviewed the literature about hearing screening of young children with OAEs, including measurement techniques, screening considerations, test environment, and time. Three limitations of OAEs as a screening technique are cited in the 2011 Guidelines.

One limitation is the difficulty of recording OAEs in the low frequency range (< 1000 Hz) due to contamination from physiological and ambient noise. The same limitation also applies to pure tone hearing screening in the preschool population. ASHA and AAA guidelines recommend the use of pure tone stimuli of 1000, 2000, and 4000 Hz, but not 500 Hz. Published research shows that DPOAE measurement for test frequencies of 2000 Hz and above is adequately sensitive to middle ear dysfunction and

cochlear hearing loss affecting lower frequencies (see Dhar & Hall, 2012 for review). Although DPOAE are plotted as a function of the higher of the two test frequencies (f_2), the actual distortion product that is measured arises from a lower frequency region in the cochlea as predicted with the equation: $2f_1 - f_2$. In other words, the DP frequency is always lower than either of the two stimulus frequencies (f_1 or f_2).

Another limitation cited in the 2011 AAA Guidelines is the possibility that children with ANSD will be missed with reliance on OAE screening. Although this possibility exists, it is remote due to the rather low prevalence of ANSD, particularly in the well-baby nursery population. It is not reasonable to insist that a hearing screening strategy designed for detection of relatively few children with ANSD be used for all children. Almost all babies with ANSD who are admitted to an intensive care nursery will be identified and diagnosed within the perinatal period. Consideration of JCIH (2007) recommendations offers valuable guidance in addressing this limitation. A preschool child at risk for ANSD who has not yet been diagnosed can presumably be identified based on a “yes” answer to one or more simple questions: 1) Did the child require admission to an intensive care nursery at birth? 2) Is there any evidence of a neurological problem? 3) Does the child have an older sibling with known hearing loss? Children who are at risk for ANSD should undergo pure tone hearing screening, if feasible. At risk children who cannot be tested with a behavioral technique like pure tone screening, or even those who can, should then be tested with acoustic reflexes. Absent acoustic reflexes and/or abnormal pure tone thresholds would prompt a referral for comprehensive audiologic and medical assessment.

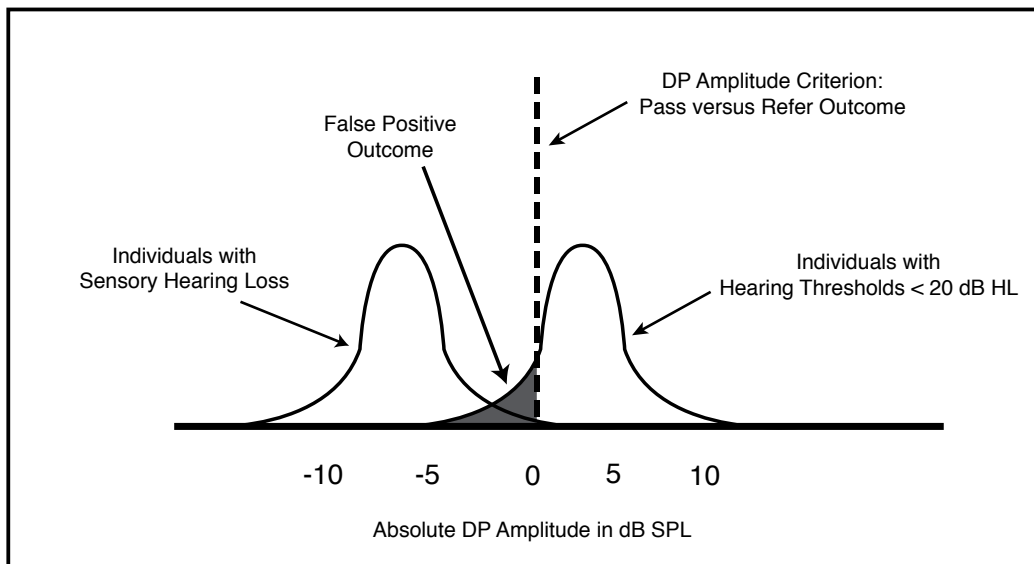
The third limitation cited in the 2011 AAA Guidelines is the possibility of recording an apparent OAE in children with mild-to-moderate hearing loss. The Guidelines caution

that pass/fail criteria in OAE-based preschool hearing screening must be “chosen carefully to maximize sensitivity and specificity” (p. 32). Clearly, a preschool hearing screening technique must have the best possible test performance. The problem with false-negative screening errors (i.e., a pass outcome in children with some degree of sensory hearing loss) is associated with reliance on a pass/fail criterion that is based on the relative difference between OAE amplitude versus noise floor levels, and without regard to the absolute OAE amplitude value. Most published studies in neonatal and preschool hearing screening have employed a pass criterion limited to an OAE-to-noise floor difference of > 3 or > 6 dB SPL.

A simple strategy for increasing sensitivity to varying degrees of sensory hearing loss is the addition of a second criterion involving the absolute amplitude of OAEs. Sensitivity of OAE screening to even mild sensory or conductive hearing loss is achieved with criteria for a pass outcome of an OAE amplitude minus noise floor difference of 6 dB SPL *plus* the requirement for an absolute OAE amplitude of ≥ 0 dB SPL. Building both of these requirements into the automated pass-fail algorithms of DPOAE screening equipment could be done easily by manufacturers if there were a demand for it. Long-standing research on the relation between OAE amplitude and hearing threshold levels supports the application of these two criteria in combination for identification of persons with any degree of sensory hearing loss involving the outer hair cells (Gorga et al., 1997).

The application of an absolute amplitude level of 0 dB SPL to differentiate children with no hearing loss versus some degree of sensory hearing loss is illustrated in Figure 1. The dashed vertical line depicts the decision criterion of 0 dB SPL. Most children with hearing thresholds of less than 20 dB HL within the region of the OAE test frequencies have OAE amplitudes ≥ 0 dB SPL. As with any sensitive

Figure 1. Pre-School Hearing Screening with OAEs



Note. DP = distortion product; HL = hearing level; SPL = sound pressure level.

screening measure, there is a possibility that a child with normal hearing will not meet this criterion. Among the common explanations accounting for a false-positive hearing-screening outcome is middle ear dysfunction. Insisting on a rather rigorous criterion of ≥ 0 dB SPL for absolute OAE amplitude in defining a pass outcome enhances screening detection of children with sensory hearing loss. Indeed, sensitivity of this OAE strategy for identifying middle ear or cochlear auditory dysfunction in preschool children may well exceed the sensitivity of pure tone hearing screening.

To summarize, the best use of OAE screening for young children would include the use of pass-fail algorithms that incorporate two criteria for pass. First is to document the presence of OAE activity with verification that OAE amplitude for the test frequencies is at least 6 dB greater than noise floor at the same frequencies. The second criterion, taken only for children who meet the first criterion, is to document that absolute OAE amplitude for the test frequencies is at least 0 dB SPL.

Closing Comments

The EHDI process is not flawless. Some children do not undergo hearing screening within the first month after birth even in the current era of UNHS. Two more serious problems compromise the goals of EHDI programs. One double-pronged problem is the rather sizeable proportion of children failing newborn hearing screening who are lost to follow-up before diagnostic hearing testing is completed or before intervention for hearing loss is implemented. Another problem is that a substantial number of children who had normal hearing at birth acquire a late-onset hearing loss. Thus, there is a strong rationale for widespread and systematic preschool hearing screening. Preschool hearing screening offers a viable strategy for early detection of childhood hearing loss beyond the newborn period.

A new evidence-based and clinically feasible strategy for effective and efficient preschool hearing screening is summarized in Table 3. The strategy relies on OAEs as the primary tool for hearing screening of all preschool children from age 6 months through 5 years. Pass/fail criteria used in OAE analysis are selected with the objective of

Table 3. A New Feasible Evidence-Based Strategy for Effective and Efficient Hearing Screening in Preschool Children

<p>6 Months to 4 Years</p> <p>Primary Screening Technique: Distortion product otoacoustic emissions (DPOAEs)</p> <ul style="list-style-type: none"> • Stimulus intensity: L1 = 65 dB SPL; L2 = 55 dB SPL • F2 frequency region = 2000 to 5000 Hz • Frequencies per octave = 4 • Pass Criteria <ul style="list-style-type: none"> o DPOAE amplitude = >0 dB SPL o DPOAE – noise floor = > 6 dB <p>Secondary Screening Techniques for Refer Outcome</p> <ul style="list-style-type: none"> • Tympanometry • Acoustic reflex for broadband noise signal as indicated • Otoscopy as indicated <p>≥ 4 Years</p> <p>Primary Screening Technique: Distortion product otoacoustic emissions (DPOAEs)</p> <ul style="list-style-type: none"> • Stimulus intensity: L1 = 65 dB SPL; L2 = 55 dB SPL • F2 frequency region = 2000 to 5000 Hz • Frequencies per octave = 4 • Pass Criteria <ul style="list-style-type: none"> o DPOAE amplitude = >0 dB SPL o DPOAE – noise floor = > 6 dB <p>Follow-up Techniques for Children Who Do Not Pass DPOAE</p> <ul style="list-style-type: none"> • Tympanometry • Pure tone hearing screening at 20 dB HL if possible • Acoustic reflex for broadband noise signal if indicated • Otoscopy as indicated

Note. HL = hearing level, SPL = sound pressure level; F2 = higher test frequency; L = intensity level of F1 and F2

identifying children with hearing loss equal to or greater than 20 dB HL, a screening objective common also to the pure tone method. Tympanometry is performed for all children who do not pass the initial OAE screening in order to identify those with middle ear dysfunction that is often transient or successfully treated medically. The specific technique selected for follow-up to screening is age-dependent for children who do not pass an initial OAE screening who also have normal tympanograms and probably normal middle ear function.

For younger children under the age of 4 years, the follow-up should be done using acoustic reflex measurement. Acoustic reflex screening is conducted with a broadband noise (BBN) stimulus. BBN-evoked acoustic reflexes offer a quick and objective method for detection of likely sensory hearing loss in children with normal middle ear function as inferred from tympanometry (Hall, Berry, & Olson, 1982; Hall & Swanepoel, 2010; Kei, 2012). Pure tone hearing screening testing is the follow-up technique of choice for children of 4 years or older who do not pass OAE screening but who have normal tympanograms. Technological advances in pure tone hearing instrumentation (Wenjin et al., 2014) offer an opportunity to avoid some of the well-appreciated drawbacks associated with conventional pure tone hearing screening of preschool children detailed above.

Upon the completion of accurate OAE screening and follow-up of preschool children as just reviewed, recommendations in existing documents (e.g., JCIH, 2007; American Academy of Audiology, 2011; American Academy of Audiology, 2013) provide ample guidance on protocols for medical and audiological referral of infants and hearing screening program management.

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The Role of Family-led Disability Organizations in Supporting Families with Hearing-Related Concerns

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Abstract

A survey was conducted with state level chapters from Family Voices, Parent Training and Information Centers, and Parent-to-Parent USA to understand how their current activities support families of children with hearing-related concerns and to identify gaps in their ability to support families of children who are deaf or hard of hearing (DHH). These organizations reported that they are contacted with parent requests for information in regard to family support opportunities, early intervention, referral sources pertaining to hearing concerns, financial help, and providing information about legal rights. Results showed that the greatest challenges for these organizations were related to needing to connect families to financial resources pertaining to hearing-related needs, engaging families of children who are DHH in their organization's activities, having resources available in other languages, and identifying pediatric providers that serve DHH children. Potential ways to strengthen the capacity of these organizations to meet the needs of families with hearing-related concerns as well as increasing their awareness of partnerships with the EHDI system are discussed.

Acronyms: AG Bell = Alexander Graham Bell Association for the Deaf and Hard of Hearing; ASDC = American Society for Deaf Children; CPIR = Center for Parent Information and Resources; CYSHCN = children and youth with special health care needs; DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; F2F HICs = Family-to-Family Health Information Centers; FV = Family Voices; H&V = Hands & Voices; MCHB = Maternal and Child Health Bureau; P2P USA = Parent-to-Parent USA; PTI = Parent Training and Information

Introduction

Over the past three decades, family-led organizations have played an important role in supporting families of children with special needs (Adinbinder et al., 1998; Henderson, Johnson, & Moodie, 2014). Based on the core principle of “parents helping parents” these early organizations have served to not only connect families with one another as sources of support but also have been effective advocates in driving the direction of family-centered services and legislation.

With the recognition of family leadership as a cornerstone in driving the development of family-centered services for children and youth with special health care needs (CYSHCN; McPherson, Arango, & Fox, 1998) the number of such organizations has grown throughout the United States. (National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project, 2014; National Committee for Quality Assurance, 2011). Organizations such as the Parent Training and Information Centers, Family Voices, Family-to-Family Health Information Centers, and Parent-to-Parent USA all have state chapters as well as national headquarters. As shown in Table 1, these organizations vary in their funding and emphasis, but they all serve as an important “door” for families to enter when they need help to address concerns related to their child. The Parent Training and Information Centers (Center for Parent Information and Resources, 2015), funded under the Individuals with Disabilities Education Act (2004), have expertise in education-related issues faced by families

of children ages birth to 22 years with disabilities. Family Voices (2015) is a family-led organization established to address access to family-centered care for families of CYSHCN. Family-to-Family Health Information Centers (F2F HICs), typically awarded to Family Voices state chapters, were established to help families of CYSHCN navigate the often-confusing maze of services, especially those related to obtaining health care. Parent-to-Parent USA (P2P USA) programs focus on providing emotional and informational support to families of children who have special needs primarily by matching parents seeking support with an experienced, trained “support parent.”

Given their focus on serving families of children with diverse special needs, all of these organizations claim to address questions related to where to find services or resources pertaining to hearing. Thus, these broad-based organizations can potentially play a central role in connecting families who are concerned about their child's hearing but may not yet have a diagnosis to essential resources, such as state Early Hearing Detection and Intervention (EHDI) programs.

Additionally, these organizations could be an important partner in helping families connect to resources to meet the unique service needs of children who are DHH. A family's quality of life—defined as the degree to which the family's needs are met—is often impacted by having a child who is DHH (Jackson & Turnbull, 2004). The literature demonstrates that these families often have difficulty accessing needed care (Arehart & Yoshinago-Itano, 1999; Data Resource Center for Child and Adolescent Health,

Table 1. Descriptions of Family Organizations Surveyed

Organization	Coverage, Focus, and Website
Family Voices (FV)	Established over 30 years ago by families who strove to care for their children and youth with special health care needs (CYSHCN) in their home and community in a time when institutionalization was the norm. FV operates state affiliate chapters in most states, offering families of CYSHCN—which includes children who are DHH—resources and support to make informed decisions regarding health care, advocating for improved public and private policies, and building partnerships among families and professionals. FV operates the National Center for Family-Professional Partnerships funded by the federal Maternal and Child Health Bureau (MCHB). http://www.familyvoices.org
Family to Family Health Information Centers (F2F HICs)	These non-profit, family-staffed organizations provide information, education, training, support and referral services, outreach to underserved/underrepresented population, and guidance on health programs and policies. MCHB provides the primary funding for F2F HICs, as authorized by the Family Opportunity/Deficit Reduction Act of 2005. Through this funding, MCHB currently supports F2F HICs in all states and the District of Columbia. Family Voices provides technical assistance, training, and connections to F2F HICs. http://www.familyvoices.org
Parent Training and Information Centers (PTIs)	Each state has at least one PTI, which focuses on supporting parents of children with disabilities, including children who are DHH; some states also have Community PTIs that focus on underserved populations (e.g., low English proficiency). Their purpose is to provide parents with information and training about disabilities, rights under the Individuals with Disabilities Education Act (IDEA, 2004) and other relevant laws, and resources pertaining to education issues in particular. They conduct workshops and conferences for parents. PTIs are funded through the Office of Special Education and Rehabilitative Services as authorized by the IDEA. The Center for Parent Information and Resources (CPIR) serves as a central resource of information to the PTIs. http://www.parentcenterhub.org/find-your-center/
Parent to Parent USA (P2P)	P2P programs have offered parent-to-parent support as a core resource for families with children (including those who are DHH) who have a special health care need, disability, or mental health issue. Their main approach is to match parents seeking support with a one-to-one “match” with an experienced, trained “Support Parent” who provides emotional support and assistance in finding information and resources. To date, 32 states have P2P affiliate programs, and 2 have a P2P nonmember—or emerging—program. P2P USA was created in 2003 with funding from the Robert Wood Johnson Foundation and obtains funding through other donations. http://www.p2pusa.org

2015). Additionally, parent-to-parent support is particularly important for hearing parents of DHH children (Hintermair, 2000). Families of children newly-diagnosed as DHH expressed a preference for discussion with other parents of children with hearing loss over discussion with parents of children without hearing loss (Jackson, 2011). Therefore, organizations such as Parent-To-Parent USA—with the mission of connecting parents with other parents who have gone through similar experiences—can connect families with groups such as Hands & Voices, the American Society for Deaf Children (ASDC), or the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell).

Finally, these organizations can play a valuable role in meeting needs that are universal to all families of children with special needs, such as insurance coverage or education rights. Family Voices and the Family-to-Family Health Information Centers can help families in need of financial support to obtain needed audiological evaluations or hearing assistive technology. Parent Training and Information (PTI) Centers, for example, ensure that the educational and early intervention service needs for children who are DHH are provided in accordance with federal and state laws and regulations.

In spite of the potential for these organizations to support the needs of families who have questions or concerns about their child who is DHH, little is known about the extent to which these family organizations are currently contacted by families with hearing-related concerns. Understanding the extent to which they link families with DHH resources as well as being aware of the challenges experienced by these groups would help ensure that families of children who are DHH receive the assistance and support they need.

Methods

An online survey was conducted with four organizations to determine the number of families that contact them with hearing-related concerns, the types of information and referrals they provide, and the challenges they face in supporting these families.

Subjects and Recruitment

Subjects consisted of state-level directors from the following organizations:

1. Family Voices (FV)
2. Family-to-Family Health Information Centers (F2F HICs)
3. Parent Training and Information Centers (PTIs)
4. Parent-to-Parent USA (P2P USA)

National leaders of these organizations were contacted prior to survey administration to ensure their support in dissemination of the survey. The national offices provided a list of state affiliates, and they each sent a formal request to their members to respond to the survey that was integrated into a standardized recruitment letter developed by the researchers.

During the initial recruitment process, it became apparent that many of the state affiliates of these organizations were actually housed within the same organization. For example, New Jersey's Statewide Parent Advocacy Network houses the state's FV, F2F, PTI, and P2P USA. This is because some organizations received grants to operate multiple programs and it was financially practical to house these grants under one roof with a shared staff. However, varying individuals may staff each of these different organizations. To ensure that the survey reached all potential state leaders, the online survey was sent to whomever was listed as the state-level contact according to the national level office.

A total of 164 surveys were sent and 127 responses were received representing 77% of the targeted respondents. Responses were obtained from 96% of the F2F HIC programs, 85% of the Family Voices state chapters, 84% of the PTIs, and 58% of Alliance Members of the P2P USAs. When asked to identify all of the organizations the respondent represented, 58% reported that they represented more than one organization (e.g., FV and F2F). When multiple responses were received for the same

organization, information was consolidated, resulting in a total of 104 responses that were analyzed.

Survey Development

An online survey that consisted of eight multiple choice questions with options for adding open-ended responses was developed by the researchers, with initial content created based on input from the National Center for Hearing Assessment and Management's family advisory members. A paper version of the survey was then piloted with three state level administrators representing the aforementioned organizations. Revisions were made based on recommendations, and the resulting survey was sent using SurveyGizmo. The survey contained questions to ascertain (a) the number of families that contact them with hearing-related issues; (b) the types and content of information they provide to families; (c) the challenges they face in trying to meet the needs of families who have children with hearing-related issues; and (d) the extent to which they partner with other DHH organizations including their EHDI program.

Data Entry and Analysis

Data entry and analyses were conducted using Microsoft Excel. Descriptive univariate analyses (primarily frequency distributions) were conducted. Given the uniformity in responses across the three organizational groups, the responses were collapsed to present an overall picture of the role of these organizations in supporting families with hearing-related concerns.

Results

The results from the online survey, primarily in the form of frequency distribution, are presented below. Findings are reported in relation to the main topics of the survey:

1. The number of families with hearing-related concerns who contact the organizations,
2. The types of information provided,
3. The self-reported challenges of the organizations,
4. The relationship of the organization with the state EHDI program.

Number of Contacts Regarding Hearing Issues

Respondents from each organization were asked to identify how many families, on average, contact them for information or support pertaining to hearing-related needs within a one-year time period. Their responses, based on the categories offered them, are provided in Table 2. The largest number of respondents (28%) reported 1-10 families, while 18% of respondents reported 11-25 families, another 18% reported 25-50 families, 15% reported 50-100 families, and close to 23% reported being contacted by more than 100 families each year. Roughly 11% reported that they did not know how many contacted them with this specific need.

Table 2. How Many Families with Hearing-Related Concerns Contact You on an Annual Basis?

Number of Families	<i>n</i>	Percent of Responses
1-10	29	22%
11-25	19	18%
25-49	19	18%
50-100	15	15%
100-199	7	7%
200 or more	2	2%
Don't Know/Can't Estimate	12	12%

Table 3. What Types of Information Do You Provide to Families With Hearing Related Needs (Check All That Apply)

Type of Information	<i>N</i>	%
Parent support opportunities	92	94%
Addressing EI issues/finding EI services	90	90%
Where to go if concerned about hearing loss	87	92%
Addressing school issues/finding educational services	86	80%
Paying for services/insurance issues	74	90%
Legal rights on behalf of child	68	67%
Other health issues	65	82%
Where to find pediatric providers for hearing evaluation	64	76%
Information regarding hearing aids	38	55%
Information regarding cochlear implants	38	49%

Note. EI= Early Intervention

Types of Information Provided

Respondents were provided with a list of options pertaining to the types of information they could provide to families of children with hearing-related needs. Table 3 reflects the percent of programs reporting specific types of information provided to families. Nearly 90% of the programs reported that family support opportunities were requested, along with requests for information addressing early intervention issues. Information in response to “where to go if family is concerned about the child’s hearing loss” was identified as information provided by nearly 85% of the programs. Roughly 72% of the programs reported providing information pertaining to questions about how to pay for services or insurance-related issues. Two-thirds of the programs reported providing information about legal rights, and slightly more than 60% reported providing information on where to find pediatric providers as well as providers for other health-related issues. Approximately 37% of the programs provided information pertaining to cochlear implants or hearing aids.

Slightly less than half of the programs reported providing information about communication options. When reviewing the types of communication options discussed by this subgroup, 88% reported that they present information about sign language, total communication, and listening and spoken language approaches. Over 20% of the programs reported providing information about an array of other communication options, such as assistive technology or cued speech.

Challenges of Family Organizations

To identify the issues facing these family organizations, respondents were asked, “What are the challenges or frustrations your organization faces in trying to help families with children with hearing-related needs?” As shown in Table 4, knowing about financial resources to cover hearing-related services (such as hearing aids) was identified as a challenge by 61% of respondents, followed by having materials available in languages other than English (47%), and engaging families of children who are

DHH in the organization’s activities, such as training and newsletters (44%). Identifying health care and education providers with experience in serving infants and young children with/at risk for hearing loss was identified by 41% of respondents, and providing objective information to families about communication options was checked by 37% of the programs. “Explaining to families the importance of hearing screening or diagnostic follow-up” was identified as a challenge by 29% of respondents.

Respondents also were given the opportunity to write in other types of challenges or frustrations they face. Many of the comments dealt with access to care issues. For example, one respondent wrote, “It is sometimes hard for families to find the services that are being provided... (especially) in rural areas.” Others voiced frustration with schools and other services for children who are DHH, such as the comment that “Sometimes the school districts are biased as to communication options, they tend to promote the mode for which they have proficient employees and not according to what families may want.” Getting timely referrals as well as connections to early intervention also were identified as frustrations experienced. Supporting parents who are DHH themselves was identified as a challenge, along with identifying adequate supports for children with multiple diagnoses. Five programs said that they would like to be able to connect families of children who are DHH with other families but that they lack the contacts or hearing-loss specific groups in their state.

Referrals to EHDI System Partners

The extent to which these family-led organizations connect families with the state EHDI program and other hearing-related organizations was investigated. As shown in Table 5, programs were asked to identify from a list to which organizations they refer families of children with hearing-related needs. Almost 70% of the respondents reported that they refer families to the state EHDI program, with roughly half of the respondents identifying the state association of the deaf as well as the state school for the deaf. About 44% of programs reported referring families to a disability rights organization. The most frequently mentioned hearing-specific family support groups were Hands & Voices (41%) and AG Bell (26%).

Respondents were asked specifically about the ways that they are working with their state’s EHDI program. As shown in Figure 1 the majority of respondents reported making referrals to one another (60%). Other responses included working together on training activities (20%), being on their state EHDI advisory board or task force (17%), developing materials together (14%), and working on grants together (11%).

Discussion

The purpose of this study was to understand the role of broad-based family organizations that support families of children with special needs in helping families with hearing-related concerns. Additionally, the researchers sought to understand the needs of these organizations to better support their capacity as a partner in the broader

Table 4. What Are Challenges You Face in Helping Families (Check All That Apply)

Type of Challenges	<i>n</i>	% of Programs
Importance of screening and follow-up	30	29%
Information regarding communication options	38	37%
Identifying pediatric DHH providers	42	41%
Engaging DHH families	45	44%
Materials available in other languages	48	47%
Knowing DHH financial resources	63	62%

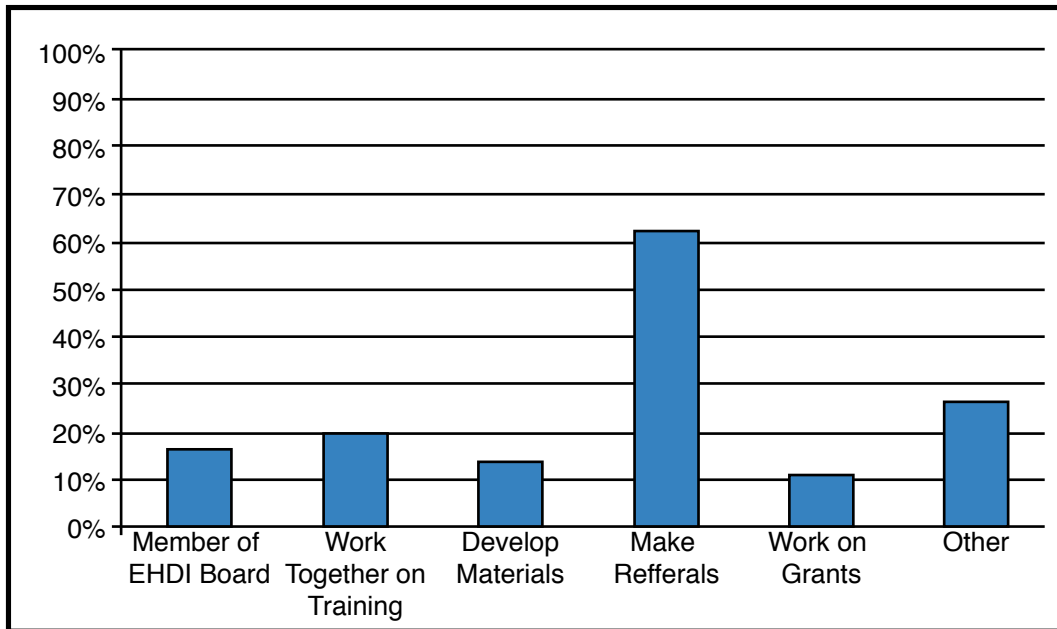
Note. DHH = deaf or hard of hearing.

Table 5. To Which Organizations Do You Refer? (Check All That Apply)

Type of Challenges	<i>n</i>	% of Programs
Hands & Voices	42	41%
Disability Rights Organizations	45	44%
AG Bell	27	26%
State Association of the Deaf	55	53%
State School for the Deaf	53	51%

Note. AG Bell = Alexander Graham Bell Association for the Deaf and Hard of Hearing.

**Figure 1. In Which Ways Do You Work With Your State EHDl Programs?
(Check All That Apply)**



Note. EHDl = Early Hearing Detection and Intervention.

service system for families of children who are DHH. Family Voices, Family-to-Family Health Information Centers, Parent Training and Information Centers, and Parent-to-Parent USA state chapters were invited to participate.

Although survey findings show that these organizations are being contacted by families with hearing-related issues, the number of families reaching out to them is relatively small in relation to the number of children who are DHH. Based on the numbers reported by all of the respondents and assuming that the non-respondents were contacted about the same number of times, there were approximately 6,000 contacts with these organizations during a 12-month period. Even if all of these contacts were by different people (which is unlikely), this number is a tiny percentage of the estimated 100,000 to 350,000 school-aged children in the U.S. with permanent bilateral hearing loss greater than 25 dB (Lin, Niparko, & Ferrucci, 2011; Lundeen, 1981). The fact that such a small number of families of children who are DHH are contacting these organizations is consistent with reports in the literature about the difficulty families report about accessing information, obtaining resources, and finding social support (Jackson, 2011; Jackson & Turnbull, 2004). The results of this study reinforce the need for increased awareness about these family organizations. EHDl system stakeholders—EHDl program coordinators, physicians, audiologists, and early interventionists—can all help connect families to these resources.

When asked about the types of information they provide to families, slightly less than half of the organizations reported that they provided information about communication options. Although they appear to be providing information about the main types of communication modalities used with children who are DHH, the level of expertise and their ability to clearly explain the various options and

considerations is unknown. Delivering information in an unbiased manner and understanding the complexity of the decision making process for families in selecting communication modalities is critical. Because this is an important issue that has been cited in the literature as a frustration for families (Jackson, Becker, & Schmitendorf, 2002), methods to support these broad family organizations warrants further exploration. It also is important to note that about a third of respondents identified “providing information about communication options” as a challenge. These results speak to the importance of linking families to hearing-specific resources that have the expertise to address this complex decision.

The survey sheds light on additional challenges these organizations face in supporting families with hearing-related concerns. Knowledge about financing hearing assistive technologies and care, having materials available in multiple languages, and explaining the importance of hearing screening and follow up were reported as issues these organizations face in their efforts to help families.

Since it’s unlikely that these broad-based organizations can be experts on every disability, it is important that they refer families to hearing loss-specific services and organizations that have the needed expertise. The extent to which these organizations make referrals to other DHH-related state resources such as Hands & Voices or AG Bell, as well as state Schools for the Deaf and EHDl programs showed that roughly half of these organizations referred families to their state’s School for the Deaf or state Association of the Deaf, and even fewer organizations referred families to Hands & Voices and/or AG Bell. Ideally, higher referral rates are desirable. It is important to note, though, that these latter two organizations are not currently present in all states, which likely influences the lower percentage

of referrals. Regardless, tools such as the “*Just in Time Hearing Related Resources for Families*” (National Center for Hearing Assessment and Management, 2014) can be distributed to all family organizations, providing them with concrete information about essential resources that they in turn can share with families.

Both disability specific and non-disability specific organizations have contributions to make in the support of families who have children who are DHH, particularly for DHH children with additional special needs. For example, Family Voices has considerable experience in regard to financing strategies and communicating with insurance companies, and they could be a valuable partner in working toward more hearing assistive technology coverage in states. Parents to Parents can help connect families with other parents who have children with similar multiple needs, such as autism and hearing loss. Parent Training and Information Centers can lend expertise to families facing legal disputes about educational placements.

Opportunities for these organizations to contribute to the EHDI system in particular are worthy of expansion. In addition to the frequent referrals they are already making, these organizations can contribute by having their voice heard on state EHDI advisory boards, assisting in training, assisting in raising public awareness of the importance of early screening and timely diagnosis, and connections to early intervention services.

There are limitations to this study. First, the data were obtained primarily via respondent recollection of their activities over the past year and dependent on the knowledge base of the respondent about their organization. Additionally, since many of the organizations were integrated under the same infrastructure “umbrella” in their state, it is difficult to isolate the activities of one particular organization, such as analyzing all the responses of Family-to-Family Health Information Centers alone. Therefore, there is a need for more in-depth analyses to guide the direction of how to provide targeted support to specific family organizations. Finally, this study focused primarily on the provision of information to help families connect with needed resources and to navigate the service system. Further research on how organizations can address other important aspects for families of children who are DHH (i.e., emotional support, building confidence, and competence) is warranted (Henderson et al., 2014). This is likely an appropriate activity for stakeholders within specific states who desire to ensure comprehensive family support systems.

All of these organizations, both broad-based organizations as well as DHH-specific family organizations, play an essential role in supporting EHDI systems by bringing the family perspective to the table—an essential component for creating family-centered service systems. They can emphasize important needs of families that the service system should address and they can, in turn, ensure families get accurate information about DHH services. In

a recent analysis of family participation in serving children with special health care needs, “a key finding is that while some state and local government entities incorporate and support robust family participation, overall involvement of families is very inconsistent and often fairly anemic in policy making and implementation of decisions” (O’Sullivan & Tompkins, 2014). State EHDI programs can work on strengthening their support for families as well as family-professional partnerships by outreach to all family organizations in their state.

There is much work to be done, and it will take collaboration and shared leadership to ensure all families who have children who are DHH obtain the knowledge, support, and decision-making skills in accordance with their needs. Successful outcomes for children who are DHH are tied to well-supported families. When family-led organizations collaborate and work together for this shared purpose, families and children are the beneficiaries.

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Outsourcing Hospital-Based Newborn Hearing Screening: Key Questions and Considerations

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Abstract

This article reviews the essential components of a high quality newborn hearing screening program and examines important questions and considerations for hospitals considering outsourcing of newborn hearing screening. Specific issues include hiring, training, and evaluation of personnel; special considerations for the NICU; implications of a screening model that requires families to “opt-in;” implications for choice of technology; instrumentation and screening protocols; tracking and surveillance for infants who do not pass the initial screening; billing and collection practices; and the impact of outsourcing on a hospital’s institutional mission.

Acronyms: EHDi = Early Hearing Detection and Intervention; HIPAA = Health Insurance Portability and Accountability Act; HL = hearing loss; JCIH = Joint Committee on Infant Hearing; NCHAM = National Center for Hearing Assessment and Management; NICHQ = National Institute for Children’s Health Quality; NICU = neonatal intensive care unit; S-ABR = screening auditory brainstem response; S-OAE = screening otoacoustic emissions

For nearly 20 years, newborn hearing screening has been a standard of care throughout the United States. All 50 states and U.S. Territories provide newborn hearing screening and most have passed legislation mandating hearing screening. As a result, more than 97% of all newborns in the United States are now screened for hearing loss (Centers for Disease Control and Prevention, 2013). Historically most hospitals have assumed direct responsibility for newborn hearing screening but there is recent evidence of growth in the number of hospitals choosing to hire a contractor to provide this service. A survey conducted by the National Center for Hearing Assessment and Management (NCHAM) in November 2015, found that 25 out of 59 U.S. States and Territories (42%) reported an increase in the number of hospitals outsourcing newborn hearing screening over the past three years (NCHAM, 2015). The purpose of this article is to review the components of a quality newborn hearing screening program and to discuss important questions and considerations related to outsourcing. We will focus on: (a) prerequisites of a successful newborn hearing-screening program regardless of who performs the service, and (b) key questions and considerations for hospitals considering an outsourcing model.

Hospital-based newborn hearing screening is a complex and multifaceted endeavor. Essential components of a well run, quality program include coordination, oversight, accountability, sustainability, and protocols that reflect best practices; this is true not only for the initial screening but for tracking and follow-up that occur for infants who do not pass and/or require monitoring. Institutions must stay abreast of current guidelines for best practice and

comply with established state and national benchmarks. This generally requires a designated program manager to monitor and update policies, procedures, and protocols and to implement a competency-based training program to assure screening staff are well trained. Ongoing monitoring of performance is essential in assuring program effectiveness and efficiency. Also required is coordination of schedules to ensure full-time coverage and accountability for nursery admissions. Other responsibilities include monitoring of equipment and supplies, meeting calibration and maintenance requirements specific to each equipment manufacturer, and procedures to address equipment problems when they arise. Coordination and oversight also include monitoring of quality indicators such as pass/fail rates, missed screens, and corrective action if quality indicators decline.

In addition to these technical and administrative components, a quality program should promote buy-in from key stakeholders and support staff within the institution involved in newborn care. This includes communication with neonatologists, pediatricians, audiologists, nursing staff, discharge coordinators, clinical educators, hospital administrators, midwives, chief nursing officers, chief executive officers, information technology personnel, and risk managers. Also important is ongoing internal advocacy and awareness with hospital administrators and other stakeholders to sustain the institutional commitment and ensure the necessary human and institutional resources.

Newborn hearing screening also requires the implementation of numerous policies, procedures, and protocols designed to fit each hospital’s unique footprint.

Protocols include the timing of screenings based on the average length of stay; the number of inpatient screening attempts; outpatient screening protocols; choice of screening technology and modality which includes screening otoacoustic emissions (S-OAE), screening auditory brainstem response (S-ABR), or both; stimulus levels; recording parameters that determine pass/fail criteria; and when applicable, compatibility of instrumentation with state tracking and data management systems. Hospitals must stay current with statutory rules, regulations, and guidelines that impact protocols, and partner with state early hearing detection and intervention (EHDI) programs to ensure accurate, comprehensive, and timely reporting of screening outcomes. In addition, standardization regarding the content and method of communication with families must be considered before, during, and after the screening process especially in lieu of recent changes resulting in more programs moving to bedside screening in an effort to provide a family-friendly birthing experience. Procedures for documentation and dissemination of results internally and to physicians, families, and other stakeholders are hospital-specific but must be in place. For all infants who do not pass, there must be detailed provisions for tracking and follow-up. The National Institute for Children's Health Quality (NICHQ) recommendations (Russ, Hannah, DesGeorges, & Forsman, 2010), which have proven to be effective in this regard, include scheduling of outpatient appointments, multiple contact numbers for the family, reminder calls for appointments, and communication of findings and recommendations to the primary care provider. Also essential is compliance with institutional guidelines including the Health Insurance Portability and Accountability Act (HIPAA) and universal precautions as well as compliance with risk management and other relevant legal requirements.

For infants requiring special care in the neonatal intensive care unit (NICU) there are a number of special considerations. The NICU is a complex screening environment that requires effective communication and coordination with NICU staff and audiologists. Key components include close communication with NICU staff to determine when infants are medically stable for screening and documentation of risk factors. The method of communication with families and delivery of results is a critical consideration due to the many health complexities families are likely facing. Clear and explicit culturally sensitive instructions and education must be provided regarding referral of infants who do not pass, and next steps should be outlined for those who passed but have risk factors for late onset hearing loss. If an audiology program exists within the hospital, clear lines of communication must be established between the nurseries and the audiologists with procedures designed to ensure a smooth handoff (e.g., scheduling appointments, coordination of services, removing barriers that prevent seamless referrals). Protocols to ensure careful accounting and tracking of transfers must also be in place. Successful

hearing screening in the NICU requires effective and trusting inter-professional relationships among NICU staff, neonatologists, and the audiologists who provide technical and programmatic oversight.

Finally, a collaborative and coordinated effort with families, physicians, and the state EHDI program is essential for ensuring timely and appropriate referrals, minimizing loss to follow-up, and providing a safety net to keep babies in the system. A strong partnership with the state EHDI program is essential to synchronize activities and minimize duplication of follow-up efforts; and sharing of information must be done in compliance with statutes, rules, and guidelines, including consent to involve other agencies.

Outsourcing Newborn Hearing Screening

Outsourcing is a practice used by companies and institutions to reduce costs by transferring work to outside suppliers rather than completing it internally (Investopedia, n.d.). In the U.S. there are many models for outsourcing newborn hearing screening including local or regional contractors, community partnerships, corporate providers, and smaller companies. The concept of outsourcing is often well received by hospital administrators and nursing staff. Potential advantages include personnel and equipment provided and maintained by the contractor as part of a service delivery model described by some as a "turnkey" operation that relieves the hospital of all responsibilities associated with newborn hearing screening. The contractor handles hiring, training, scheduling, and monitoring of screeners as well as reporting outcomes to the state EHDI program at no charge to the hospital. Some providers have developed attractive educational materials in multiple languages.

There are, however, a number of key questions if outsourcing is being considered. As noted earlier there are dozens of essential components of a quality newborn hearing screening program. Hospitals contemplating an outsourcing model must ensure that each of these components is provided at the highest level of quality and compliance. In addition, several considerations unique to a contracted model must be carefully evaluated such as hiring of personnel; special considerations for the NICU; "opting in" vs. "opting out;" choice of technology, instrumentation, and screening protocols; essential functions related to tracking and surveillance; partnering with the state EHDI program; billing and collection practices; and the impact of outsourcing on a hospital's institutional mission. Each of these considerations will be examined separately.

Personnel

The selection of screening personnel is critically important in any setting. If newborn hearing screening is to be provided by a contractor, the hospital will need to be fully comfortable with the selection and training of personnel.

This raises several important questions. Will the training be competency-based and will there be a re-certification process? How will performance be monitored and what responsibilities are assumed? And how will each of these issues be addressed within the well-baby nursery and NICU. Communication with families is especially critical. How will the contractor interact with the family and explain findings and recommendations? How will effective communication and collaboration with hospital staff be established? Each of these critical questions must be carefully and thoroughly considered.

Special Considerations NICU

A successful screening program in the NICU will potentially yield the highest number of infants with sensory/neural hearing loss to be found in any screening environment. Indeed, the prevalence of permanent hearing loss for infants requiring special care can be 30 times higher than those with uncomplicated birth histories (Hille, 2007). The NICU is also the setting most likely to yield infants who are eventually diagnosed with auditory neuropathy spectrum disorder (Berg, Spitzer, Towers, Bartosiewicz, & Diamond, 2005). It is imperative, therefore, that screening/referral in the NICU be handled optimally. A number of unique and special issues exist in the NICU, however, that complicate the screening process. The NICU is a highly complex screening environment. Effective communication, coordination, and teamwork are essential. Babies are continuously being transferred in and out, and as they are transferred to another hospital, the time window for screening is often narrow. Some NICUs are moving directly to diagnostic ABRs performed by an audiologist for infants who do not pass. Would this be possible in an outsourced model and what are the implications?

Opting-in vs. Opting-out

In most hospitals, newborn hearing screening is a standard of care, meaning that screening occurs prior to discharge unless the family declines. EHDI programs across the nation worked for years to achieve this outcome and many consider it to be a major public health accomplishment. A hospital's decision to hire a contractor to perform newborn hearing screening creates an opt-in versus an opt-out model. That is, instead of newborn hearing screening being provided without separate consent, families are asked during the birth admission, typically at bedside, if they are interested in having this service provided. This raises several important questions. How would screening be presented to families and how would refusals be managed? What stakeholders will be contacted when a family declines (e.g., pediatrician, state EHDI program)? What is the risk to the hospital for babies not screened? Will declines increase because of potential burdens such as additional charges, immigration status, or other concerns families may have?

Choice of Hearing Technology/Instrumentation/Protocols

Many contractors will have preferred equipment and protocols. Larger corporate providers may be committed to using only the instruments they manufacture or those provided by companies with whom they have negotiated a volume discount. Although these arrangements are certainly understandable from a business standpoint, the hospital's choices may be limited for instrumentation, selection of protocols such as a two-step screening with S-OAE followed by S-ABR, or changes in instrumentation as new technology becomes available.

Tracking and Surveillance

Loss-to-follow-up and loss-to-documentation for infants who do not pass the initial hospital-based screening is a major concern throughout the nation (Gaffney, Green, & Gaffney, 2010). Furthermore, some infants pass the screening but have risk factors for later-onset hearing loss. If newborn hearing screening is outsourced, what specific services will the contractor provide and how will they be provided? How will the hospital monitor the accuracy and timeliness of documentation? This is important for internal/legal purposes and to ensure compliance with state EHDI reporting requirements. Many hospitals conduct outpatient rescreening. How will this be handled and how will the hospital ensure optimal tracking and surveillance?

Partnership with the State EHDI Program

There are a number of reasons why a strong alliance, partnership, and ongoing working relationship between the contractor and the state EHDI program is important. Partnering with the state EHDI program helps not only to coordinate follow-up efforts and ensure compliance with state reporting requirements, it also promotes optimal outcomes for babies and families. Alignment with state screening guidelines, best practice recommendations, available resources for families and providers as well as attendance at state stakeholder meetings are essential functions. If newborn hearing screening is outsourced who will monitor these activities and services and how will they be coordinated with the state EHDI program?

Billing and Collection

When the hospital provides newborn hearing screening, the charges are usually bundled with other laboratory tests and services and included in the periodic review of inpatient costs with the payer. If newborn hearing screening is outsourced, families are typically billed separately for newborn hearing screening. This raises an important question. How much will the contractor charge and what happens if there's an unpaid balance? We have observed that a typical charge is around \$250, but we have seen anecdotal reports of newborn hearing screening charges in excess of \$500. Many contractors state that they do not engage in aggressive collection efforts, but if the family is

uncomfortable expressing concern about their charges, they can be faced with a significant financial burden. Incidentally, based on anecdotal parent reports, some contractors do indeed pursue assertive balanced-billing collection. It should also be noted that some states require screening as part of the birth admission, thus precluding a separate bill.

There is another aspect of billing for newborn hearing screening that the authors find perplexing and somewhat paradoxical. Most hospitals do not think of newborn hearing screening as a profitable endeavor and indeed many have expressed concern about the cost of consumables and the staff time required for screening. Yet the same hospitals may be approached by for-profit contractors willing to compete for their business. The explanation for this appears to be related to the billing process and what is allowable for hospitals vs. contractors. Contractors employ their own personnel and own the equipment; this allows them to bill for both a professional fee and a technical component. In contrast, hospitals are only allowed to bill for the technical component. This results in higher reimbursement for contractors for both private insurance and Medicaid.

External Evaluation of the Contractor

Hospitals considering outsourcing must also determine how their contracted services would be monitored and evaluated. Although the contractor may assume responsibility for day-to-day operations, the hospital has ultimate responsibility for ensuring that each infant is appropriately screened and, when indicated, referred for outpatient rescreening or diagnostic assessment. If the hospital elects to outsource the screening program it must determine who will perform the external monitoring and evaluation, what the review will consist of, how often the review will be provided, and the time/costs associated with this activity. If the expertise needed to provide rigorous ongoing review does not exist within the hospital organization, an outside professional well-versed in newborn hearing screening (e.g., a pediatric audiologist) will be needed.

Internal Communication

Some hospitals, especially those in academic medical centers and children's hospitals, have a longstanding investment in early hearing detection and intervention and will prefer to manage the screening program internally at all levels. But apart from the specific activities related to hearing screening, it is important to be mindful of potential concerns elsewhere in the institution related to outsourcing. If outsourcing is being considered, in addition to hospital administrators and nursing staff, it is critically important to include all institutional stakeholders in the discussion. This includes audiologists, pediatricians, otolaryngologists, and other medical providers such as those involved with metabolic screening or other laboratory testing.

Summary

Newborn hearing screening is a complex and multifaceted endeavor with many technical and inter-professional components within and external to the institution (see Appendix). The potential advantages and disadvantages of hiring an outside contractor to provide this service will be determined, in part, by the status of a program prior to outsourcing. If the institutional commitment and resources are in place, many hospitals value the ownership of the newborn screening program and the direct control this enables over selection of protocols and procedures, instrumentation, communication with families, and determination of billing and collection procedures. They also prefer the ability to treat newborn hearing screening as an institutional standard of care that does not require families to opt-in through bedside consent. But not all hospitals are willing, or in some cases, able to make the necessary investment of time and resources. And it must be acknowledged that healthcare is changing, with a growing number of hospitals joining health care systems aimed at achieving cost savings and greater uniformity among system partners.

The authors are neither for nor against outsourcing newborn hearing screening, but we feel strongly that it is not a decision to be taken lightly. Over a period of 15 years our nation progressed from screening fewer than 4% of newborns for hearing loss to more than 96% (White, 2015). This is a remarkable achievement worthy of celebration, but it is important to remember that the percentage of infants screened is a *quantitative* metric. Careful consideration of the issues that define the *quality* of newborn hearing screening is vitally important and must be examined rigorously with a commitment to the highest standards of patient care, not only for the screening itself but for each component of this critical first-step in the EHD process.

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Appendix

Important Questions and Considerations for Hospitals Considering Outsourcing Newborn Hearing Screening

A comprehensive newborn hearing screening (NBHS) program must:

- Ensure coordination, oversight, accountability, sustainability
- Employ policies, procedures, and protocols based on established best practices for screening, tracking, and follow-up (e.g., Joint Committee on Infant Hearing 2007 Position Statement, National Initiatives for Children's Healthcare Quality [NICHQ])
- Apply established benchmarks for quality improvement/quality assurance (QI/QA)
- Employ well-qualified and well-trained screening staff with appropriate continuing education
- Have buy-in from nursery support staff, administrators, stakeholders
- Have good working relationships with providers, audiologists, other stakeholders
- Be closely linked and conducted in accordance with the state EHDI program
- Employ a designated program coordinator/manager to:
 - Monitor and update policies, procedures, and protocols
 - Implement competency-based training to all screening staff
 - Coordinate schedules to ensure full time coverage
 - Ensure accountability for all nursery admissions
 - Monitor equipment, supplies, and maintenance
 - Respond to equipment problems if/when they arise
 - Monitor quality indicators (refer rates, missed rate)
 - Generate and disseminate program reports
 - Serve as a liaison between the hospital and the state EHDI program
 - Monitor compliance with state guidelines and reporting

Key questions for initial hospital-based screening:

- o What screening protocols would be used for well-baby and neonatal intensive care unit (NICU) screening?
- o What is the proposed timing of screenings?
- o How many inpatient screenings will be attempted?
- o Are both ears required to pass during the same screening session?
- o What are protocols for babies with unilateral hearing loss (HL) or external ear anomalies?
- o What screening technology/protocols are proposed?
 - Modality (screening otoacoustic emissions [S-OAE], screening auditory brainstem response [S-ABR], both)?
 - Stimulus level, test parameters, pass/fail criteria
 - Compatibility with state tracking and data management program
- o Special considerations for NICU and high risk infants
 - How would babies be determined eligible (medically stable) for screening?
 - Would chart reviews be conducted to determine risks for late onset HL?
 - Can you be confident of well-coordinated working relationships with NICU staff, neonatologists, and audiologists?
 - Would a pediatric audiologist provide oversight of the NICU screening program?

Documentation of screening results:

- o Are there state and/or facility requirements regarding how, what, and where results are documented (e.g., electronic medical/health record; discharge summary) and if so, how will they be monitored?

Communicating screening results:

- o Who will inform parents/caregivers and answer their questions?
- o How will information be conveyed? (written, oral, both, state brochure)?
- o How will the hospital ensure that information is delivered

accurately and with cultural sensitivity?

For infants who require out-patient rescreening and follow-up:

- o Will outpatient rescreens be provided and if so when/where?
- o What specific procedures will be followed when a baby fails the inpatient screen and needs to be seen for rescreening (e.g., NICHQ recommendations are to schedule rescreening appointment, phone numbers, reminder calls, fax to primary care physician, etc.)
- o What specific procedures will be followed when a baby fails the outpatient screen (e.g., immediate scheduling of follow-up audiology appointments)
- o How will those infants be tracked?

Compliance with institutional guidelines:

- o How will training/compliance be handled for institutional requirements related to HIPAA, universal precautions, medical record access?
- o How will equipment manufacturer's recommendations be implemented and monitored?
- o What are the implications of outsourcing for liability and risk management?

Other Important Considerations:

Opting-In vs. Opting-Out:

- In most hospitals NBHS is a standard of care; this means all infants are screened prior to discharge unless the family declines.
- If NBHS is outsourced, families are asked by the contractor if they want their baby screened for hearing loss.
- How would the screening option be presented to families and how would refusals be managed?
- What is the risk to the hospital for babies not screened?
- Will declines increase because of concerns regarding additional charges, immigration status, etc.?

Choice of hearing technology/instrumentation and protocols:

- Many contractors have preferred equipment/protocols. Will you have choices for screening technology, equipment, and protocols (e.g., two-step OAE+ABR protocol)?

Tracking and Surveillance:

- Loss-to-follow-up and loss-to-documentation are major concerns throughout the nation. Also, some infants pass the screening but have risk factors for later-onset HL.
- If NBHS is outsourced, what specific services related to tracking and surveillance will the contractor provide and how will they be provided?
- How will the hospital ensure that tracking and surveillance are optimal?

Partnership with the state EHDI program:

- A strong partnership, alliance, and ongoing working relationship with the state EHDI program is important. Aligning with state screening guidelines, best practice recommendations, available resources for families and providers, as well as participating in state and regional stakeholder meetings are vitally important activities.
- If the NBHS program is outsourced, how will they be coordinated with the state EHDI program and by whom?

Billing and collection:

- Families will receive a separate bill for NBHS. How much will the contractor charge and what happens if there's an unpaid balance?

Communication within the hospital if outsourcing is under consideration:

- If outsourcing is being considered should it be thoroughly reviewed and discussed with all institutional stakeholders?
 - Audiologists
 - Pediatricians
 - Otolaryngologists
 - Nurses
 - Hospital Administrators
 - Other service providers (e.g., those involved with metabolic screening)

Promoting Early Identification and Intervention for Children Who Are Deaf or Hard of Hearing, Children with Vision Impairment, and Children with DeafBlind Conditions

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Abstract

Children who are deaf or hard of hearing (DHH) with Vision Impairment (VI) have unique needs requiring adaptations to intervention strategies, compared to those strategies used for DHH or VI alone. Based on the National Center on DeafBlindness Census data, 6% of the total number of reported children who are DeafBlind are in the birth through two age range (Part C eligible), and 12% are in the three through five years age range (Part B eligible), suggesting that there may be a gap in identification of children who are DeafBlind within Part C programming.

This work is intended to allow for improved identification of children of hearing loss, vision impairment, and children with both hearing and vision needs (DeafBlind). The authors provide principles to guide evidence-based best practice for Early Intervention providers. Resources for expanding supports for young children who are DeafBlind are also included.

Acronyms: ASHA = American Speech-Language Hearing Association; ASQ = Ages and Stages Questionnaire®; CMV = cytomegalovirus; DeafBlind = children with both hearing and vision needs; DHH = deaf or hard of hearing; DHH Plus = deaf or hard of hearing plus developmental disabilities; EI = Early Intervention; EHDl = Early Hearing Detection and Intervention; IDEA = Individuals with Disabilities Education Act; IEP = Individualized Education Plan; IFSP = Individualized Family Service Plan; INSITE = IN-home Sensory Impaired Training and Education; JCIH = Joint Commission on Infant Hearing; NCDB = National Center on DeafBlindness; O&M = orientation and mobility; VI = vision impairment

Introduction

Children who are deaf or hard of hearing with vision impairment (DeafBlind) have unique needs and require adaptations to intervention strategies, compared to those strategies used for children who are deaf or hard of hearing (DHH) or who have vision impairment (VI) alone. Compared to the general population, there are higher rates of developmental delays in children who are DHH (approximately 40%; Gallaudet Research Institute, 2011; Nikolopoulos, Lioumi, Stamatakis, & O'Donoghue, 2006; Szymanski, Brice, Lam, & Hotto, 2012) and in children with VI (up to 66%; Hatton, Bailey, Burchinal, & Ferrell, 1997; Rahi, Cable, & the British Childhood Visual Impairment Study Group, 2003; Mervis, Boyle, & Yeargin-Allsopp, 2002; Mervis, Yeargin-Allsopp, & Boyle, 2000).

Children who are DHH with developmental disabilities have been described as being "Deaf/HH Plus" to indicate their needs while still keeping a positive developmental perspective for the future (Wiley, St. John, & Lindow-Davies, 2015). The Joint Committee on Infant Hearing (JCIH) published a supplement to their 2007 position statement (JCIH, 2013) focusing on the needs of children who are DHH related to intervention services, and included a tenet on serving children who are DHH Plus.

By the very nature of having a developmental concern, children enrolled within Part C programs (often referred to as Early Intervention [EI] services) are more likely to also have a hearing loss or vision loss. Causes of developmental delay (such as prematurity, congenital infections, and certain genetic syndromes) can confer risk for hearing loss and/or vision loss. Therefore it is important to recognize a co-existing hearing loss or vision impairment, as the combination of hearing loss and vision impairment can impact various domains of development. Hearing loss is commonly attributed to impacting language development while vision impairment is attributed to impacting motor development. EI providers can play a critical role in the identification of hearing and vision difficulties in young children, thus allowing access to needed services and improving child and family outcomes.

Children with both hearing loss and vision impairment (DeafBlind) have needs which further complicate intervention strategies. Children who are DeafBlind benefit from early specialized intervention services. With the term DeafBlind, it is important to recognize that it does not imply full deafness and full blindness, but rather includes children with any degree of hearing loss and any degree of vision impairment impacting educational needs. The Individuals with Disabilities Education Act (IDEA, 2004) specifically defines DeafBlindness as "concomitant hearing and visual

impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness” (U.S. Department of Education, IDEA Part 300/A/300.8D). Unfortunately, the diagnosis of vision or hearing loss, or the recognition that both are occurring, can be delayed due to a number of barriers (Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Chapman, et al., 2011; Mark & Mark, 1999; Williams et al., 2013).

Census data collected by the National Center on DeafBlindness (NCDB, 2014) provides information about this population, and system gaps that may exist. DeafBlindness is a low incidence disability with great variability. In the U.S., there are about 10,000 children (ages birth to 21) with DeafBlindness (NCDB, 2014). For a sub-set of the data ($N = 9,384$) 89% of the children had one or more additional conditions. Among the children with data on age ($N = 9,384$), 6% were in the birth through two age range (Part C eligible), and 12% were within the three through five year age range (Part B eligible). This two-fold increase suggests improved recognition at older ages. There are also conditions which occur in early childhood (such as traumatic brain injury, post-natal infections) that can contribute to new cases of children who are DeafBlind entering the census at older ages. For a sub-set of children ($n = 8,822$) that had data regarding their IDEA Part B Reported Category, only 17% had an educational category of DeafBlind, while 35% were categorized as having multiple disabilities. It may be difficult, however, to interpret this information as processes vary in determination of educational category.

The data from the NCDB (2014) survey is concerning in that all children in the census in fact meet the educational definition of DeafBlind, but are not identified as such in educational settings. This may suggest that educational teams note that other issues are more prominent in guiding the educational planning. It is also concerning that the primary needs related to the dual sensory impairment may be under-recognized using U.S. Department of Education data. Although the census is limited by those who are reported and may have reporting biases (potentially more complex children reported), there is a high rate of issues noted in this population beyond merely hearing and vision.

The field of special education has specific training for educators related to DHH and VI, however, there are not specific training programs for children who are DeafBlind. The IN-home Sensory Impaired Training and Education (INSITE; Ski-Hi Institute) curriculum addresses many tenets helpful in serving children who are DeafBlind. State DeafBlind Projects are agencies that can provide this unique perspective for families and educators (see NCDB State Project List, n.d. for a list of the agencies in each state). Because there are best practices within the field of deaf education and the field of vision impairment, it can be helpful to understand best practices for each educational category separately and then bring the two fields together.

Children who are DeafBlind cannot be simply served by each area of expertise without integration of the learning needs and based on the specific skills and needs of the individual child. In this paper we will review the needs of those with DHH and VI separately and then review the needs when hearing loss and vision impairment co-occur. The goal of this paper is to discuss strategies to decrease the age of identification of hearing and vision impairments of children enrolled in Early Intervention, thus improving access to appropriate interventions to help children meet their potential.

This document includes sections on best practices as well as tools to consider in meaningfully supporting children who are DHH, children with VI, and children who are DeafBlind. We have also included decision trees to improve the identification of children who are DeafBlind to ensure EI providers consider these potential needs for children within Early Intervention services.

Principles Guiding Best Practice

- Recognition is the first step toward accessing specialized services.
- Integration of expertise within the context of services is essential for optimal outcomes for children.
- When transitioning children who are DHH, children with VI, and children who are DeafBlind to Part B programming, it is essential for the EI team to describe the impact of specialized services for the child’s needs which impact the educational setting.
- A strengths-based approach is essential.
- Family-to-Family Support is an important component of family-centered intervention.

There can be state-by-state variability in eligibility services for children who are DHH, children with VI, and for children who are DeafBlind. For the purpose of this document, we will include definitions from the United States Department of Education IDEA Regulations Part 300/A/300.8 (U.S. Department of Education IDEA, n.d) with the recognition that Part C providers should refer to state-specific guidelines.

Deaf or Hard of Hearing Best Practices

Definition

“Deafness” means a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification that adversely affects a child’s educational performance and “Hearing Impairment” means an impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance but that is not included under the definition of deafness in this rule (IDEA, 2004).

Early Identification of Hearing Loss

- Early identification and intervention is associated with

improved language, social-emotional, and academic outcomes (Meinzen-Derr, Wiley, & Choo, 2011; Moeller, 2000; Kennedy et al. 2006; Vehaert, Willems, Van Kerschaver, & Desloovere, 2008; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

- Universal Newborn Hearing Screening programs do not identify all children with hearing loss (due to screening equipment thresholds and the possibility of late-onset or progressive hearing loss). Therefore, a high level of suspicion is important to identify hearing loss in all children (JCIH, 2007). Resources for accessing audiology services include:
 - o State services directories: many state Early Hearing Detection and Intervention (EHDI) programs have state-based pediatric audiology services directories that can be provided by the state EHDI coordinator (<http://infanthearing.org/status/cnhs.php>).
 - o National resource: Early Hearing Detection & Intervention - Pediatric Audiology Links to Services (EHDI-PALS; <http://www.ehdipals.org/>).
- Infants and children of any age or developmental abilities can have their hearing evaluated by audiologists knowledgeable in pediatric hearing.
- A functional listening evaluation is important and can guide intervention services (American Speech-Language Hearing Association [ASHA] Practice Policy, 2006).
- Children with an identified hearing loss should be reported to the state EHDI program at any time during their enrollment in Early Intervention (JCIH, 2007).
- Children who are identified with any type or degree of hearing loss should have their vision evaluated by an ophthalmologist knowledgeable in pediatrics (JCIH, 2007; Figure 3).

Early Intervention for Hearing Loss

Permanent hearing loss of any degree or type should be considered an established condition which automatically implies eligibility for Part C programming (JCIH, 2013), however there is state-to-state variability in eligibility determination. States should provide specialized services and should be included on the Individualized Family Service Plan (IFSP) of all children who are DHH (JCIH, 2013). Best practices for intervention for children who are DHH have been established by the Joint Committee on Infant Hearing (2013).

Vision Impairment Best Practices

Definition

“Visual impairment” including blindness means an impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness (IDEA, 2004).

Early Identification of Vision Impairment

- Recognizing risk factors and visual behaviors in young

children can improve early identification of vision impairment (Taking a Look, n.d.; Figures 1 and 2).

- A child’s ophthalmological report will provide the foundation for understanding the child’s underlying vision concerns (Figure 3). Children with cortical vision impairment have a brain-based reason for their vision difficulties (with a normal eye exam). This sometimes requires a neurologist or ophthalmologist with specific expertise in this type of vision impairment to recognize the vision loss.
- A functional vision assessment is essential and can guide interventions to account for the child’s visual skills (Figure 3).
- Children with vision impairment should have an evaluation of hearing as a hearing loss would impact access to information and alter intervention strategies (Figure 3).

Early Intervention for Visual Impairment

- Vision loss should be considered an established condition that automatically implies eligibility for Part C programming, however there is state-to-state variability in eligibility determination.
- Specialized services are important to guide a child’s programming (U.S. Department of Education, n.d.).
- Although vision services (vision specialists, orientation, and mobility) can be limited in many areas, it is important to link children with service providers closest to the family’s home. School districts may also be aware of services for the family’s geographic location.

DeafBlind Best Practices

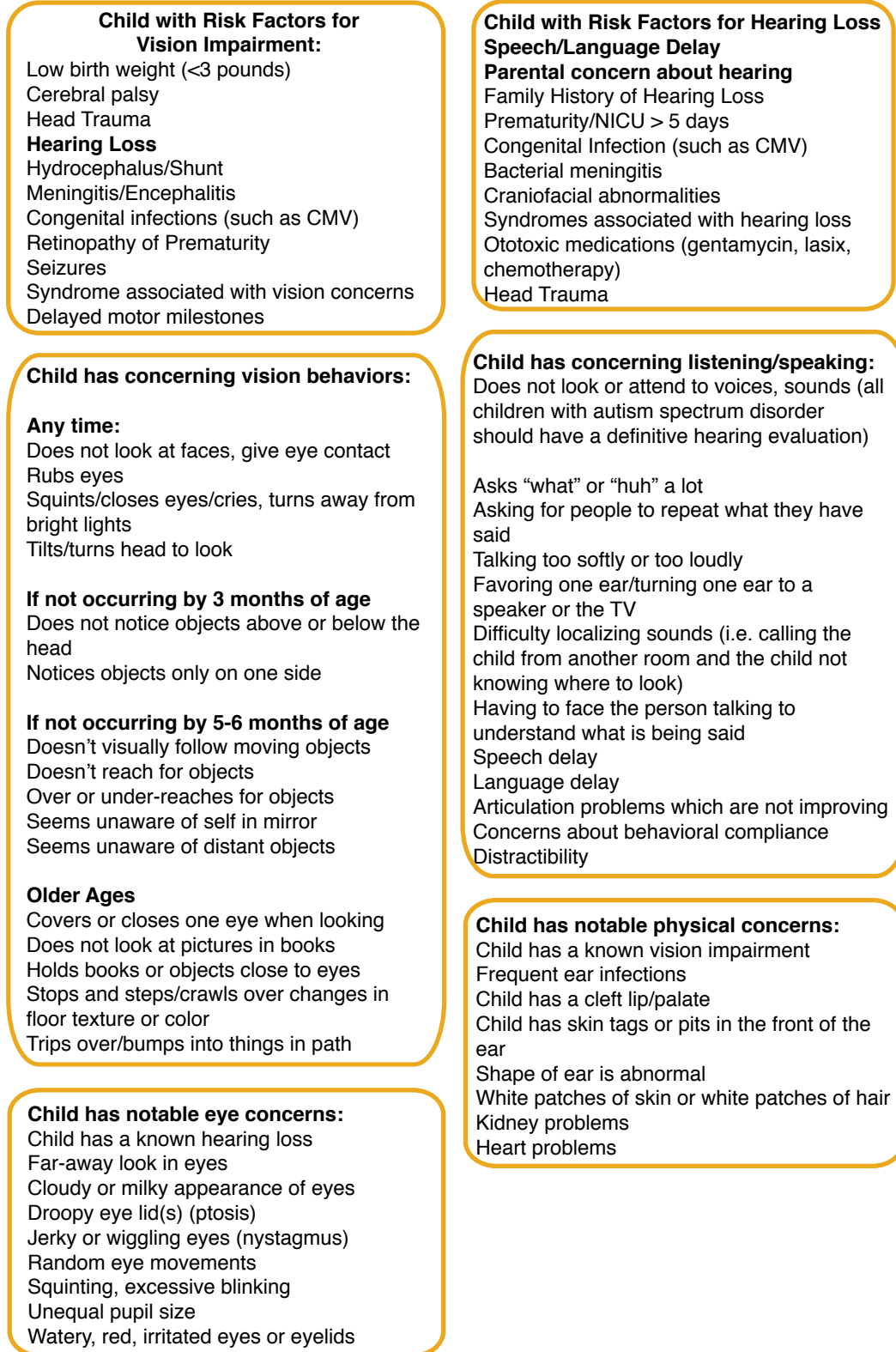
Definition

“DeafBlindness” means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. A child does not have to be totally deaf and totally blind to receive this educational category (IDEA, 2004).

Early Identification of DeafBlindness

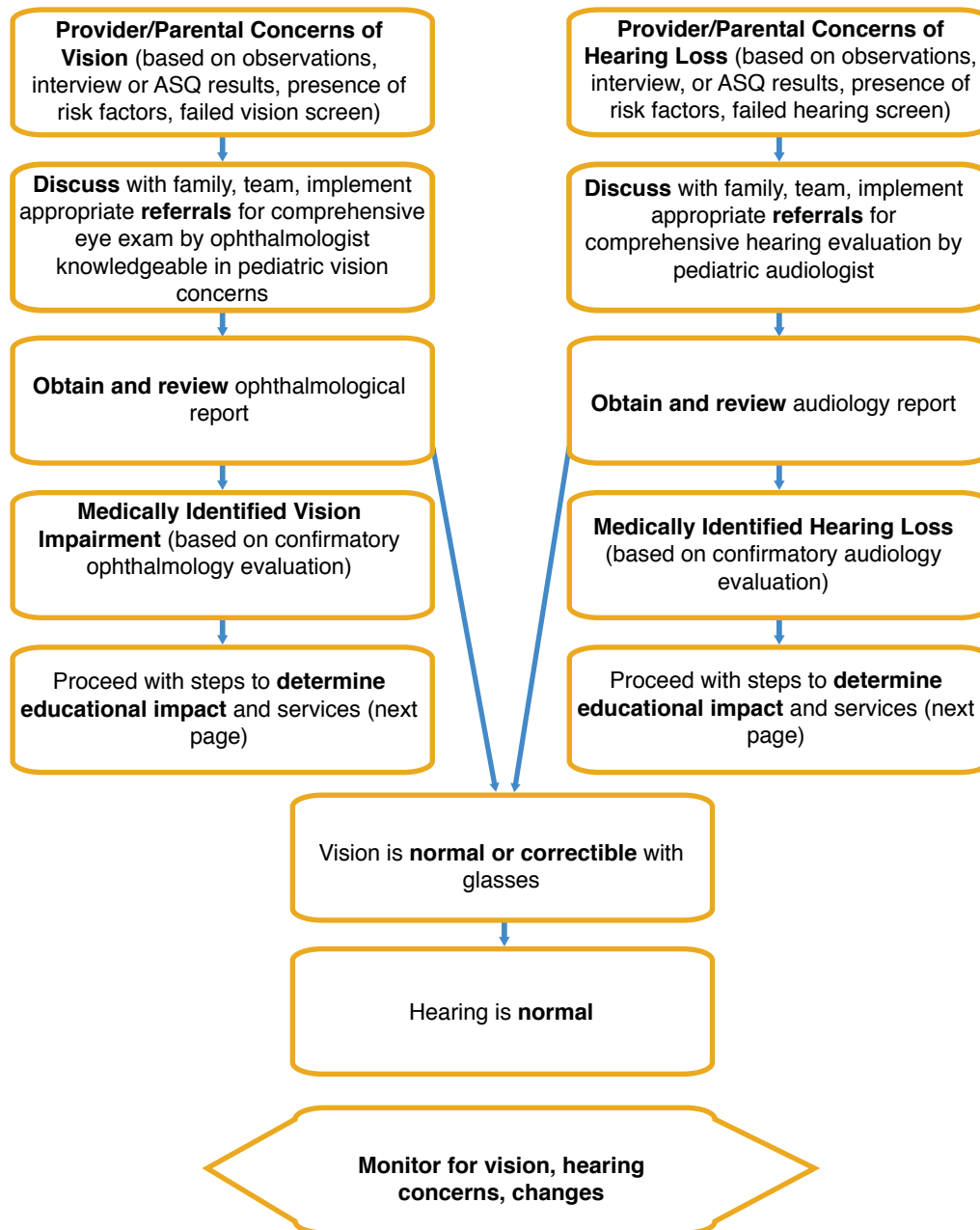
- Early identification of children who are DeafBlind can allow families and intervention specialists to develop appropriate team support for needs and access therapeutic specialists to address both developmental and educational needs (Figures 1 and 2).
- Reporting children who are DeafBlind to the State DeafBlind Centers for Education census (National Center on DeafBlindness, 2014) allows continued national and state support and assistance for children with this low incidence condition as well as provides a mechanism to initiate technical assistance and supports for the families and Early Intervention providers (Figure 3).

Figure 1. Risk Factors and Behaviors Suggesting A Possible Vision and/or Concerns in Young and School-Aged Children.



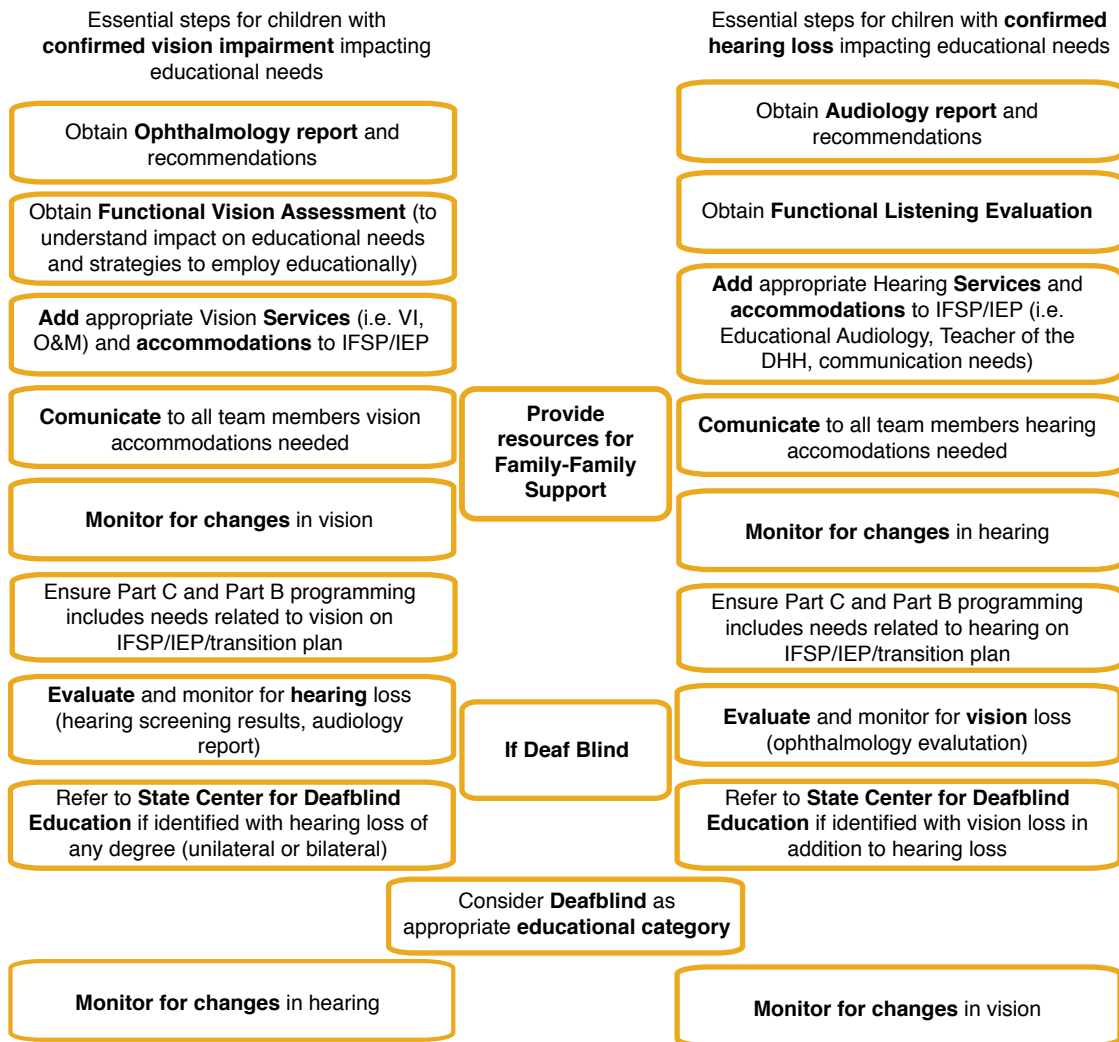
Note. CMV = cytomegalovirus; NICU = neonatal intensive care unit

Figure 2. Next Steps If A Child Has Concerns About Vision or Hearing



Note. ASQ = Ages and Stages Questionnaire©

Figure 3. What To Do For Children with Known Vision Impairment and/or Hearing Loss



Note. IEP = Individualized Education Plan; IFSP = Individualized Family Service Plan; O&M = orientation and mobility; VI = vision impairment

Table 1. Online Resources Relevant to Children who are DeafBlind

Resource	Description	URL
National Center on Deaf-Blindness	National technical assistance center funded by the federal Department of Education. NCDB includes several national initiatives, as well as a diverse library of resources and information for families and professionals. Resources also available in Spanish.	https://nationaldb.org
National Family Association for Deaf-Blind	National association with large network of families focusing on Deaf-Blind issues. Provides opportunities to connect with other families, and well as online learning, resources, and shared stories.	http://nfadb.org/
Center for Parent Information and Resources, Deaf-Blindness	Basic information, and a collection of resources including state specific for deaf-blind children	http://www.parentcenterhub.org/repository/deafblindness/
iCanConnect	Campaign by the National Deaf-Blind Equipment Distribution Program. Provides technology, training, and resources to individuals who qualify.	http://www.icanconnect.org/
Ski-HI Institute IN-home Sensory Impaired Training and Education	Program offering in-home support, as well as a resource manual for families with infants, toddlers and pre-schoolers, age birth to five, with sensory impairments and additional disabilities.	http://skihi.org/INSITE.html
Perkins School for the Blind	School for the blind with expertise in serving children who are DeafBlind, library of webinars and resources.	http://www.perkins.org/
American Foundation for the Blind	Foundation committed to ensuring individuals with vision impairments have equal access and opportunities. Website includes resources, e-learning courses, an online parent community, and advocacy efforts.	http://www.afb.org
Hands and Voices	Parent-driven support organization for families of children with hearing loss, providing unbiased support and information regarding all methods of communication.	www.handsandvoices.org/
Early Hearing Detection & Intervention - Pediatric Audiology Links to Services (EHDI-PALS)	Information, resources, and services directory for finding audiology services for children with hearing loss.	http://ehdipals.org/
Taking a Look Checklist: A First Step in Vision Assessment for Ohio's Infants and Toddlers	A checklist for parents and professionals to help identify children who need referral for possible vision problems.	http://www.helpmegrow.ohio.gov/~media/HelpMeGrow/ASSETS/Files/Professionals%20Gallery/HMG%20Home%20Visiting/HV%20Screening%20Tools/Taking%20a%20look.pdf

Early Intervention for DeafBlindness

- DeafBlindness should be considered an established condition which automatically implies eligibility for Part C programming.
- The integration of specialized hearing and vision services are important to guide a child's programming.
- Accessing technical assistance from the state Deafblind Centers for Education (NCDB state project list, n.d.) can help facilitate a team approach to a child's needs.
- When transitioning to Part B programming children who are DHH, children with VI, and children who are DeafBlind, it is essential for the EI team to describe the impact of specialized services for the child's needs which impact the educational setting (U.S. Department of Education, n.d.).

Resources

Figures 1–3 provide a structure by which EI providers can ensure that children entering Part C services systematically address vision and hearing needs. They provide easy-to-use tools to improve the identification and intervention services for children with hearing and vision needs. By systematically using these tools for children entering Part C systems, EI providers may be more inclined to consider the vision and hearing needs of children served.

Table 1 provides online resources for further information guiding practices for identified children.

Conclusion

Children enrolled in Early Intervention Services benefit from early identification of hearing and vision needs. Hearing and vision impacts child development and identified hearing loss and/or vision impairment requires alterations in how intervention is approached. Building strategies to systematically identify needs and access broader team members to meet a child's specific needs will improve our intervention for children who are DHH, children with VI, and children with DeafBlindness.

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Professional Competence to Promote Resilience for Children Who Are Deaf or Hard of Hearing and Families Living in Poverty

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Abstract

Poverty has a tremendous impact on the educational results of all children, including those who are deaf or hard of hearing. With targeted, evidence-based interventions during the first three years of life, EHDl professionals can assist families in mitigating the negative effects on children's development associated with poverty. Even though EHDl professionals often serve children and families living in poverty, university-based personnel preparation programs for EHDl professionals offer limited instruction and experience in how to best serve children and families living in poverty. The purpose of this article is to explore the degree to which EHDl professionals are prepared to serve children who are deaf or hard of hearing and their families living in poverty and to identify opportunities to improve professional knowledge and skills. A framework is presented and the comments of professionals are offered to improve professional preparation programs and to ultimately enhance services for children and their families.

Acronyms: DHH = deaf or hard of hearing; EHDl = Early Hearing Detection and Intervention; IFSP = Individual Family Service Plan

Introduction

Poverty has a tremendous impact on the educational achievement of all children, including those who are deaf or hard of hearing (DHH). With targeted, evidence-based interventions during the first three years of life, Early Hearing Detection and Intervention (EHDl) professionals can assist families in mitigating the negative effects of poverty on children's development. For the purpose of this paper, we will use the term *EHDl professionals* to refer to those audiologists, speech-language pathologists, teachers of the deaf, and related service providers who serve children ages birth to three. Some, but not all, EHDl professionals provide direct service to children and their caregivers. Some, but not all, EHDl professionals serve children and families who live in poverty. When EHDl professionals enter the workforce with a strong awareness regarding the risks associated with childhood poverty and a variety of effective practices and strategies which can be used to serve this population, then the EHDl system will promote resilience and improve outcomes for young children who are DHH and their families living in poverty.

The paper provides (a) a summary of the current literature outlining the effects of poverty on the development of young children and recommendations for serving children living in poverty including those who are DHH; (b) the results of a survey of EHDl professionals exploring the awareness, preparation, and needs of these professionals related to this topic; and (c) implications and recommendations for effective practice. We also direct readers to a supplemental resource we have written— *Fostering Resilience for Children Living in Poverty: Effective Practices & Resources for EHDl Professionals* (Voss & Lenihan, 2016)— which includes a framework of effective practices and strategies, resources, teaching materials, and further content for professional preparation and development; and can be

accessed at http://www.infantheating.org/issue_briefs/Fostering_resilience_in_children_living_in_poverty.pdf

The Effects of Poverty on Child Development

The earliest years of childhood are a critical period for learning and impact long term cognitive, language, and social outcomes. However, young children living in poverty face increased risk of poor social, emotional, behavioral, and educational outcomes. Recent neurobiological evidence suggests poverty negatively impacts brain development as well (Evans & Schamberg, 2009; Garner et al., 2012; Lipina & Colombo, 2009; Lipina & Posner, 2012; Noble, Houston, Kan, & Sowell, 2012; Rao et al., 2010). By using effective interventions and strategies, EHDl professionals can promote children's resilience and help parents buffer their children from the deleterious effects of poverty. Professional preparation programs at universities and professional development programs offered by organizations, schools, and agencies need to provide content and experiences that facilitate the development of these effective strategies (Amatea, Cholewa, & Mixon, 2012; Gorski, 2013; Hughes, 2010; Voss & Lenihan, 2014). Recent estimates suggest more than 15.8 million American children live in poverty (Jiang, Ekono, & Skinner, 2015a). According to the U.S. Census Bureau, the number of children living in poverty in the U.S. has been on the rise since 2000, increasing by 23% between 2007 and 2013. One baby is born into poverty every 29 seconds. The National Center for Children in Poverty reports that 47% of infants and toddlers (approximately 5.3 million) live in low-income families (Jiang, Ekono, & Skinner, 2015b). The poverty rate in the United States is higher than any other industrialized nation. Young families, those with the primary caregiver under 30 years old, seem to be most vulnerable to poverty, with rates nearing 38% (Children's Defense Fund, 2015; Ratcliffe, 2010; Redd, Sanchez Karver, &

Murphey, 2011).

Families of children with disabilities or health impairments are at additional risk, already facing increased levels of stress and financial costs, as compared to families with typically developing children (Evans & Kim, 2010; Mitchell & Campbell, 2011; Neuman, 2009; Parish, Shattuck, & Rose, 2009; Shahtahmasebi, Emerson, Berridge, & Lancaster, 2011; Walker et al., 2011). According to Park, Turnbull, & Turnbull (2002), “It is becoming increasingly evident that poverty has a tremendous impact on the educational results of all children, including those with disabilities. Thus, poverty is not a secondary topic in the field of special education services and disability policy anymore” (p. 152).

The numerous challenges facing families living in poverty include food insecurity, housing insecurity, health disparities, access to hearing technologies, lack of transportation, increased risk of child maltreatment, and lack of enriching environments and relationships. Children living in poverty may lack appropriate nutrition, access to health care, and experience diminished quantity and quality of caregiver language input and stimulation (Clearfield & Jedd, 2013; Cooper, 2010; Eshbaugh et al., 2011; Garrett-Peters, Mills-Koonce, Zerwas, Cox, & Vernon-Feagans, 2011; Sohr-Preston et al., 2012). Research exploring the intersection of poverty, parenting activities, and the impact on child language development is of particular interest to EHDI professionals. Converging evidence indicates that language is one of the developmental systems most at risk for children in poverty (Fernald, Marchman, & Weisleder, 2013; Hackman & Farah, 2009; Hackman, Farah, & Meaney, 2010). Reviews of behavioral, electrophysiological, and neuroimaging studies suggest that both language and cognitive control are most sensitive to differences in socioeconomic status (Hackman & Farah, 2009; Lipina & Colombo, 2009). A groundbreaking study, conducted by Hart and Risley (1995) explored the language experiences of young children across socioeconomic strata. Compared to children from professional and working-class families, children living in poverty were exposed to 30 million fewer words during the first three years of life and had smaller vocabularies and lower IQ scores at age 3 and later. The study also showed that encouragements, questions, and responsiveness from parents were beneficial for language acquisition. Suskind (2015) applied this research to her work with children using cochlear implants in an effort to improve language acquisition.

Despite the serious threats to development stemming from life in impoverished environments, children are resilient. With targeted, evidence-based interventions during this sensitive time, professionals can support families in minimizing the negative impact of poverty on development. Garner and colleagues (2012) noted, “Protecting young children from adversity is a promising, science-based strategy to address many of the most persistent and costly problems facing contemporary society, including

limited educational achievement, diminished economic productivity, criminality, and disparities in health” (p. e228). The provision of high quality early intervention programs can significantly contribute to improved child outcomes as measured by educational success, workplace productivity, responsible citizenship, and successful parenting of the future generations (Center on the Developing Child, Harvard University, 2007; National Scientific Council on the Developing Child, 2004). Although it may not be possible to provide educational intervention for all risk factors stemming from poverty, researchers, educators, and practitioners can design comprehensive programs and interventions to combat the effects of poverty on development by striving for a model of resilience and promoting positive reaction to adversity (Gorski, 2013; Jensen, 2013; Thomas-Presswood & Presswood, 2007). Voss and Lenihan (2016) have identified six effective practices and associated strategies that EHDI professionals can use to foster resilience and to maximize development of children who are deaf or hard of hearing and live in poverty. These practices include

1. Identify personal bias;
2. Build relationships;
3. Assess family needs;
4. Provide resources and support;
5. Educate families on quality instruction;
6. Increase agency wide awareness.

See Appendix A for strategies associated with these practices.

Research and experience suggest that the most effective strategies and practices for mitigating the deleterious effects of poverty on the development of children who are DHH will include family-centered, interdisciplinary, strengths-based programs (Joint Committee on Infant Hearing [JCIH], 2013). Although much more research is needed regarding the efficacy of specific interventions, key factors to emphasize are that professionals be able to build warm, positive, responsive relationships with young children and families, to create language-rich environments, and to ensure consistent levels of child participation (Center on the Developing Child, Harvard University, 2007; National Scientific Council on the Developing Child, 2004).

The strongest evidence to date addresses the benefits of supporting the caregiver-child relationship (Eshbaugh et al., 2011; Komro, Flay, & Biglan, 2011; Mercy & Saul, 2009; Milteer, Ginsburg, Council on Communications and Media Committee on Psychosocial Aspects of Child and Family Health, & Mulligan, 2012; Phillips & Lowenstein, 2011; Thompson, 2011; Wikeley, Bullock, Muschamp, & Ridge, 2009). Paul Tough (2011) cites the Adverse Childhood Experiences Study as showing that the primary intervention for young children with adverse experiences should include enhancement of supportive relationships among educators, parents, and young children. These enhanced relationships will serve to buffer developing children from the adverse effects of poverty. “Parents and other caregivers who are able to form close, nurturing relationships with their children

can foster resilience in them that protects them from many of the worst effects of a harsh early environment” (Tough, 2012, p. 28).

EHDI professionals can support caregivers in improving their child’s language experience by encouraging increased caregiver responsivity, contingency, joint attention, and frequent syntactically complex and lexically rich child-directed talk (Gilkerson & Richards, 2008; Hoff, 2006; Suskind, 2015). Effective EHDI professionals acknowledge the additional challenges resulting from poverty, recognizing how they might interact and influence family goals and priorities for the child who is DHH (Hamren, Oster, Baumann, Voss, & Berndsen, 2012). Although the scope of practice for many EHDI professionals does not encompass direct service provision, those who are aware of the importance of such interactions can help ensure that children are receiving services from appropriately prepared professionals who can help maximize the child’s development.

Professional Competence of EHDI Providers

EHDI professionals include speech-language pathologists, educators, and audiologists who are working with children who are DHH. Professional organizations including the American Speech Language and Hearing Association, the Council for Education of the Deaf, and the Division of Early Childhood of the Council for Exceptional Children, provide guidance for the curriculum in professional preparation programs in each of these disciplines. The Supplement to the Joint Committee on Infant Hearing Position Statement (2013) also provided recommendations for professional competencies. Although the JCIH document included standards related to socioeconomic status, the standards lacked specificity and the document reported limited research on how professional preparation programs can provide content and experiences to develop the knowledge and skills needed to be effective in working with children and families living in poverty.

Hughes (2010) reported that the limited way in which the topic of poverty is addressed by teacher preparation programs is a disservice to future professionals. Professional preparation programs must develop an awareness of the realities while avoiding stereotyping. Amatea, Cholewa, and Mixon (2012) studied the impact of a university course designed to influence the attitudes of pre-service teachers about how they might work with low-income families. The authors found that “after completing the course, [the pre-service teachers’] attitudes were less stereotypic, they were more confident about using family-centric involvement practices, and conceptualized student’s problems in less blaming terms” (p. 801). Ulluci and Howard (2015) provided anchor questions that teacher educators explored with pre-service teachers to reduce stereotypic perceptions about educating students from impoverished backgrounds. Service learning projects and practicum experiences with low-income children and

families in teacher preparation programs have helped teacher candidates confront their own biases and reframe theories of poverty (Conner, 2010; Dunn-Kenney, 2010).

Eric Jensen (2013) and Paul Gorski (2013), leaders in professional preparation and development who address the challenges that students in poverty face, recommended evidence-based strategies for improving children’s academic outcomes. Content from their work can be aligned with professional development for EHDI professionals. Jensen’s work focused on learner engagement and factors and strategies that impact engagement. Gorski (2013) suggested that effective professional development opportunities related to poverty must focus on teacher efficacy and must be ongoing, nuanced, customized, and context-specific rather than one-time workshops that may increase deficit views of children and families living in poverty. The content needs to be framed positively and recognize professional expertise and commitment.

Professional Preparation and Experience

Although it is clear that poverty affects the family’s ability to access intervention and the outcomes of children, little is known about the degree to which EHDI professionals are knowledgeable about these issues; are aware of resources, strategies, and activities to assist them; and have been prepared to effectively serve children and families who live in poverty. To better understand professional preparation and experience, we collected responses from 121 EHDI professionals. Even though this convenience sample of EHDI professionals is not large, there are important insights about how infants and young children who are DHH and live in poverty can be provided with more effective services. We asked these EHDI professionals to respond to the following questions:

1. What are the current practices (strategies, activities, and resources) you use in working with families of children who are DHH and live in poverty?
2. To what extent did your professional preparation address ways to support families who live in poverty?
3. What are your professional development and learning needs related to serving families who have children who are DHH and live in poverty?
4. What recommendations do you have for professional preparation programs in regard to working with families of children who are DHH and are living in poverty?

To collect responses to the above questions, an email invitation was sent to members of the Association of College Educators of the Deaf/Hard of Hearing listserv, Fontbonne University deaf education and speech-language pathology alumni, Auditory Verbal Therapists Yahoo! Group listserv, and a list of EHDI early intervention providers supplied by the National Center on Hearing Assessment and Management (NCHAM). An invitation was also disseminated in a weekly Alexander Graham Bell Association for the Deaf/Hard of Hearing e-newsletter. The web-based survey was also distributed widely to an

unknown number of users via social media with a message encouraging professionals to forward it to colleagues who were in the target audience. The survey is provided in Appendix B.

The survey responses provided both quantitative and qualitative information. Respondents answered questions about demographic information, familiarity with resources, the extent to which the respondent's professional preparation program addressed support for families, the respondent's attendance and interest in professional development in various areas, and the importance of specific strategies and activities. Finally, open-ended questions requested information about what experiences or assignments had impacted the respondent's ability to serve children and families in poverty and what they wished they had known prior to beginning their career.

Responses were collected from 121 professionals¹ (66 teachers of the deaf [54.5%], 45 speech-language pathologists [37.2%], 12 special educators [9.9%], and 8 audiologists [6.6%]). Of the 121 people, 39 (32.2%) identified themselves as Certified Listening and Spoken Language Specialists™. Professional experience ranged from 1 year (3.4%) to 15 or more years (48.7%), with 61.2% having ten or more years of experience. Sixty-four respondents (52.9%) indicated their current role included providing services for 0-3 year old children. Of those providing services to 0-3 year old children, 46.2% identified their employers as private programs ($n = 30$), 29.2% as public programs ($n = 19$), 33.8% as school settings ($n =$

22), 9.2% as hospital settings ($n = 6$), 16.9% as agencies ($n = 11$), and 16.9% as other ($n = 11$). The respondents serving children through early intervention also identified their model of service delivery as home visiting (66.7%, $n = 44$), center-based individual (60%, $n = 39$), center-based group (32.3%, $n = 21$), tele-intervention (4.62%, $n = 3$) or other (4.62%, $n = 3$) including program administration, university clinic, and other community-based program.

Respondents were asked to indicate their use and familiarity with a list of 20 resources. The five resources most used or referenced were

- AG Bell Knowledge Center (76.1%)
- Early Head Start (45.6%)
- Zero to Three (42.1%)
- Project ASPIRE (28.1%)
- Maternal Infant and Early Childhood Home Visiting (12.6%)

Respondents indicated they were familiar with, but had not used resources from Children's Defense Fund, The Play and Learning Strategies (PALS) and the National Center for Children in Poverty.

Respondents were asked to rate the extent to which their professional preparation programs addressed seven challenges that are encountered by children and families who live in poverty. As seen in Table 1, the two highest rated challenges, were (a) access to hearing technologies (76.3%), and (b) lack of enriching environments (59.7%). More than 80% of the respondents indicated that the

¹ Total responses will not equal 100% because some professionals belong to more than one group.

Table 1. Respondents' Ratings of Professional Preparation and Development Needs

Area	Addressed <i>multiple times or consistently</i> in professional preparation programs	Attended professional development addressing this topic $n = 107$	Desire additional professional development addressing this topic $n = 109$
Food insecurity	12/113 (10.6%)	28 (26.22%)	79 (72.5%)
Housing insecurity	17/113 (15.0%)	27 (25.2%)	82 (75.2%)
Health disparities	30/114 (26.3%)	51 (47.7%)	86 (78.9%)
Access to hearing technology	87/114 (76.3%)	93 (86.9%)	57 (52.3%)
Lack of transportation	20/112 (17.9%)	29 (27.1%)	66 (60.6%)
Increased risk of child maltreatment	34/114 (29.8%)	55 (51.4%)	71 (65.1%)
Lack of enriching environments and relationships	68/114 (59.7%)	84 (78.5%)	75 (68.8%)

challenges associated with lack of transportation, housing insecurity, and food insecurity were infrequently or never addressed in their preparation programs.

Respondents were also asked to identify those areas for which they had attended professional development opportunities or training. The majority indicated they had attended professional development opportunities designed to address the challenges associated with access to hearing technologies (86.9%) and lack of enriching environments and relationships (78.5%). Fewer respondents had attended professional development designed to address challenges associated with increased risk of child maltreatment (51.4%), health disparities (47.7%), lack of transportation (27.1%), food insecurity (26.2%), and housing insecurity (25.2%). The greatest proportion of respondents indicated their desire to seek professional development related to: health disparities (78.9%), housing insecurity (75.2%), and food insecurity (72.5%).

Respondents were also asked to rate the importance of various strategies and activities to support families who live in poverty. To further explore how strategies were being used, we examined the responses by those who were currently working as early intervention (EI) providers ($n = 64$). The EI respondents rated the following strategies as highly important:

- Ask meaningful questions and listen, listen, listen (93%)
- Make families feel comfortable (93%)
- Use language the family understands and explain new terms (93%)
- Instill a sense of confidence and self-worth (92%)
- Recognize priorities may be different than ours (90%)
- Use positive statements about the child and family (90%)
- Comment on child's strengths and development (88%)
- Identify strengths of the family (88%)
- Use daily routines such as mealtime for listening and language development (88%)
- Provide authentic affirmation (87%)
- Implement play activities (86%)
- Recognize and acknowledge the positive aspects of child-caregiver interaction (83%)
- Determine the best time and place to meet with the family based on the family's needs (78%)
- Assess with team members when appropriate (69%)

Strategies listed on the survey that were unfamiliar to a large number of respondents included:

- Host an open house for community agencies that provide services for families (15.3%)
- Identify community resources for food assistance such as the "backpack snack" programs or community garden programs found in many communities (12.1%)
- Use the Individual Family Service Plan (IFSP) team social worker to assist in goals related to food, housing and health (12.1%)
- Obtain gas cards or bus passes from community resources to support transportation needs (11.9%)
- Create a list of food pantry locations and contact

information (10.3%)

- Participate in activities with colleagues to increase agency-wide effective practices such as book study, poverty simulation, and resource simulator (10.3%)

When asked, "Are there other strategies or activities you use to support children and families living in poverty that this survey has not yet listed?" 29 respondents noted specific strategies or activities they had used to support children and families living in poverty. All of the strategies listed in response to this question could be classified in the six effective practices identified by Voss & Lenihan (2016).

There were 59 responses to the question, "When you think back to your university preparation, what were the formative experiences or assignments that had the greatest impact on your ability to serve children and families living in poverty?" Thirty respondents described experiences or assignments that occurred through in-course awareness activities ($n = 16$) including panels, case studies, readings, discussions and simulations; as part of practicum ($n = 12$), or through extracurricular service learning ($n = 2$). The other 29 commenting respondents noted that they recalled no formative experiences or assignments related to serving children and families in poverty as part of their university preparation. Three respondents noted life experiences relative to this topic (e.g., living in an impoverished area, growing up in poverty, serving in the Peace Corps) not specifically part of their university preparation.

There were 53 responses to the question, "What do you wish you would have known about serving children and families living in poverty prior to beginning your career?" These responses focused primarily on four areas. First, many comments addressed the need to learn more about ways to access resources. For example,

- "I wish I knew more resources to offer families in my state and how to access them."
- "Resources....where to start."
- "Information on community resources and how to help families access these resources."

Several comments addressed the need to know more about the impact of poverty on child development.

- "So many times these kids have fallen through the cracks early in life due to poverty issues and have not had appropriate hearing services or intervention. Then they are starting very late and at an even greater disadvantage and the problems become compounded to the point where they are nearly impossible to solve."
- "A family in poverty may have different priorities because they are trying to survive."

Respondents also addressed a desire to understand how poverty impacts the role of the professional:

- "I wish I would have been more forward in speaking out about food and housing insecurity—and insisting that part of all work with families is to respect their fundamental needs for food and shelter as well as supporting their children's growth in all areas."
- "How to empower families and help them advocate for the services they need."
- "How to assess families' needs without it seeming

judgmental or biased.”

- “That it affects everything we do with a family.”
- “How different our priorities can be. If I’d known this, I’d have kept from being so frustrated that it didn’t seem like we were on the same page.”

The fourth area that emerged was that respondents wished they had known more about safety of children and indicators of child maltreatment.

- “[How] to focus on the child and his/her needs...safety... signs of abuse, especially sexual abuse.”
- “How to ensure kids are safe and have access to healthy food when they are out of school.”

Several respondents reiterated the lack of professional preparation related to serving children who live in poverty.

- “Programs should absolutely talk loudly about these issues with practical tasks and strategies provided to address and not just criticize.”
- “Experience and exposure would have been key, but that is almost impossible to provide by the university.”
- “I learned much about minority cultures, but very little about addressing the needs of low SES families.”

Respondents were also asked, “What else would you like to share with investigators exploring the practitioner preparation focused on serving children and families living in poverty?” Responses represented the complexity of the issue of poverty and its impact, as well as the need for additional preparation in these areas. Although some comments addressed concepts mentioned earlier, additional comments contributed uniquely important information. One concept that emerged was the respondents’ emotional response to the topic (e.g., gratitude that a program addressed this topic, frustration, and overwhelming feelings of inadequacy to address this topic). Another concept that emerged was the desire for greater mentoring and support on the job in order to learn how to address the circumstance of poverty (e.g., job shadowing, co-treating, mentoring, working with senior experienced therapist, etc.). A third concept reflected the respondents’ respect and sensitivity toward the families they serve.

- “Often times, the solutions to a situation are limited. . . be realistic about what can and cannot be fixed in a situation. Recognize your role and your limitations. Always be respectful of the family members—no one really knows what the family has been through.”
- “It is clear that this needs to be discussed more at the degree preparation level. It is also important for leadership in medical settings to be aware of needs and discrimination related to poverty. Although my university did a wonderful job preparing us for multicultural and bilingual issues, I cannot recall detailed discussion about serving families in poverty. I wonder if the issue of poverty has (in the past) seemed “too big” and too unfunded to tackle?”
- “This is such an important topic and preparation programs should spend much more time focused on this than they do currently. Poverty doesn’t end when a child turns 3. All pre-service teachers need this information

because poverty impacts students throughout their years in school.”

- “This issue needs to be a “when” you encounter a family....rather than an “if” you encounter a family living in poverty issue. I have seen many homeless families that just want to help their children, but they needed shelter and food before hearing aid batteries. So, I had to locate the resources for all of it—thankfully we had social workers that knew what to do. This is an important issue!”
- “Every family has cultural differences; families living in poverty are not all just ‘one thing,’ but all have different skills and needs.”

Implications for EHDl Professionals

Although the responses from the relatively small number of respondents described above may not be generalizable to all EHDl professionals, they provide some initial information that is valuable for EHDl professionals and those responsible for their preparation. It is clear that most professional preparation programs offer limited instruction and experience in how to best serve children and families who live in poverty. EHDl professionals may learn interventions and strategies for promoting resilience on the job or through professional development activities, but these experiences vary widely.

Respondents also provided important insights that can be used to improve preparation programs. First, while many respondents were able to identify numerous resources they have consulted along with a variety of strategies and activities they use to serve children and families in poverty, some professionals were entirely unfamiliar with many resources, strategies, and activities. Further, the list of practices used in the survey was not exhaustive. There are many more resources available to EHDl professionals which this survey did not explore.

Second, EHDl professionals identified the extent to which their professional preparation programs addressed the challenges facing families who live in poverty. Access to hearing technologies and lack of enriching environments were the highest rated challenges. Further, it is alarming that 40.4% of programs from which these respondents received their training either infrequently or never addressed lack of enriching environments and relationships. Because food and housing insecurity are primary challenges stemming from poverty that directly impact the ability for children and families to access services and intervention support, it is a major concern that professional preparation programs are infrequently or never addressing these topics. More than 80% of the respondents indicated that the challenges of lack of transportation, housing insecurity, and food insecurity were infrequently or never addressed in their preparation programs.

Of concern, 70.2% of respondents indicated that their professional preparation programs infrequently or never addressed the topic of increased risk of child maltreatment.

Although it is possible these programs did address the topic of child maltreatment, they might not have addressed the fact that children living in poverty are at an increased risk. Our concern is that some programs do not address the topic at all. This is especially concerning because all EHDI professionals, independent of discipline, are mandated reporters of child maltreatment, with moral and legal responsibility to recognize and respond to incidences of child maltreatment.

Third, respondents repeatedly indicated they have professional development or general learning needs related to poverty. The top two challenges addressed by professional preparation programs and those professional development topics most often mentioned by our respondents included access to hearing technologies (86.9%) and lack of enriching environments and relationships (78.5%). This is not surprising given the focus on communication development. However, if professional development opportunities are in place to enhance the participants' knowledge or skills, programs might make a greater shift in their professionals' knowledge and skills by addressing topics less frequently addressed and more specific to living in poverty. Although the resources available to those responsible for offering professional development may be limited, they are not entirely absent. Thus, it is critically important that professional development facilitators or program administrators appreciate the impact these learning opportunities can have on improving professionals' knowledge and skills in the area of serving families living in poverty.

Fourth, the EHDI professionals responding to this survey recommended that personnel preparation programs should intentionally address in course work and practical experience how to work with families of children who are DHH and are living in poverty. Respondents also emphasized the power of strong mentoring and ongoing professional development on this topic.

Conclusions

The information collected from EHDI professionals described here is a first step. Additional research with larger, better defined, and more representative samples would be useful to confirm what was reported here. Additionally, interviews and surveys with families living in poverty who have been served by EHDI programs would enable us to examine how families perceive the system, and what is working and not working. It would also be useful to review course syllabi in personnel preparation programs with respect to how issues related to poverty are being addressed in course outcomes and activities. Such an analysis could lead to the development of a tool that could be used to conduct an internal review of course outcomes and activities. A syllabi review, in conjunction with surveys of professionals and families, could identify the gaps in preparation, and opportunities for program improvement, relative to serving children and families living in poverty.

The NCHAM Issue Brief, *Fostering Resilience for Children Living in Poverty: Effective Practices & Resources for EHDI Professionals* (Voss and Lenihan, 2016), provides definitions and data on poverty, and a description of the issues including research, trends, and the impact on child development. This document offers a framework of effective practices and strategies, a description of family influences that professionals can impact and a list of exemplary programs including awareness and advocacy activities, home visiting, and family support. Finally, this document provides guidance for faculty and program administrators to develop course and professional development content through case studies, questions for reflections, group discussion prompts, visuals, and a multimedia presentation related to how services are best provided to families and children who are DHH and living in poverty. This document is most effective when used in conjunction with other resources such as Jensen (2009, 2013), Gorski (2013), Neuman (2009), and Suskind (2015).

In sum, the practices that promote resilience for children and families living in poverty are the same practices that will support and enhance development for all children. However, it cannot be overstated that when considering a vulnerable population of children, as those are who live in impoverished environments, it is of critical importance to use effective practices that may be uniquely needed by this population. More research is necessary so that professional preparation programs have evidence-based strategies and activities to thoroughly address this topic through course work and practical experiences. Only when EHDI professionals enter the workforce with a strong awareness regarding the risks associated with childhood poverty and a variety of effective practices and strategies will we promote resilience and improve outcomes for young children who are DHH and their families living in poverty.

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Appendix A.

A Framework of Effective Practices and Strategies to Promote Resilience

1. Identify Personal Bias

- Reflect on our experiences, values, and attitudes related to poverty.
- Read articles and explore websites about poverty.
- Be present, non-judgmental, and selfless.



- Find the strengths in each family.
- Recognize priorities may be different than ours.
- Watch, listen, learn.
- Hold high expectations for achievement.

2. Build Relationships

• Parent-Professional

- Use positive statements about the child and family—be specific.
- Instill a sense of confidence and self-worth.
- Provide feedback and authentic affirmation to make families feel comfortable.
- Use language the family understands and explain new terms.
- Talk with caregivers about their lives to know what their tangible and intangible contributions can be.
- Support families in determining what they can and want to contribute.
- Ask meaningful questions and listen, listen, listen.

• Parent-Child

- Recognize and acknowledge the positive aspects of child-caregiver interaction.
- Note appropriate attachment between child and caregiver.
- Comment on child's strengths and development.
- Provide resources for caregivers to develop positive relationship with child—print, online, and community resources.

3. Assess Family Needs

- Identify strengths of the family.
- Assess with team members, when appropriate.
- Determine type of poverty experienced by the family—financial, emotional, mental, physical, support systems, role models.
- Consider Maslow's Hierarchy of Needs in recognizing family priorities.
- Determine the best time and place to meet with the family based on the family's needs.
- Observe trends in communication access; keep previous contact information and extended family contacts.
- Use a written agreement that discusses roles and responsibilities of early intervention provider and family.
- Guide families in documenting appointments and sessions.

4. Provide Resources and Support

• Listening Technology

- Seek funding to provide free hearing screenings to childcare programs in neighborhoods with limited resources.
- Find pediatric audiology programs that provide services at low or no cost.
- Seek funding to provide hearing aid batteries at low or no cost.

• Access to Services

- Obtain gas cards or bus passes from community resources to support transportation needs
- Assist in arranging medical transportation for audiology services
- Host an open house for community agencies that provide services for families

- Meet with the family at the local public library to encourage use of the library for literacy
- Create a list of medical clinics that provide free or reduced cost services
- **Food, Housing, Health**
 - Identify community resources for food assistance such as the “backpack snack” programs or community garden programs found in many communities
 - Explore governmental agencies at the state and local level that may provide support such as Supplemental Security Income, Medicaid and the U.S. Department of Health and Human Services/Regional Centers
 - Develop collaborative relationships with social workers and social service programs in the community
 - Use appropriate snack activities during sessions to encourage the use of healthy snacks
 - Create a list of food pantry locations and contact information
 - Use the Individual Family Service Plan team social worker to assist in goals related to food, housing, and health
 - Be aware of religious organizations in the community that the families may connect with for support
- **Keep everyone safe**
 - Discuss safety concerns as related to scheduling of time and place of family sessions, lead paint poisoning, and access to outdoor play
 - Protect children from child abuse and neglect by providing resources and support and by using Johnson’s Observe Understand & Respond: The OUR Children’s Safety Project



5. Increase Awareness and Advocate

• Agency-wide

- Participate in activities with colleagues to increase agency-wide effective practices such as book study, poverty simulation, and resource simulator.

• Community-wide

- Be aware of legislative initiatives that could provide support for children living in poverty and advocate with governmental leaders for the implementation of such policies.

6. Educate Families on Quality Instruction

- Identify quality instruction within the intervention program
- Use relevant, authentic, and multi-cultural activities and materials
- Implement play activities recommended by American Academy of Pediatrics (AAP) and Play and Learning Strategies (PALS)
- Avoid bringing toys and equipment that the family wouldn’t typically have in their home
- Teach families how to create activities out of materials in their home such as building towers, cards and puppet theaters from cereal boxes, or using towels, sheets, clothes pins, toilet paper tubes etc. for dramatic play
- Use daily routines such as mealtime for listening and language development
- Bring materials for an art project and leave some materials behind so that families can use the materials to recreate or extend the activity
- Sing songs, recite rhymes, and participate in movement and fingerplays
- Encourage caregivers to teach you the songs they use or remember from their childhood
- Provide written descriptions of activities you use in your session to encourage repetition
- Establish family support groups for parent-to-parent interaction and learning
- Support families in selecting quality childcare by using resources such as Childcare Aware (<http://www.naccrra.org/> or www.childcareaware.org/)
- Teach families about the characteristics of quality early childhood education.



Appendix B.

2015 Survey of EHDl Professionals



Serving Children and Families Living in Poverty: Perspectives on Provider Preparedness

Serving Children and Families Living in Poverty – Perspectives on Provider Preparedness

You are invited to participate in a research study being conducted by investigators from Fontbonne University. Please consider completing this survey investigating perspectives on serving children and families living in poverty. Investigators are exploring pre-service preparation, in-service support, and overall attention towards the service delivery for a population of learners living in poverty. By doing so, you'll be contributing knowledge to the field on how to best prepare future professionals.

The survey should take approximately 15 minutes to complete.

Taking part in this research study is completely voluntary. If you do not wish to participate in this study, simply delete this invitation or disregard this link. Should you choose to participate, by submitting the survey, you are consenting to the use of your responses in this study. You may choose to drop out at any time by exiting out of the survey browser. We will not collect your name or personally identifying information about you. It will not be possible to link you to your responses on the survey.

To take the survey, click next to begin.

Feel free to forward this invitation and web-link to other professional colleagues who may be eligible to participate. If you have any questions about the research study please contact Dr. Jenna Voss (jvoss@fontbonne.edu) or Dr. Susan Lenihan (slenihan@fontbonne.edu) at 314.889.1407. If you have questions about the rights of research participants, please contact the Institutional Review Board for the Protection of Human Subjects in Research, Office of the Vice President for Academic Affairs, 202 Ryan Hall, Fontbonne University, 6800 Wydown Boulevard, St. Louis, MO 63105.

Thank you very much for your participation.

Next

1. I have ___ years of experience in my profession.

2. My profession is (Check all that apply):

- Teacher of the Deaf
- Audiologist
- Speech Language Pathologist
- Special Educator
- Certified LSL Specialist
- Other (please specify)

3. My employer is characterized as (Check all that apply):

- Private
- Public
- School
- Hospital
- Agency
- Other (please specify)

4. My service delivery model can be described as (Check all that apply):

- Home Visiting
- Center based: Individual
- Center based: Group
- Other (please specify)

5. My degree and area of study relevant to my current role (e.g., MA Early Intervention in Deaf Education):

6. Note - your response to this prompt is optional.
My professional preparation program (e.g., university) was:

Next

7. Does your current role include providing early intervention services for children who are deaf/hard of hearing, ages birth through three (Part C)?

Yes

No

If no, please describe your current role.

8. Is your employer identified by the federal government as a high need district?

9. Do you currently have children living in poverty on your caseload?

Next

10. Are you familiar with the following resources?

	Unfamiliar	Familiar, but have not used it	Familiar and have used, reference, or consulted it.
National Center for Children in Poverty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Children's Defense Fund	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Center on the Developing Child at Harvard University	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Promise Neighborhoods- Creating Nurturing Environments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early Head Start (EHS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frank Porter Graham Child Development Center Abecedarian Project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Save the Children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Maternal Infant and Early Childhood Home Visiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse Family Partnership- and the Child FIRST Program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Children's Learning Institute	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Plan and Learning Strategies (PALS) curriculum	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comer School Development Program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing the Odds for Children at Risk: Seven Essential Principles of Education Programs that Break the Cycle of Poverty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
AG Bell Listening and Spoken Language Knowledge Center	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Project ASPIRE (Achieving Superior Parental Involvement for Rehabilitative Excellence)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Food Research and Action Center (FRAC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Zero to Three	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Urban Institute	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Observe, Understand and Respond: The O.U.R Children's Safety Project - Hands and Voices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child Welfare Information Gateway	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

11. Please rate the following: My professional preparation program addressed how to support families in the following areas:

	Not at all	Infrequently	Multiple Times	Consistently
<i>Food Insecurity</i> - as defined as lack of dependable access to enough food for healthy living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Housing Insecurity</i> - as defined as a range of circumstances, including but not limited to: multiple families sharing single family dwellings, lower quality homes, temporary housing, and use of extended stay hotels as primary residence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Health Disparities</i> - as defined as differences in which disadvantaged social groups systematically experience worse health or greater health risks than more advantaged social groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Access to hearing technologies</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Lack of transportation</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Increased risk of child maltreatment</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Lack of enriching environments and relationships</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

12. In my career I have attended professional development that addressed how to support families in the following areas (Check all that apply):

- Food insecurity* - as defined as lack of dependable access to enough food for healthy living
- Housing insecurity* - as defined as a range of circumstances including but not limited to: multiple families sharing single family dwellings, lower quality homes, temporary housing, and use of extended stay hotels as primary residence
- Health disparities* - as defined as differences in which disadvantaged social groups systematically experience worse health or greater health risks than more advantaged social groups
- Access to hearing technologies*
- Lack of transportation*
- Increased risk to child maltreatment*
- Lack of enriching environments and relationships*

13. I would like additional professional development in the following areas (Check all that apply):

- Food insecurity* - as defined as lack of dependable access to enough food for healthy living
- Housing insecurity* - as defined as a range of circumstances including but not limited to: multiple families sharing single family dwellings, lower quality homes, temporary housing, and use of extended stay hotels as primary residence
- Health disparities* - as defined as differences in which disadvantaged social groups systematically experience worse health or greater health risks than more advantaged social groups
- Access to hearing technologies*
- Lack of transportation*
- Increased risk to child maltreatment*
- Lack of enriching environments and relationships*

Next

14. Rate your knowledge of the following categories of effective practices and strategies as related to serving children and families living in poverty:

	Unfamiliar	Familiar, but have not used it	Familiar and I have used/referenced
Identify Personal Bias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Build Relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access Family Needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Document What Works	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep Everyone Safe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide Resources and Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educate Families on Quality Instruction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Increase Awareness and Advocate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. Rate (between 1 and 5) the importance of using these strategies or activities to support families living in poverty: (Note* after you've rated these strategies/activities, you will have an opportunity to comment).

	1- Not Important	2	3	4	5- Extremely Important	N/A - This is unfamiliar to me
Reflect on personal experiences, values and attitudes related to poverty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read articles and explore websites about poverty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognize priorities may be different than ours	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hold high expectations for achievement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use positive statements about the child and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Instill a sense of confidence and self-worth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide authentic affirmation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make families feel comfortable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

Next

16. CONTINUED: Rate (between 1 and 5) the importance of using these strategies or activities to support families living in poverty: (Note* after you've rated these strategies/activities, you will have an opportunity to comment).

	1- Not Important	2	3	4	5- Extremely Important	N/A - This is unfamiliar to me
Note appropriate attachment between child and caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognize and acknowledge the positive aspects of child-caregiver interaction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use language the family understands and explain new terms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide resources for caregivers to develop positive relationships with child - print, online and community resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identify strengths of the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talk with caregivers about their lives to know what their tangible and intangible contributions can be	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ask meaningful questions and listen, listen, listen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comment on child's strengths and development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

Next

17. CONTINUED: Rate (between 1 and 5) the importance of using these strategies or activities to support families living in poverty: (Note* after you've rated these strategies/activities, you will have an opportunity to comment).

	1- Not Important	2	3	4	5- Extremely Important	N/A - This is unfamiliar to me
Guide families in documenting appointments and sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep previous contact information and extended family contacts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use a written agreement that discusses roles and responsibilities of early intervention provider and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess with team members when appropriate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consider Maslow's Hierarchy of Needs in recognizing family priorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discuss safety concerns as related to scheduling of time and place of family sessions, lead paint poisoning and access to outdoor play	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Determine type of poverty experienced by the family - financial, emotional, mental, physical, support systems, role models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Determine the best time and place to meet with the family based on the family's needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

Next

18. CONTINUED: Rate (between 1 and 5) the importance of using these strategies or activities to support families living in poverty: (Note* after you've rated these strategies/activities, you will have an opportunity to comment).

	1- Not Important	2	3	4	5- Extremely Important	N/A - This is unfamiliar to me
Find pediatric audiology programs that provide services at low or no cost	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assist in arranging medical transportation for audiology services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Create a list of medical clinics that provide free or reduced cost services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obtain gas cards or bus passes from community resources to support transportation needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meet with the family at the local public library to encourage use of the library for literacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protect children from child abuse and neglect by providing resources and support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Host an open house for community agencies that provide services for families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seek funding to provide hearing aid batteries at low or no cost	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

Next

19. CONTINUED: Rate (between 1 and 5) the importance of using these strategies or activities to support families living in poverty: (Note* after you've rated these strategies/activities, you will have an opportunity to comment).

	1- Not Important	2	3	4	5- Extremely Important	N/A - This is unfamiliar to me
Use the IFSP team social worker to assist in goals related to food, housing and health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use relevant, authentic and multi-cultural activities and materials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Create a list of food pantry locations and contact information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identify community resources for food assistance such as the "backpack snack" programs or community garden programs found in many communities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Develop collaborative relationships with social workers and social service programs in the community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be aware of religious organizations in the community that the families may connect with for support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Explore governmental agencies at the state and local level that may provide support such as SSI, Medicaid and DHHS/Regional Centers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use appropriate snack activities during sessions to encourage the use of healthy snacks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

Next

20. CONTINUED: Rate (between 1 and 5) the importance of using these strategies or activities to support families living in poverty: (Note* after you've rated these strategies/activities, you will have an opportunity to comment).

	1- Not Important	2	3	4	5- Extremely Important	N/A - This is unfamiliar to me
Be aware of legislative initiatives that could provide support for children living in poverty and advocate with governmental leaders for the implementation of such policies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teach families about the characteristics of quality early childhood education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participate in activities with colleagues to increase agency-wide effective practices such as book study, poverty simulation and resource simulator	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sing songs, recite rhymes, and participate in movement and fingerplays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support families in selecting quality childcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support families in selecting quality childcare 1 - Not Important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide written descriptions of activities you use in your session to encourage repetition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establish family support groups for parent-to-parent interaction and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Implement play activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avoid bringing toys and equipment that the family wouldn't typically have in their home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bring materials for an art project and leave some materials behind so that families can use the materials to recreate or extend the activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teach families how to create activities out of materials in their home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use daily routines such as mealtime for listening and language development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

Next

21. Are there other strategies or activities you use to support children and families living in poverty that this survey has not yet listed? If so, please list them here.

22. When you think back to your university preparation, what were the formative experiences or assignments that had the greatest impact on your ability to serve children and families living in poverty?

23. What do you wish you would have known about serving children and families living in poverty prior to beginning your career?

24. What else would you like to share with investigators exploring the practitioner preparation focused on serving children and families living in poverty?

Thank you for taking the time to complete this survey. Your responses are valued and will contribute to our understanding of professional preparation related to serving children and families living in poverty.

WIC Participation as a Risk Factor for Loss to Follow-Up in the Wisconsin EHD System

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Abstract

In 2011, Wisconsin's Early Hearing Detection and Intervention (EHD) program, Wisconsin Sound Beginnings (WSB), developed multiple strategies to reduce loss to follow-up (LTFU) for babies who did not pass their newborn hearing screening: Medical Outreach, Family Outreach, Regional Outreach, and WIC Alert. WSB evaluated the outcomes of babies identified as at-risk for LTFU to determine whether WIC participation was an indicator of their risk for LTFU. Additionally, WSB evaluated whether babies who were identified as at-risk for LTFU and receiving WIC services in two WIC projects serving areas and populations with known health disparities, were at even greater risk for LTFU. WSB found no statistically significant differences in outcomes between babies who were WIC participants and those who were not. This paper discusses implications of this research for other EHD programs.

Acronyms: ABR = Auditory Brainstem Response; CDC = Centers for Disease Control and Prevention; DRDC = Disability Research and Dissemination Center; EHD = Early Hearing Detection and Intervention; GLITC = Great Lakes Inter-Tribal Council; LTFU = loss/lost to follow-up; MOU = Memorandum of Understanding; OAE = Otoacoustic Emission; SES = socioeconomic status, UCEDD = University Center for Excellence in Developmental Disabilities; WE-TRAC = Wisconsin EHD Tracking, Referral and Coordination; WIC = Special Supplemental Nutrition Program for Women, Infants, and Children; WSB = Wisconsin Sound Beginnings

Background

Early Hearing Detection and Intervention (EHD) programs work to ensure babies are screened for hearing loss and receive timely follow-up and intervention. After a baby receives a non-passing hearing screening at the hospital, follow-up hinges on many factors. Understanding what characteristics may indicate that a family is less likely to respond to follow-up attempts, and therefore less likely to receive needed services, may help EHD programs best direct their outreach to ensure babies receive the EHD follow-up care they need. Research on risk factors for healthcare utilization and health outcomes has shown that low socio-economic status, low maternal education, geography, and race/ethnicity are related to lower healthcare utilization and poorer health outcomes (Boss, Niparko, Gaskin, & Levinson, 2011; Call, McAlpine, Johnson, Beebe, McRae, & Song, 2006; Centers for Disease Control and Prevention [CDC], 2009, 2013; Lu & Halfon, 2003; Smith & Boss, 2010). However, healthcare providers and EHD programs have varying degrees of access to information related to these social determinants of health. Identifying which, if any, of these social determinants of health might be risk factors that could be appropriately relied upon to help focus follow-up strategies is important. One possible factor is a family's participation in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). The program has low-income eligibility requirements, which might make WIC participation an adequate proxy for other established risk factors for

low healthcare utilization. Nationally, the question being considered is whether collaboration between EHD programs and WIC programs is effective in reducing loss to follow-up (LTFU) for newborn hearing screening. No studies known to these authors have shown whether WIC participation may relate to EHD LTFU.

Wisconsin Sound Beginnings (WSB) is Wisconsin's EHD program, ensuring all babies born in Wisconsin are screened for hearing loss, receive timely diagnosis, and access quality early intervention. When designing its LTFU prevention outreach strategies, WSB wanted to focus its efforts on families with lower socioeconomic status, lower maternal education, underserved geographic areas or members of a racial or ethnic group with known systemic barriers to positive birth and health outcomes. However, WSB did not have access to this type of baby- or family-specific information when designing its LTFU prevention strategies. Participation in the WIC program was suggested by a Wisconsin EHD quality improvement learning collaborative in 2010 as a way to identify families with potentially lower maternal education and household income. WIC programs provide nutrition education, breastfeeding education and support, supplemental nutritious foods, and referrals to other health and nutrition services for children and families (National WIC Association, 2014, 2015). Wisconsin WIC services are provided throughout the state via more than 200 clinic sites, managed by 70 local WIC Projects, the majority of which are run by the local County (see Figure 1). Similar to other

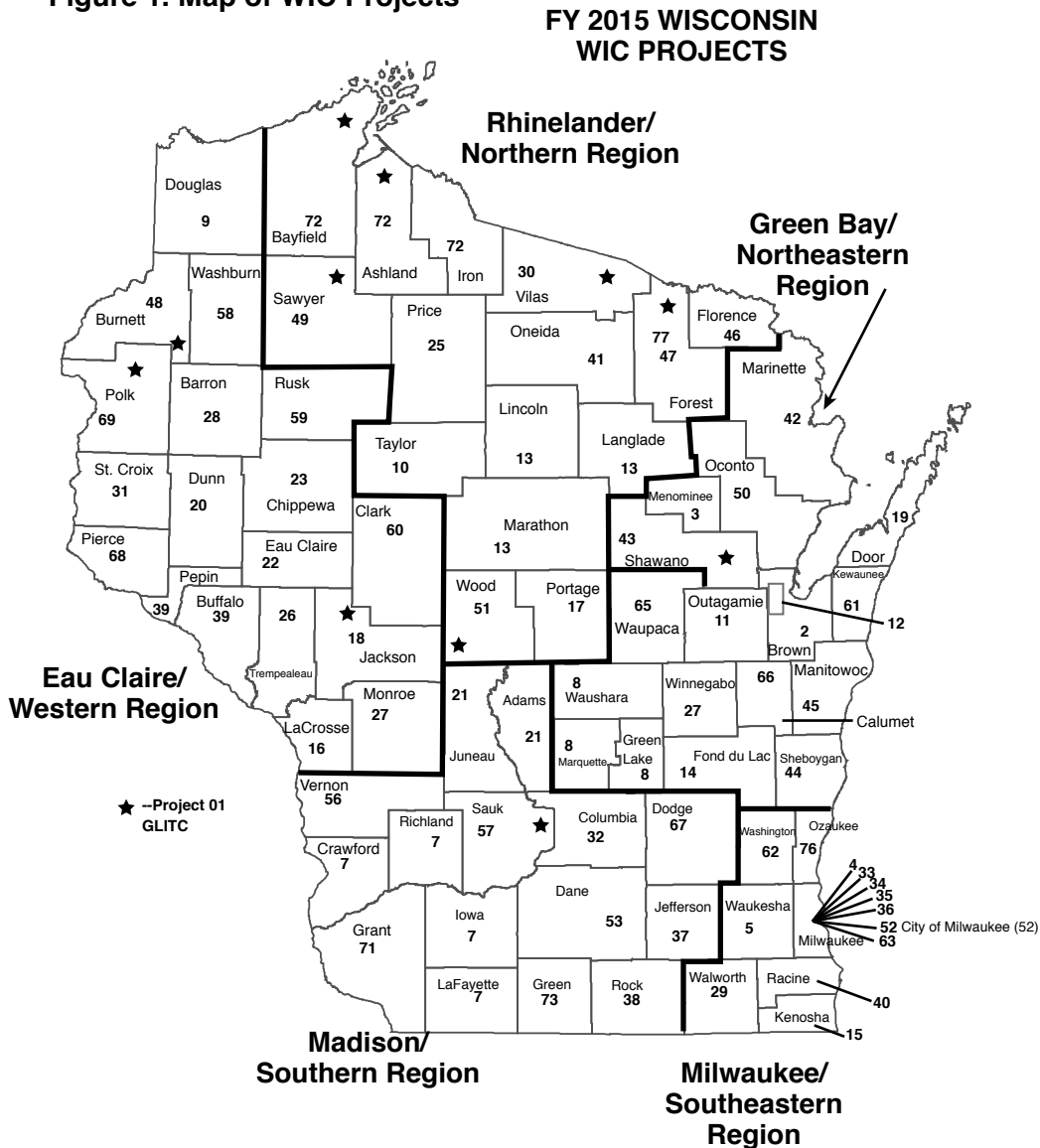
states, approximately 50% of babies born in Wisconsin are eligible for WIC (United States Department of Agriculture, Food, and Nutrition Services, 2015).

Local experts in the learning collaborative believed that potentially a disproportionate percentage of babies who did not pass their hearing screening and did not receive follow-up would also be WIC participants and that collaboration with WIC could help reduce LTFU. Additionally, they considered that a combination of geographic, racial/ethnic, and socioeconomic characteristics, plus WIC participation, could indicate an infant was at even greater risk for LTFU. Learning collaborative members suggested that (a) families receiving WIC services from a Great Lakes Inter-Tribal Council WIC site, which serves Native American families living in rural, resource-limited areas of the state; and (b) families receiving WIC services from a City of Milwaukee WIC site, which serves primarily African American and Hispanic families living in a populated, urban part of the state, would be at the greatest risk for LTFU. WSB and Wisconsin's WIC program developed

and signed a Memorandum of Understanding (MOU) in 2011, giving WSB staff access to WIC's statewide data system, permission for child-specific data to be shared, and communication to take place between EHDI and WIC staff. Program evaluation was planned, and later funded by a 2-year research project (see Acknowledgements), to determine if WSB's assumptions about WIC as an indicator of risk for EHDI LTFU were correct. The results of this evaluation would have implications for other states who might wish to investigate whether partnering with their state WIC program would improve EHDI follow-up rates.

Concurrently in 2011, WSB designed and implemented four LTFU prevention strategies aimed at reducing LTFU: (a) Medical Outreach, (b) Family Outreach, (c) Regional Outreach, and (d) WIC Alert. Medical Outreach proved highly effective at resolving 60% of the cases initially identified as at-risk for LTFU. Cases that only required Medical Outreach are not included in the analysis presented in this paper. The group of babies whose cases remained unresolved after Medical Outreach was the

Figure 1. Map of WIC Projects



focus for the additional prevention strategies and is the population for whom the results in this paper are described.

WSB designed the next levels of LTFU prevention strategies around the following assumptions (a) babies identified as at-risk for LTFU and who were WIC participants would be less likely to receive follow-up than babies not in WIC; and (b) babies identified as at-risk for LTFU and WIC participants receiving services in the Great Lakes Inter-Tribal Council (GLITC) and City of Milwaukee WIC would be less likely to receive follow-up than babies not in WIC or babies at other WIC sites.

The following analysis investigates the validity of those assumptions by determining (a) if WIC participants were less likely to have their cases resolved, irrespective of the LTFU prevention strategies they received, and (b) among babies who received Regional Outreach, if GLITC and City of Milwaukee WIC participants were less likely than babies elsewhere to have their case resolved.

Methods

Design

To identify individual babies at-risk for LTFU, WSB used its real-time, web-based data system, WE-TRAC (Wisconsin EHDI Tracking, Referral and Coordination). WE-TRAC enabled WSB to determine if Wisconsin meets the benchmarks established by the Joint Committee on Infant Hearing (JCIH) 1-3-6 guidelines (JCIH, 2000). Babies who did not pass their inpatient screening at the hospital and had not had follow-up documented in WE-TRAC by 30 days of age were deemed “at-risk for LTFU.” In other words, their case had not been resolved through follow-up activities including re-screening by the 1 month JCIH guideline. These unresolved at-risk cases went on to receive one or more of WSB’s LTFU prevention strategies: Medical Outreach, Family Outreach, Regional Outreach, and WIC Alert. For the WIC Alert strategy, WSB used an existing notification/alert function in WIC’s statewide data system to inform local WIC staff that the baby in their care needed EHDI follow-up (see Figures 2 and 3).

All babies with cases identified as unresolved received Medical Outreach (see Figure 4). During Medical Outreach, WSB staff contacted birthing units, audiologists, and primary care providers to determine (a) if there was a documentation error (i.e., the baby had already received follow-up and results needed to be documented in WE-TRAC) or (b) if the baby was actively in the process of receiving follow-up (i.e., had an appointment scheduled). If neither of these two situations were true, WSB determined that the baby’s case required additional LTFU prevention. WSB determined whether the baby was a WIC participant (participation status), and any additional LTFU risk factors identified during Medical Outreach (i.e., barriers to care such as insurance issues, transportation issues, and/or non-working contact information) to determine the next LTFU prevention strategy the case would receive. Babies whose cases were not resolved by Medical Outreach fell into one of three intervention groups (see Table 1).

Group 1 included babies whose cases were not resolved by Medical Outreach alone and who were not WIC participants. After Medical Outreach, these babies typically received Family Outreach. During Family Outreach, WSB contacted the baby’s family to answer any questions about the newborn screening process, provide information, and encourage follow-up. If during Family Outreach, the baby did not go on to actively engage in EHDI follow-up, WSB could not reach the family, or if additional risk factors for LTFU were identified, then the baby’s case received Regional Outreach. Regional Outreach included an in-home or in-community re-screen using either Auditory Brainstem Response (ABR) or Otoacoustic Emission (OAE) equipment.

Group 2 included babies whose cases were not resolved by Medical Outreach alone and participated in WIC, but were enrolled in WIC projects other than GLITC or City of Milwaukee WIC. These cases received the Group 2 WIC Alert Strategy. WSB staff placed the WIC Alert in the baby’s file in the WIC data system. All babies in Group 2 received the WIC Alert strategy and any combination of the other strategies—Family Outreach and/or Regional Outreach—as determined by their identified risk factors (see Figure 4).

Figure 2. Alerts Placed by Group

WIC Alert Group 2	HEARING SCREENING ALERT: Baby did not pass newborn hearing screening and needs follow-up. Give family Hearing Screening Follow-up Letter and review it when you interact w/family.
WIC Alert Group 3	HEARING SCREENING ALERT: Baby did not pass newborn hearing screening. Wisconsin Sound Beginnings can conduct a hearing screen with baby’s next WIC appointment. Call WSB Regional Outreach Specialist 123-555-1234 to coordinate care.
2015 WIC Alert (Groups 2 and 3 receive same Alert)	HEARING SCREENING ALERT: Baby did not pass newborn hearing screening. Call WSB Regional Outreach Specialist 123-555-1234 to coordinate care.

Figure 3. Letter Babies in Group 2 Were to Receive at their WIC Clinic

Dear Parent,

Your baby's newborn hearing screen results indicate that they need an additional hearing test. Don't wait! It is very important that this next test is done immediately!

If you have questions about newborn hearing screening or need help scheduling the follow-up hearing test, ask your baby's doctor or contact the Wisconsin Sound Beginnings Regional Outreach Specialist at 1-123-456-7891. If you have any problem getting to the follow-up test, tell her. She may be able to help!

Babies learn to talk from what they hear. The first years of life are important and hearing is connected with all areas of development. If your child does have an issue with their hearing, there is help. The sooner you find out, the better it is for you and your child.

If you believe that your baby passed the hearing test in both ears, please notify your WIC contact or the Wisconsin Sound Beginnings program directly: toll-free at 1-123-555-1234. The Wisconsin Sound Beginnings Program is responsible for making sure that every baby has completed hearing testing. If you have any questions or concerns please call us at the number listed above or contact us through our website at www.improveehdi.org/wi/feedback.cfm.

Thank you for taking this very important step to help your baby grow and learn.
Sincerely,



Elizabeth Seeliger, Program Director
Wisconsin Sound Beginnings
1 West Wilson Street
Madison, WI 53703

Group 3 included babies whose cases were not resolved by Medical Outreach and were receiving WIC services in a GLITC or City of Milwaukee WIC site. After Medical Outreach, this group received the Group 3 WIC Alert and Regional Outreach, the most intensive level of outreach, due to the assumption that these babies were at greatest risk for LTFU and therefore should receive the most intensive follow-up efforts (see Figure 4).

Data collected for an evaluation study of these intervention strategies were used to test the assumptions underlying the study.

Sample

The current study focused on babies who fell into the following three categories—Group 1, Group 2, or Group 3 during 2011 to 2014. There were 489 babies whose cases were not resolved by Medical Outreach and received additional LTFU prevention strategies. Due to missing data, four of these cases were dropped from the current study, leading to an analytic sample of 485. This included a relatively equal distribution across the study period, with 51 (20.5%) babies who were born in 2011 (study started in mid-2011), 168 (34.6%) babies in 2012, 153 (31.6%) babies in 2013, and 113 (23.3%) babies in 2014. The 485

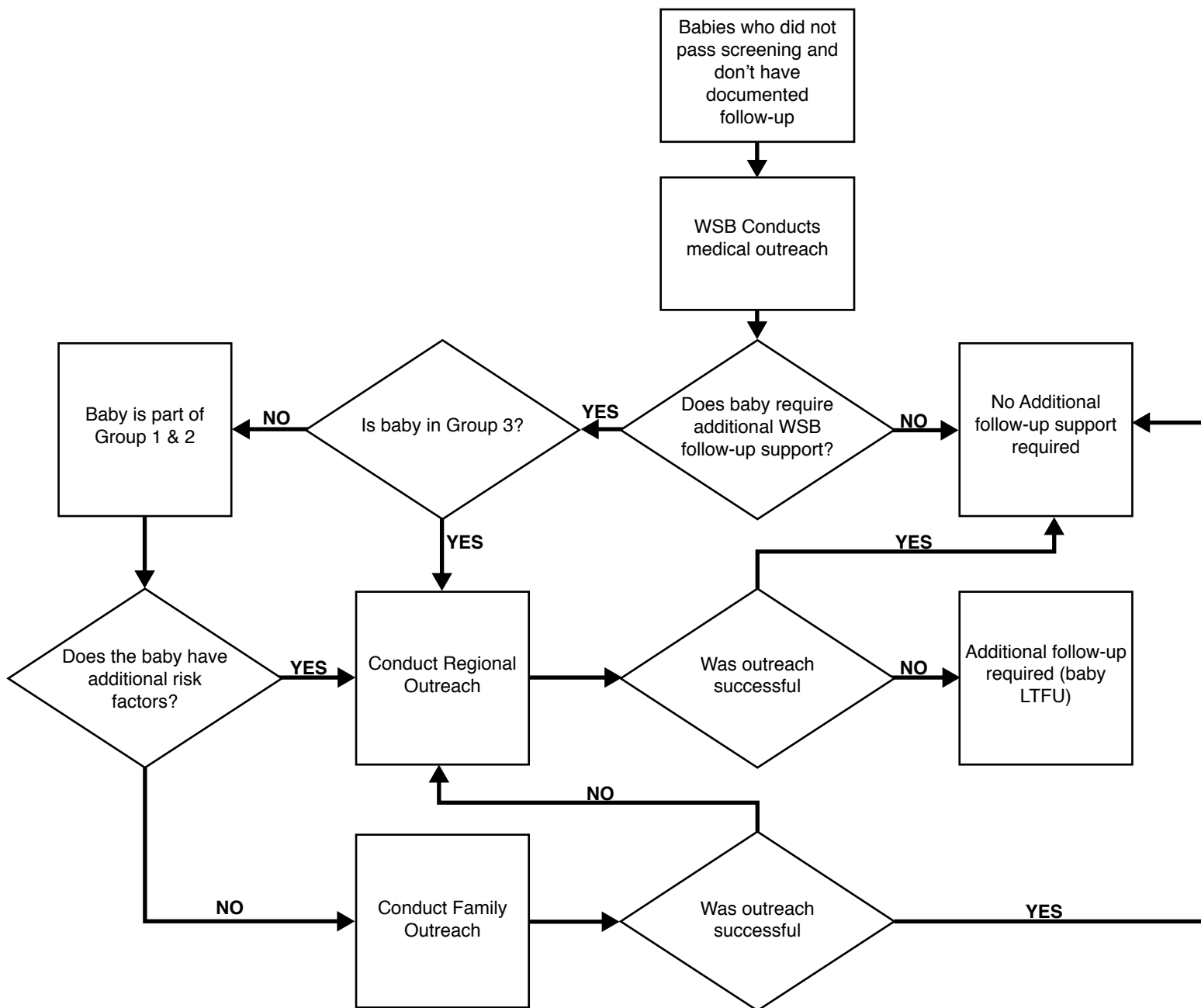
babies were categorized into the three groups, with 262 babies (54%) that fell into Group 1, 189 (39%) in Group 2, and 34 (7%) in Group 3 (see Table 1).

Babies could receive a number of different LTFU prevention strategies. Within the sample of 485 babies, 73% (354/485) received Family Outreach, 46% (223/485) received a WIC Alert (Groups 2 and 3) and 33% (160/485) received Regional Outreach. Furthermore, 59% (286/485) received one intervention, 30% (145/485) received two interventions, and 11% (53/485) received all three interventions. Of the 485 babies receiving LTFU prevention, 79.6% (386/485) had their case resolved (i.e., re-screening, diagnostic audiology services and/or referral to early intervention were completed) and did not become LTFU.

Measures

The dependent variable in this study was Case Resolution. A baby's case was defined as resolved if the baby received follow-up services (i.e., re-screening, diagnostic audiology services, and/or referral to early intervention). The baby's case was defined as LTFU if the baby did not receive follow-up services, regardless of reason.

Figure 4. Work Flow for Babies Identified as At-Risk for LTFU



Note. LTFU = loss to follow-up; WSB = Wisconsin Sound Beginnings.

There were three covariates used in this study. First, study authors created a measure, Intervention Amount, to indicate the amount of WSB-intervention that each case received. The Intervention Amount was defined as the sum of LTFU prevention strategies received (Family Outreach, Regional Outreach, and WIC Alert). Cases could receive between one and three of these strategies. Second, study authors created a variable, Any WIC, to indicate whether the case received WIC services from any of the Group 2 or Group 3 WIC sites. Third, study authors created a variable to indicate whether babies were Group 3 (GLITC or City of Milwaukee WIC), Group 2 (WIC participation in any of the other WIC sites) or Group 1 (no WIC participation) babies.

Analyses

Two sets of analyses, using SAS 9.4 (SAS Institute, Cary NC), were conducted to examine whether WIC participation was a risk indicator for EHDl LTFU. The first set of analyses aimed to answer whether WIC participants were less likely to have their case resolved irrespective of the number of LTFU prevention strategies they received. Study authors conducted a logistic regression analysis in which Case Resolution was regressed on the Any WIC variable and the Intervention Amount variable (Model 1). The authors also analyzed whether Group 3 babies (the group assumed to be at highest risk for LTFU) compared to Group 1 and

Table 1. Description and Distribution of Groups

Group	Description	Distribution
Group 1	Babies whose cases were not resolved by Medical Outreach and were not WIC participants. Received Family Outreach and/or Regional Outreach.	54% (262/485)
Group 2	Babies whose cases were not resolved by Medical Outreach and received WIC services in other WIC sites (not GLITC or City of Milwaukee). Received WIC Alert and Family Outreach and/or Regional Outreach.	39% (189/485)
Group 3	Babies whose cases were not resolved by Medical Outreach and received WIC services in a GLITC or City of Milwaukee WIC site. Received WIC Alert and Regional Outreach.	7% (34/485)

Note. GLITC = Great Lakes Inter-Tribal Council; WIC = Women, Infants, and Children.

2 babies, were less likely to have their case resolved, controlling for the Intervention Amount (Model 2).

The second analysis attempted to understand whether Group 3 babies who received Regional Outreach were less likely to have their case resolved than Group 1 and Group 2 babies who received Regional Outreach. Group 1 and 2 cases that received Regional Outreach included cases that were not resolved by any of the other interventions and would be the best comparison to Group 3 babies who were assumed to need this most intensive intervention from the beginning. If the Group 3 babies were found to be less likely to have their case resolved than the other groups, this might suggest that the assumption WSB made might be correct for babies who were WIC participants in GLITC or Milwaukee WIC projects. To test this, study authors created a subset of the data to only include cases that received Regional Outreach ($n = 161$). Then, study authors conducted a Chi-square analysis to examine differences in Case Resolution rate distributions for two groups—Group 3 babies vs. Group 1 and 2 babies.

Results

Analyses were conducted to determine whether WIC participation was a predictor for a case being LTFU rather than resolved. Specifically, the first set of analyses aimed to answer whether WIC participants were less likely to have their case resolved irrespective of the amount of intervention they received compared to non-WIC participants. Model 1, which compared the likelihood of case resolution between babies who had any WIC participation to babies that did not have WIC participation, controlling for the amount of intervention they received, suggested that WIC participation was not related to case resolution ($p = .07$). Furthermore, Model 2, which compared the likelihood of case resolution between babies that had

GLITC or City of Milwaukee WIC participation to everyone else, controlling for the amount of intervention they received, showed that GLITC and City of Milwaukee WIC participation was not related to case resolution ($p = .31$). See Table 2 for additional details. This suggests that WIC participation may not act as an indicator of risk for LTFU.

The second set of analyses, conducted for cases that received Regional Outreach, investigated whether there were differences in case resolution between GLITC or City of Milwaukee WIC participation (Group 3) and all other babies who received Regional Outreach (Group 1 and Group 2). Among Group 3 babies that received Regional Outreach ($n = 20$), 85% had their case resolved. Among Group 1 and 2 babies that received Regional Outreach ($n = 141$), 68% had their case resolved. Although initially this might look like an important difference, the chi-square analysis revealed that the distributions for case resolution between the groups were not statistically different ($\chi^2 = 2.39, p = .12$). This suggests that even among the most difficult-to-resolve cases, GLITC/City of Milwaukee WIC participation may not be an indicator of risk.

Discussion

WSB designed its LTFU prevention outreach on assumptions that (a) babies identified as at-risk for LTFU and who were WIC participants (Group 2 and 3) would be less likely to receive follow-up than babies not in WIC (Group 1); and (b) babies identified as at-risk for LTFU and WIC participants receiving services in GLITC and City of Milwaukee WIC (Group 3) would be less likely to receive follow-up than other babies (Group 1 and 2). When WSB initially designed its targeted LTFU prevention strategies and its process for identifying the target population of babies at-risk for LTFU, WSB did not have access to data elements such as maternal education, race/ethnicity, or

Table 2. Summary of Logistic Regression Analyses for Variables Examining WIC as a Predictor of Risk for Becoming Lost to Follow-up (N = 485), Controlling for Intervention Amount

Variables	Model 1			Model 2		
	B	SE B	e ^B	B	SE B	e ^B
Any WIC (Group 2 and 3 vs Group 1)	0.54	0.30	1.72	--	--	--
GLITC and City of Milwaukee WIC (Group 3 vs Group 1 and Group 2)	--	--	--	0.50	0.50	1.66
Intervention Amount	-0.71**	0.20	0.49	-0.48**	0.15	0.62
χ ²	12.73**			10.43**		
df	2			2		

Note. e^B = exponentiated B; GLITC = Great Lakes Inter-Tribal Council; WIC = Women, Infants, and Children. Intervention Amount ranged from 1 to 3.
**p < .001.

family income. WIC participation, with its established income eligibility limits, seemed like an appropriate proxy for lower socioeconomic status (SES). Assumptions around income as a risk factor emerged from the learning collaborative and were supported by evidence indicating that the lowest levels of education and income are most common and persistent among subgroups that also exhibit the poorest health outcomes (Boss et al., 2011; Braveman, Cubbin, Marchi, Egerter, & Chavez, 2001; Cutler & Lleras-Muney, 2006; Smith & Boss, 2010). However for the first assumption, study results indicated that babies who did not pass their hearing screening and were enrolled in WIC were no more or less likely to have their cases resolved than families not participating in WIC. Either WIC participation did not serve to identify the babies with lowest SES, which might put them at high risk for LTFU, or SES was not the important LTFU risk indicator WSB assumed it would be.

Within the WIC participant populations described in this study, WSB identified WIC projects that served families with potentially a greater number of cumulative risk indicators for poor health outcomes, with the contributions of low SES, geographic, and racial/ethnic barriers to accessing services. WSB used WIC status in two particular WIC projects (GLITC and the City of Milwaukee) to serve as a proxy for these additional cumulative risk factors. However, these analyses suggest that regarding the second assumption, populations in these two WIC groups were not more at risk for LTFU than either non-WIC participants or participants in other WIC projects. In fact, because WSB designed its LTFU prevention strategy based on the belief that Group 3 babies would be at greater risk for LTFU, WSB provided them immediately with Regional Outreach and bypassed Family Outreach. When comparing Group 3 babies with other babies who also received Regional Outreach, there was not a statistically significant difference

in outcomes. This suggests that even among the most difficult-to-resolve cases, WIC participation in a locale thought to be at higher-risk for LTFU did not appear to indicate a greater risk for LTFU when intensive prevention strategies were available.

Additionally, when controlling for the amount of intervention babies in the three groups received, there was no statistically significant difference in outcomes. In fact, the more prevention strategies a case received, the less likely the case was to be resolved. This is most likely due to the design of WSB's LTFU prevention strategies, which work as a funnel, with the most at-risk cases receiving the most intensive strategy, Regional Outreach.

WSB's analysis also found that a smaller percentage of babies than anticipated were identified as at-risk for LTFU and also were identified as WIC participants. Although state and national estimates identify 50% of babies as eligible for WIC, less than half of the babies identified as at-risk for LTFU beyond Medical Outreach were WIC participants.

Limitations

The findings in this evaluation are subject to the following limitations: (a) Prior to 2011, WSB reported information retrospectively (typically six months after the last birth of the previous year) on babies who were LTFU. The tracking of babies at-risk for LTFU began concurrently with the implementation of the LTFU prevention strategies. Therefore, comparisons to baseline data analyses were not possible. (b) The small sample size for some analyses led to reduced power to detect differences between groups. Thus, if study authors had a larger sample with which to conduct analyses, study results may have been different. (c) Additionally, WIC participation remains unknown for babies whose cases did not require support beyond

Medical Outreach. Since Medical Outreach resolved 60% of the cases initially identified as potentially at-risk for LTFU, this represents a comparatively large group of babies whose risk factors and WIC participation remains unexplored.

Implications and Future Directions

Although state EHDI programs made significant progress in the past decade increasing the percentage of babies screened from 83% to 98%, most recent data indicates 32% of babies who did not pass a hearing screening were still reported as Lost to Follow-Up (as defined by CDC) or Lost to Documentation (CDC, 2003; Williams, Alam, & Gaffney, 2015). WSB offers the following suggestions for decreasing the LTFU rates based on implications of this evaluation: (1) Targeting Outreach, (2) Analyzing LTFU, (3) Predicting Populations At-risk for LTFU, and (4) Stabilizing and Building Systems.

1) Targeting Outreach: To use limited resources most efficiently, EHDI programs often focus outreach efforts on targeted populations to see the greatest reductions in loss to follow-up while using the least amount of resources. However, states may be determining the target population without access to the descriptive data necessary to make evidence-based predictions of who is at-risk for LTFU. They also may not be able to easily evaluate who is LTFU. This makes it nearly impossible to assess whether their targeted outreach positively impacted the intended populations. This study demonstrated that assuming that WIC participation was a proxy for SES did not prove an effective method for identifying at-risk populations to target LTFU prevention in Wisconsin.

2) Analyzing LTFU: The LTFU population in Wisconsin is now so small (less than 145 babies in 2014) that the remaining unresolved cases have few common characteristics to use to inform population-based outreach. EHDI systems frequently rely on data trends from previous year(s) to predict who might be LTFU in the coming year. Targeting LTFU to a particular population demographic/geographic area may not be the most effective method when the LTFU population is so small.

3) Predicting Populations At-Risk for LTFU: The underlying assumption that there would be a disproportionate percentage of babies at-risk for EHDI LTFU who were WIC participants impacted how WSB designed its LTFU prevention strategies. The reasons that this did not prove to be an effective way to identify babies at risk for LTFU are not clear. WSB has begun to examine additional factors including whether a family able to enroll in a program such as WIC, may be better equipped to access other kinds of programs and support systems, such as EHDI follow-through.

4) Stabilizing and Building Systems: EHDI programs also need to focus efforts on building greater systems to support babies at-risk for LTFU. The CDC recommends EHDI programs investigate strategies to reduce LTFU that take advantage of new and creative collaborations

and opportunities (Williams et al., 2015). Like Wisconsin, other state EHDI programs may also be housed within the same department as their state's WIC programs, making an EHDI and WIC collaboration well-aligned to meet this recommendation. The WSB-WIC partnership, organized and solidified by the MOU, with both the state WIC program and local WIC, allowed WSB to implement the WIC Alert LTFU prevention strategy while placing a minimal burden on WIC staff. By allowing EHDI staff access to the existing WIC data system, EHDI staff assumed the task of placing the Alerts. This was efficient because it did not require any costly, time-consuming development of information systems linkages. It was also effective because the EHDI staff knew which babies needed which intervention strategy. By using an existing Alert mechanism within the data system that local WIC clinics were familiar with, the need for WIC staff training was minimal.

In 2012, WSB developed a data use agreement with Wisconsin's vital records office, providing WSB with demographic information, including race/ethnicity, maternal education, and maternal age on a baby-specific basis. One area for future investigation in Wisconsin is to evaluate whether there are any trends or common characteristics among babies identified as at-risk for LTFU and those who become LTFU. In 2015, Wisconsin started documenting these key demographic characteristics for each individual baby identified as at-risk for LTFU, including cases resolved by Medical Outreach alone, to determine if there are any demographic trends that might inform future LTFU prevention efforts.

Conclusions

Since implementing its LTFU prevention strategies in 2011, WSB reduced by nearly 50% the number of babies who did not pass their hearing screening and did not receive follow-up (WSB Annual Report, 2014, 2015). WSB has maintained this lower LTFU rate (WSB Annual Report, 2014, 2015). Along with reducing LTFU through its four prevention strategies, WSB has increased its partnerships, improved its data quality, and conducted more regular data analysis. The goal of these efforts is to continue to design and implement efficient, effective, high-leverage strategies that reduce LTFU and improve and stabilize EHDI systems of care.

WSB targeted outreach to families participating in WIC as one way to design efficient and effective LTFU prevention strategies. Despite WSB finding no statistically significant differences in EHDI follow-up outcomes between WIC participants and non-WIC participants, WSB programmatically determined that the WSB-WIC partnership remains important. Particularly when trying to reach families that may not be accessing any other systems, such as primary care or EHDI follow-up care, WIC participation remains an important opportunity to successfully reach families. For some individual babies identified as at risk for EHDI LTFU and who were enrolled in WIC, the WIC-WSB partnership meant the difference

between the baby's case being resolved or not. Additionally, Wisconsin WIC remains an informed, committed partner in reducing LTFU for babies who did not pass their hearing screening. WIC staff report continued interest in assisting families in getting EHDI follow-up services as part of their overall mission to refer and connect children with appropriate services.

Although WIC participation was not a predictor of LTFU in Wisconsin, it may be one in states with a higher LTFU rate, less access to additional demographic characteristics, higher poverty rates, higher WIC enrollment, or other factors. The WSB-WIC collaboration allowed WSB to investigate whether this was an effective mechanism to leverage EHDI resources. Although not statistically significant, the partnership did enable Wisconsin Sound Beginnings to support families that would not have been reached through traditional EHDI channels. This has made the WIC-EHDI partnership valuable.

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Readability, User-Friendliness, and Key Content Analysis of Newborn Hearing Screening Brochures

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Abstract

Readability, user-friendliness, and key content are important components of newborn screening brochure design. Health information at a sixth grade or below reading level, designed for ease of navigation, with easily identifiable "action steps" can help adults with limited literacy skills find, understand, and use health information. The purpose of this study was to quantify the readability, user-friendliness, and key content components of newborn hearing screening brochures. Five readability formulae (FRE, F-K GL, FOG, FORCAST, and SMOG) were used to estimate reading levels of English language EHDl brochures ($N = 48$). Twenty-three participants assessed brochures for user-friendliness. Three participants assessed brochures to determine if key content elements were included and if so, the ease of locating them. Readers are provided with simple steps to follow during brochure design to maximize the message in parent education materials. This study forms the framework for quality improvement efforts and research-to-practice initiatives in the fields.

Acronyms: ASL = Average Sentence Length; ASW = Average Number of Syllables per Word; EHDl = Early Hearing Detection and Intervention; FRE = Flesch Reading Ease; F-K = Flesch-Kincaid Grade Level; FOG = Gunning FOG Index; GL = grade level; N = Number of Monosyllabic Words in a sample text; PHW = Percentage of Hard Words; RE = Reading Ease; SAM = Suitability Assessment of Materials; SMOG = Simple Measure of Gobbledygook; TSEN = Total Sentences; TSYL = Total Syllables; TW = Total Words

Introduction

The rapidly changing demographic make-up of the United States and increasing diversity play important roles in guiding public policy and efforts to reduce healthcare disparities (Humes, Jones, & Ramirez, 2011; U.S. Department of Health and Human Services, 2006). To meet these needs, increased national attention has been focused on issues such as healthcare workforce diversity, cultural competence of healthcare providers, and health literacy education (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003; Betancourt, Green, Carrillo, & Park, 2005). Growing evidence suggests limited literacy skills may be linked to poorer health decisions and healthcare outcomes (Berkman, DeWalt, et al., 2004; Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; DeWalt & Hink, 2009). To maximize the likelihood of better health outcomes, health literacy is moving to the forefront of many healthcare conversations.

Literacy is the ability to use printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential (White & Dillow, 2005). In contrast, *health literacy*, as defined by the Institute of Medicine, is "the degree to which individuals

have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 32). Results reported from the 2003 National Adult Literacy Survey revealed that almost half of the adults in the United States have basic or below basic literacy skills (Kutner, Greenberg, & Baer, 2005; Kutner, Greenberg, Jin, Boyle, et al., 2007; Kutner, Greenberg, Jin, & Paulsen, 2006; Institute of Medicine, 2004; White & McCloskey, 2006), with more than 40 million people reading below the fifth grade level (Institute of Medicine, 2004; Yin, Johnson, Mendelsohn, Abrams, Sanders, & Dreyer, 2009). Despite evidence linking health literacy and health outcomes, readability levels for a large number of adult patient education materials (Stossel, Segar, Gliatto, Fallar, & Karani, 2012; Strachan et al., 2012; Wilson, 2009; Wolf et al., 2012) and patient-reported outcome measures (Atcherson, Zraick, & Brasseur, 2011; Zraick, Atcherson, & Brown, 2012; Zraick, Atcherson, & Ham, 2012) in a number of disciplines are consistently reported at the seventh grade level (GL) or higher. Studies assessing readability and user-friendliness of educational materials targeting parents and caregivers report similar findings (Arnold et al., 2006; Freda, 2005; Hendrickson, Huebner, & Riedy, 2006; Ross & Waggoner, 2012; Wallace & Lennon, 2004).

Reading grade level estimates of patient education materials are commonly used to predict health literacy. Formulae used to estimate readability are readily accessible and add value by (a) providing information to reach the target audience, (b) enabling prediction of the ability of the target reader to understand the material, and (c) facilitating conversion of written material into plain language (Zamanian & Heydari, 2012). The primary disadvantage is the number of readability formulae available (more than 40) which produces significant variation on the same text (Wang, Miller, Schmitt, & Wen, 2013). For this reason, it is important to understand the purpose of each readability formula and the variables taken into account. Table 1 shows five common readability measures and the formulae used to estimate reading ease and grade level estimates.

Although readability levels are frequently used as a predictor of health literacy (U.S. Department of Health and Human Services, 2000), these measures fail to describe the ease by which an adult can consume and act on complex health information (Zamanian & Heydari, 2012). Arnold and colleagues (2006) developed a “User-Friendliness Checklist” consisting of 22 items grouped into five categories. This checklist takes additional variables impacting readability into account such as the layout, use of illustrations, management of information, clarity of message, and cultural appropriateness. Each of the categories on their checklist has three to five descriptors. For example, the layout descriptors include font size, font type, white space, paragraph size, and visual appeal. A

graphic of the checklist categories and descriptors is shown in Figure 1.

Usability can be defined as the combined domains of user-friendliness and key content analysis. Key content analysis focuses on providing the target population with the information most valued. Recommendations for effective communication about newborn screening have been provided by researchers who have conducted focus groups with parents, providers, and content experts (Davis et al., 2006; Kim, Lloyd-Puryear, & Tonniges, 2003). Research shows that parents value the following information about screening: (a) infant will be screened, (b) screening is beneficial, (c) rescreening may be needed, (d) method of notification if rescreening is needed, (e) specific action steps, (f) the timeframe or need to act quickly if the infant fails screening, and (g) who to contact for more information (Davis et al., 2006). These findings support recommendations by the American Academy of Pediatrics (AAP, 2000) for content inclusion for newborn screening brochures and are shown in Table 2.

Research reports indicate that parents want to receive information orally from a trusted health care provider and as a take-home brochure (Davis et al., 2006; Kim et al., 2003; National Center for Hearing Assessment and Management [NCHAM], 2015). Parents are interested in relevant and practical information emphasizing what they need to know and do (Davis et al., 2006). Targeted health information, designed for ease of navigation, with easily identifiable action steps can help adults with limited literacy skills find,

Table 1. Readability Formulae Names and Descriptions

Formula Name	Formula Description
Flesch Reading Ease (FRE)	$RE = 206.835 - (1.015 \times ASL) - (84.6 \times ASW)$ The higher the number, the easier the text is to read. The output is a number ranging from 0 to 100. The Flesch–Kincaid Grade Level (F–K) is applied to translate this value to an equivalent grade level.
Flesch-Kincaid Grade Level (F-K)	$F-K = 0.39 (TW/TSEN) + 11.8 (TSYL/TW) - 15.59$
Gunning FOG Index (FOG)	$GL = 0.4 (ASL + PHW)$
FORCAST	$GL = 20 - (N/10)$
Simple Measure of Gobbledygook (SMOG)	SMOG grade = 3 + Square Root of Polysyllable Count, Count 10 sentences in a row from the beginning, middle, and end of the text, for a total of 30 sentences. Then count every word with three or more syllables in each group, even if the word appears more than once. Calculate the square root of the number from the previous count of words, round off to the nearest 10, and then add three to the calculated number to find the SMOG grade level estimate.

Note. ASL = Average Sentence Length (i.e., number of words divided by the number of sentences); ASW = Average Number of Syllables per Word; GL = Grade Level; N = Number of Monosyllabic Words in a sample text; PHW = Percentage of Hard Words; RE = Reading Ease; TW = Total Words; TSEN = Total Sentences; TSYL = Total Syllables.

Figure 1. Twenty-Two Items Organized by Five Domains Defining User-Friendliness for Parent Educational Materials.

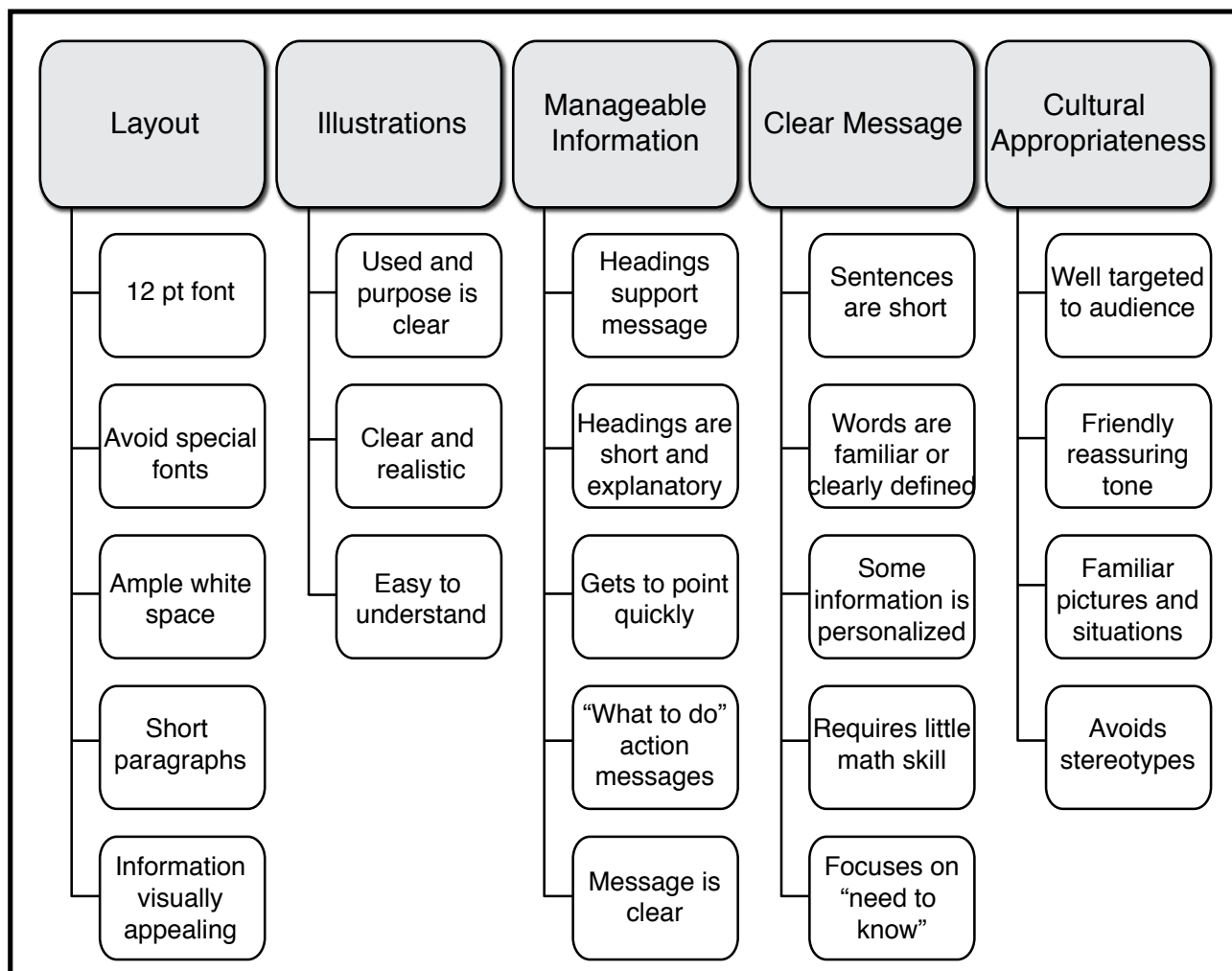


Table 2. Key Content Elements Recommended for Newborn Screening Programs

1. Why does my baby need newborn screening tests?
2. What are the benefits of newborn screening?
3. What if my baby needs rescreening?
4. How will I be notified if rescreening is needed?
5. What action steps do I need to take if rescreening is needed?
6. What is the timeframe to follow-up for rescreening?
7. Who do I contact for more information?

Note. Adapted from "Recommendations for Effective Newborn Screening Communication: Results of Focus Groups with Parents, Providers, and Experts," by T. C. Davis et al., 2006, *Pediatrics*, 117(5), S326-S340.

understand, and use health information. The concept of “action” is a vital element in the definition of health literacy. Few authors have explored these key content elements coupled with readability and user-friendliness (Arnold et al., 2006; Davis et al., 2006). Therefore, the purpose of this study was to quantify the readability, user-friendliness, and key content of newborn hearing screening brochures.

Method

This study was approved by the Institutional Review Board at the University of Arkansas at Little Rock (Protocol #12-065). All study procedures took place in the Department of Audiology and Speech Pathology at the University of Arkansas for Medical Sciences (UAMS)/University of

Arkansas at Little Rock (UALR). The study consisted of three separate analyses: (a) readability, (b) user-friendliness, and (c) key content analysis. Descriptions of these analyses are described in the Procedures section.

Participants

The readability analysis did not require human subject participation. Study participants for the user-friendliness and key content analyses were volunteers from Early Hearing Detection and Intervention (EHDI) stakeholder populations in Arkansas. Parents were recruited from the Arkansas Hands & Voices chapter. Hands and Voices is a parent/professional advocacy group for children with hearing loss and their families. In addition, students enrolled in the graduate Audiology and Speech Pathology programs at UAMS were invited to participate. Finally, audiologists and speech-language pathologists were volunteer professional staff from local health facilities or faculty from the university.

Twenty-three adults participated in the assessment of user-friendliness. Participants ranged in age from 22 to 58 years and included four parents of children with hearing loss (Parent Group, $n = 4$); five audiologists and two speech language pathologists (Professional Group, $n = 7$), five audiology students and three speech language pathology students (Student Group, $n = 8$), and four professionals not familiar with issues related to deafness (Other Group, $n = 4$). Seven were male and 16 were female; all were English speaking. Participants were taken from a convenience sample; six were African American and 17 were Caucasian. A sub-group of 3 volunteers (students) from the participant pool completed the Key Content Checklist.

Materials

All available U.S. state and territory newborn hearing screening brochures ($N = 48$) were downloaded from the NCHAM website (www.infanthearing.org), saved as electronic PDF documents and printed. The assumption was that these brochures were those in current use; therefore, no effort was made to check with state EHDI coordinators for current copies of brochures. Brochures downloaded were limited to the English version.

Procedures

Readability. Brochure text was copied from the PDF, pasted into a Microsoft Word document, and saved as an ASCII text file. Files were uploaded to readability software for analysis. Readability was assessed using the Windows-based software Reading Calculations, Version 7.5 (Micro Power & Light Co., Dallas, TX, 2008). This readability software provides automated scoring of written materials according to nine of the most popular readability formulae: Flesch–Kincaid Grade Level (F–K), Flesch Reading Ease (FRE), Gunning FOG Index (FOG), Simple Measure of Gobbledygook (SMOG), Powers-Sumner-Kearl Readability, FORCAST, Spache, Dale-Chall Readability, and Fry Graph.

We chose five of the most common formulae used in the literature for assessment of patient health materials for this study: F–K, FRE, FOG, FORCAST, and SMOG. The readability calculations were completed via the automated software application.

User-Friendliness. User-friendliness refers to the organization and complexity of the content, the appearance of the format, and overall tone and cultural appropriateness (Kim et al., 2003). The User-Friendliness Checklist (Arnold et al., 2006) categories were layout, illustrations, clear message, manageable information, and cultural appropriateness (Figure 1). Randomized numbered brochures and rating forms with instructions were included in participant packets with the informed consent form. Participants were asked to rate each checklist item ($N = 22$) for each brochure ($N = 48$) in response to the following question: “How much work does this brochure need to be user-friendly?” Answer options were transferred to an Excel spreadsheet and coded as (a) *Little* = 1; (b) *Some* = 2; and (c) *Much* = 3. Participants were provided with a visual sample for each of these categories to help maintain consistency with ratings.

Key Content Checklist. A checklist (Table 3) was developed to assess inclusion of key content areas and ease of locating the information for 48 brochures. A simple rating paradigm of *yes*, *no*, and *not applicable* (N/A) was used to quantify (a) if key content evidence was present, and if so, (b) ease of locating the information. The simple checklist regarding the presence/absence of key content and ease of location was completed by the three student volunteers from the original participant pool. Answer options were transferred to an Excel spreadsheet and coded for inclusion of content (*Yes* = 1; *No* = 2) and ability to locate content easily (*Yes* = 1, *No* = 2, *N/A* = 3).

Results

Descriptive statistics were used to summarize the data. Means (M), standard deviations (SD), and confidence intervals (CI) were computed using Microsoft Excel. Readability, user-friendliness, and key content checklist results are presented.

Readability

Table 4 shows the descriptive statistics (columns) for five readability measures (rows). The average reading ease score for the FRE was 73 (row 1) and the corresponding average grade level estimate for the F–K was 5 (row 2). These results show that the F–K grade level estimate indicates 94% of the brochures can be easily read by students in the sixth grade and below. Average grade level estimates for other formulae include the FOG at 8 (row 3), FORCAST at 10 (row 4), and SMOG at 8 (row 5).

Figure 2 shows the percent of brochures by grade level for the F–K, FOG, FORCAST, and SMOG formulae. In general, the F–K formula returns the lowest estimate and

Table 3. EHDI Checklist for Key Content in Newborn Hearing Screening Brochures

EHDI Checklist for Key Content in Newborn Hearing Screening Brochures	Content Included?		Easy to Find?		
	Yes	No	Yes	No	N/A
1. Why does my baby need newborn screening tests?					
2. What are the benefits of newborn screening?					
3. What if my baby needs rescreening?					
4. How will I be notified if rescreening is needed?					
5. What action steps do I need to take if rescreening is needed?					
6. What is the timeframe to follow-up for rescreening?					
7. Who do I contact for more information?					

Note. EHDI = Early Hearing and Detection Intervention; N/A = Not Applicable.

Table 4. Mean, SD, and Confidence Interval for Readability Formulae Used to Assess Newborn Hearing Screening Brochures (N = 48)

Readability Formula	M (SD)	95% CI	Criterion or Grade Level	Number	Percentage
Flesch Reading Ease Level (FRE)	72.98 (7.75)	[70.79, 75.17]	90 – 100	1	2%
			70 – 89	31	65%
			60 – 79	15	31%
			< 59	2	4%
Flesch-Kincaid Grade Level (F-K)	5.05 (1.45)	[4.76, 5.33]	1.0 – 2.9	1	2%
			3.0 – 4.9	24	50%
			5.0 – 6.9	20	42%
			≥ 7.0	3	6%
Gunning FOG Index (FOG)	7.52 (1.4)	[7.38, 8.38]	4.0 – 5.9	9	2%
			6.0 – 7.9	21	44%
			8.0 – 9.9	15	31%
			≥ 10.0	3	6%
FORCAST	10.09 (.66)	[9.91, 10.28]	4.0 – 5.9	3	6%
			6.0 – 8.9	17	35%
			9.0 – 10.9	23	48%
			≥ 11.0	5	10%
Simple Measure of Gobbledygook (SMOG)	7.78 (1.02)	[7.49, 8.07]	6.0 – 6.9	11	23%
			7.0 – 7.9	20	42%
			8.0 – 8.9	10	20%
			≥ 9.0	7	15%

Figure 2. Percent of Brochures by Grade Level Estimate for Four Readability Formulae: Flesch-Kincaid Grade Level (F-K), Gunning FOG Index (FOG), FORCAST, and Simple Measure of Gobbledygook (SMOG).

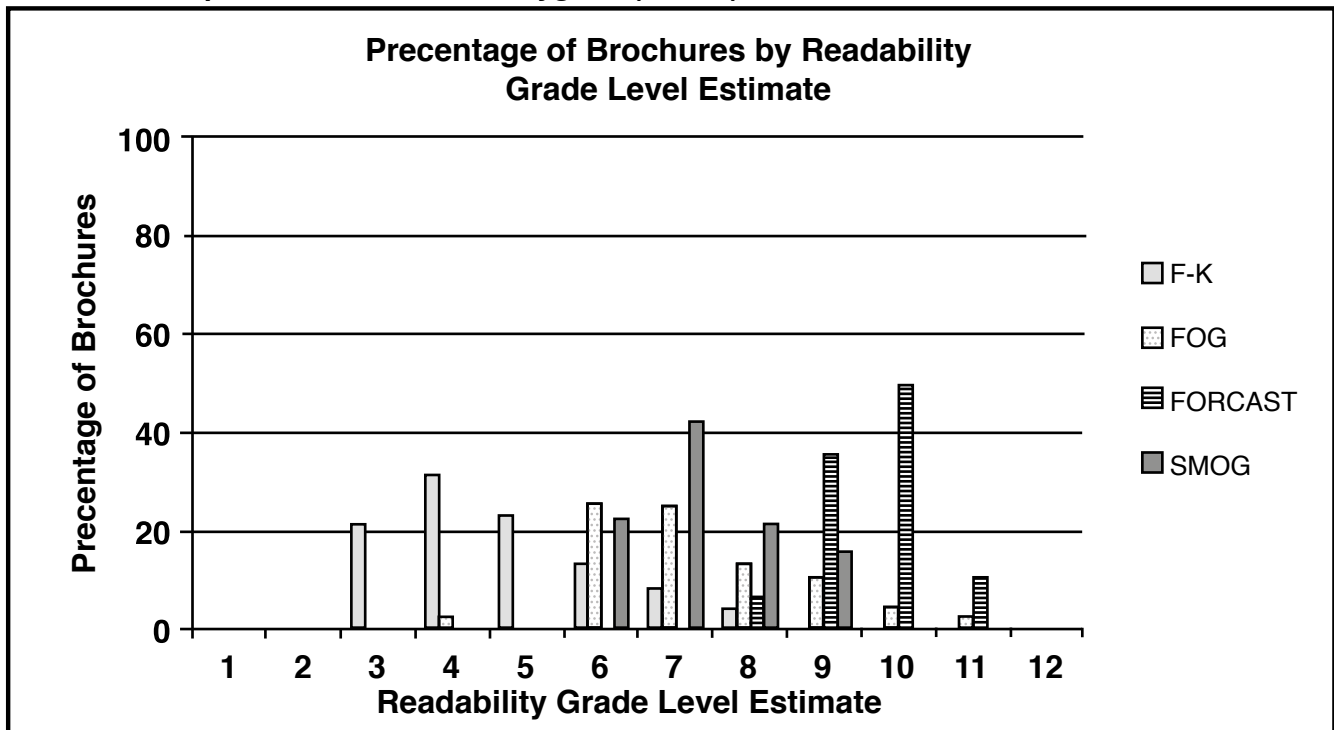


Table 5. Percentage of Responses (N = 23) for 22 Items in Five Categories to the Question: “How Much Work Does This Brochure Need to be User-Friendly?”

Specific Characteristics	Little	Some	Much
Layout makes it easier to read			
1. Font is > 12 points	61%	25%	14%
2. Avoids all capital letters, italics, and specialty fonts	73%	20%	7%
3. Ample white space	64%	28%	8%
4. Short Paragraphs (4-5 lines)	56%	27%	17%
5. Information well organized (e.g., bullets and boxes)	64%	22%	14%
Illustrations			
6. Used and serve purpose	39%	34%	27%
7. Clear and realistic	56%	20%	24%
8. Easy to understand	56%	20%	24%
Clear Message			
9. Cover, title, and headings support message	74%	15%	11%
10. Headings are short and explanatory	77%	15%	8%
11. Gets to point quickly	62%	27%	11%
12. Action Messages (what to do) are presented first	48%	38%	14%
13. Message is likely clear	67%	22%	11%
Manageable Information			
14. Sentences are short	61%	28%	11%
15. Words are familiar or defined	70%	22%	8%
16. Personalizes some information	61%	28%	11%
17. Requires little math skill	90%	5%	5%
18. Focuses on need to know	67%	22%	11%
Cultural appropriateness			
19. Well targeted to audience	74%	18%	8%
20. Friendly, reassuring tone	70%	22%	8%
21. Familiar pictures, words, and situations	64%	22%	14%
22. Avoids stereotypes	84%	8%	8%
Overall Mean Percent	65%	22%	13%

the FORCAST returns the highest equivalent grade level. The FOG and the SMOG are distributed more centrally, with the SMOG showing the tightest distribution.

User-Friendliness

Results of user-friendliness ratings ($n = 23$) for 48 brochures are shown in Table 5. Overall mean results suggest the majority (65%) need *little work*, a smaller proportion need *some work* (22%), and a few need *much work* (13%). The illustration category was rated as needing the most work. Figure 3 shows the percentages of user-friendliness ratings by the rater role (i.e., parent, professional, student, and other). Percentage refers to the number of brochures rated as needing *some* or *much* improvement.

Key Content Component Checklist.

Results of the checklist for key content components were analyzed for 48 brochures (Table 6). Percentage of brochures with inclusion of key content and the percentage of brochures in which key content was easy to locate are shown in Figure 4.

Discussion

Consideration of reading level, user-friendliness, and key content components helps maximize the potential for comprehension and use of health information. Although a substantial body of literature exists on readability measures (Atcherson et al., 2011; Freda, 2005; Hendrickson et al., 2006; Stossel et al., 2012; Strachan et al., 2012; Wallace & Lennon, 2004; Wang et al., 2013; Wilson, 2009; Wolf et al., 2012; Zamanian & Heydari, 2012; Zraick & Atcherson, 2012), few authors have assessed user-friendliness (Arnold et al., 2006) and key content (Davis et al., 2006). This study provides evidence and demonstrates how these three factors used together form best practice methodology when designing or revising patient education brochures for newborn screening.

Readability

The National Work Group on Literacy and Health (1998) recommends patient education materials to be written at or below the sixth-grade level to increase the likelihood that health information can be read and understood. Our results show considerable variability by formula, with 88% of the brochures evaluated meeting the sixth grade or lower criteria using the F–K formula (100% at the 8th grade reading level or below), 48% meeting the sixth grade or lower criteria using the FOG, 23% meeting the sixth grade or lower criteria using the SMOG, and 0% meeting the sixth grade or lower criteria using the FORCAST. This variability emphasizes the need to understand and choose appropriate readability measures (Table 5). For example, the F–K formula was designed to estimate U.S. grade level comprehension for children (using a 85% criterion), and the SMOG was developed to estimate U.S. grade level comprehension for adults (using a 100% criterion; Wang

et al., 2013; Zamanian & Heydari, 2012). As such, SMOG estimates tend to be one to two grade levels higher than the F–K. In contrast, the FOG was designed to estimate years of formal education adults needed to understand the text on a first reading. As a result, this formula generally predicts scores higher than the F–K, but lower than the SMOG, which places more weight on complexity (multi-syllabic words) than other formulas (Wang et al., 2013; Zamanian & Heydari, 2012).

The F–K and SMOG measures are widely used to assess education and health literature (Wilson, 2008). These measures have a high correlation with performance on reading comprehension tests (.88 to .91; DuBay, 2006). In contrast, the FORCAST, which is based on number of monosyllabic words and is designed for use with bulleted text and non-narrative documents, correlates poorly with reading comprehension. Copying and pasting text into an on-line readability calculator can assist brochure design by calculating the F–K, FOG, and SMOG grade level estimates (Adamovic, 2009).

User-Friendliness

The 22-item checklist highlights important factors not taken into account by readability measures alone (Arnold et al., 2006). Focus on aspects to ensure a visually appealing well-formatted brochure increases the likelihood that information will be read, understood, and used. Mean ratings for this study shows similar responses for four of the five categories in this study with the majority of brochures (65%) needing little work, while 22% needed some work, and 13% needed much work. Ratings for EHDI brochures were better overall than for newborn screening brochures (Arnold et al., 2006). Application of the User-Friendliness instrument adds value to the revision of existing written parent education materials and serves as a guideline in the design of new materials.

Layout. Overall, the layout for the EHDI brochures was rated comparably among stakeholder groups. Most brochures (61%) used an appropriate font size and minimized the use of capital letters, italics, and specialty fonts (73%). In addition, the majority of brochures needed little improvement in ample white space (64%) and/or organization of information (64%). Seventeen percent of the brochures were rated as needing much improvement in shortening paragraphs to four or five sentences. Layout items for the EHDI brochures were rated higher than ratings reported for the newborn screening brochures reviewed by Arnold and colleagues (2006).

Illustrations. Illustrations are an important consideration to enhance visual appeal and reinforce the message. For the EHDI brochures, category of illustrations indicated a greater need for improvement than other categories and also showed greater variability by stakeholder group. Raters who were intimately familiar with the content (i.e., audiologists and speech pathologists) were less critical of illustrations than parents, students, and other raters. Fifty-

Figure 3. Percentage of Response Ratings to Brochures Indicating Some or Much Need for Improvement by Group (i.e., Parents, Professionals, Students, Other) and by User-Friendliness Category.

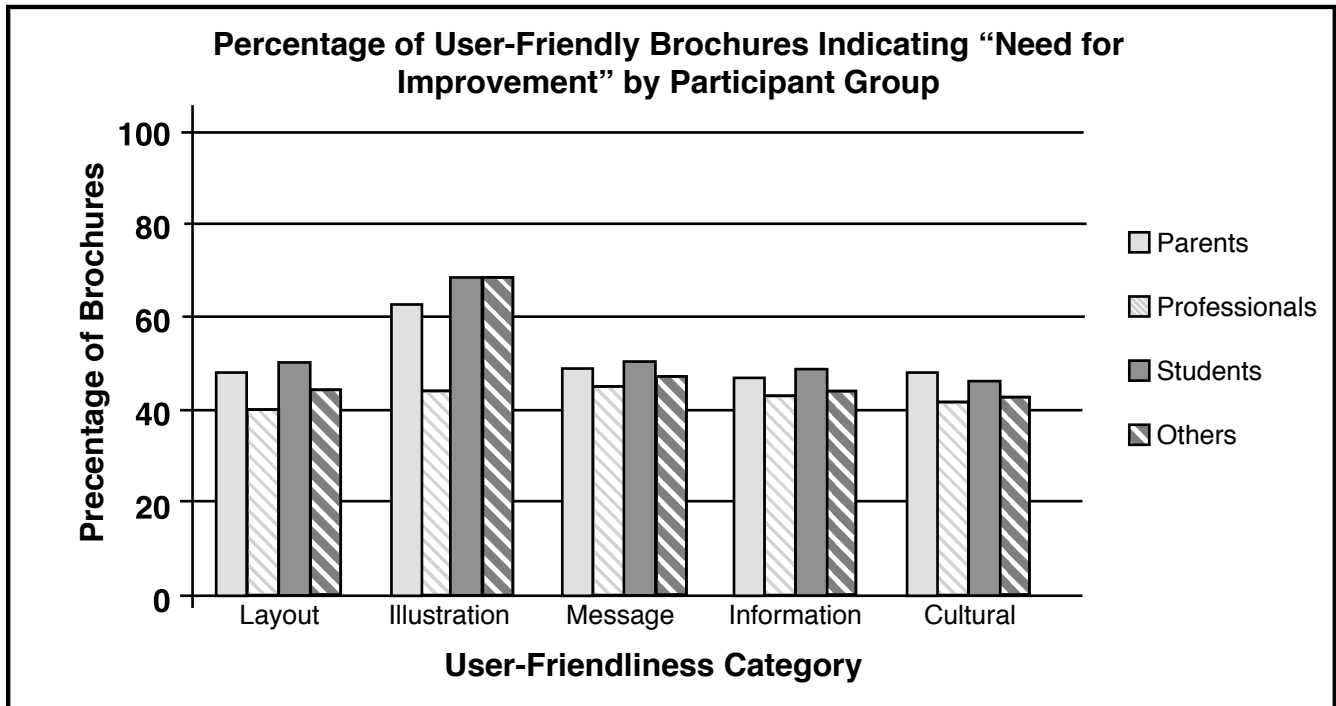


Table 6. Percentage of responses (N = 23) for 7 Items on the EHDI Key Content Checklist in Response to Two Questions: (a) Is Key Content Present? And (b) if so, is it Easily Located?

	Key Content Present?		Easily Located?		
	Yes	No	Yes	No	N/A
1. Infant will receive a birth hearing screening?	94%	6%	75%	19%	6%
2. Benefits of birth hearing screening?	88%	13%	88%	0%	13%
3. Possibility of the need for rescreening?	85%	15%	83%	2%	15%
4. Notification of need for rescreening?	73%	27%	40%	2%	58%
5. Action steps if rescreening needed?	67%	33%	63%	8%	29%
6. Motivation to act quickly?	40%	60%	29%	10%	60%
7. Who to contact for more information?	90%	10%	90%	0%	10%

Note. EHDI = Early Hearing and Detection Intervention.

six percent of the brochure illustrations were rated as clear, realistic, and easy to understand; 27% as needing much improvement in use and purpose of illustrations, while 24% were rated as needing much improvement for clarity and understanding relative to the text. These results emphasize the value of varied stakeholder group perspectives when designing or revising EHDI brochures.

Clear Message. EHDI brochures were rated similarly across stakeholder groups. Seventy-seven percent used short explanatory headings, with 74% supporting the message. Sixty-two percent needed little work in getting to the point quickly, and 67% were rated as providing a clear message. Only 48% presented action messages first, with 52% needing some or much work on content regarding next steps. In comparison to the newborn screening brochures reviewed by Arnold and colleagues (2006), the EHDI brochures included more information about action steps, although they were still rated as needing more attention to detail.

Manageable Information. Ninety percent of EHDI brochures were rated as needing minimal math skills. Sixty-one percent needed little improvement in the use of short personalized statements, 70% used familiar words, and 67% focused on the need to know. Ratings were similar across stakeholder groups with only 5% to 11% rated as needing much work. Overall, the information was rated higher for the EHDI brochures than the newborn screening brochures reviewed by Arnold and colleagues (2006).

Cultural Appropriateness. Stakeholder groups rated the cultural appropriateness similarly. Eighty-four percent of the brochures were rated as avoiding stereotypes with only 13% indicating the need for much improvement. Seventy-four percent were rated as well-targeted to the audience, 70% as using a friendly, reassuring tone, and 64% as using familiar pictures, words, and situations. Fourteen percent of the brochures were rated as needing much improvement in the use of familiar words, pictures, and situations. Overall, the cultural appropriateness of EHDI brochures was rated higher than the newborn screening documents reviewed by Arnold and colleagues (2006).

Key Concept Components

Davis and colleagues (2006) identified seven key content components that parents want to know. In this study, each brochure was rated to determine if (a) there was evidence that the key component was present, and (b) if so, the ease of locating that component. Overall, the results of this study showed 40% of the EHDI brochures included all seven key content components; with 30% of this content easily located (refer to Table 4 and Figure 4). Although the majority of EHDI brochures included content about the birth hearing screening (94%), benefits of screening (88%), need for rescreening (85%), and who to contact for more information (90%); fewer included information about how parents would be notified of the need to rescreen

(73%), specific action steps to take (67%), and motivational language indicating the need to act quickly (40%). In some cases, if the latter of this information was included, it was not easily located. For example, motivational language was present in 40% of the brochures and it was easy to locate in 29% of these brochures. Use of the evidence-based checklist when developing or revising brochures for newborn hearing screening programs provides a simple tool that can be used to ensure critical content components are included in the design and that the information can be easily located. We are unaware of any published reports regarding content analysis of these components in newborn hearing screening brochures.

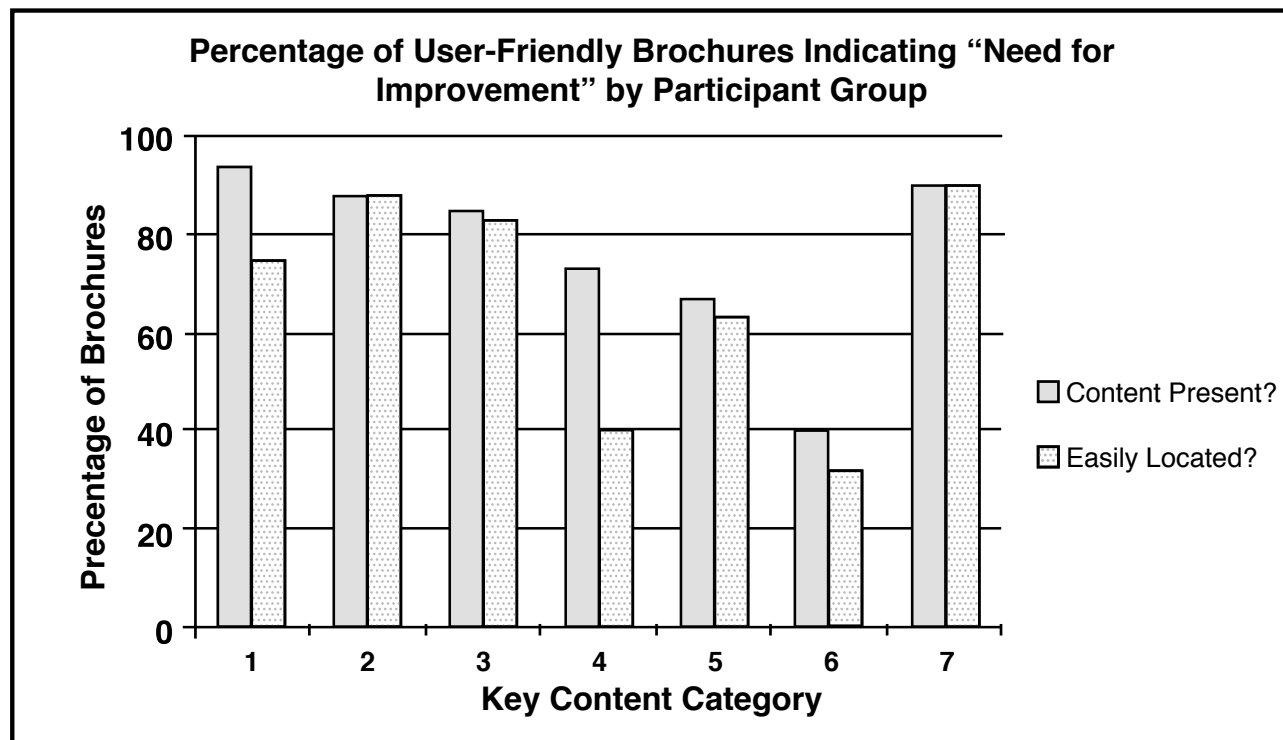
We would be remiss if we did not mention other resources and tools for evaluation of health-related information. One such tool used to assess user-friendliness and content is the Suitability Assessment of Materials (SAM; Doak, Doak, & Root, 1996). Domains included in this instrument are: (a) content, (b) literacy demand, (c) graphics, (d) layout and type, (e) learning stimulation and motivation, and (f) cultural appropriateness. Each of these factors is rated as superior, adequate, or not suitable based on objective criteria and assigned a point value. However, the SAM does not address inclusion of specific key content items. A number of other resources are available to assist in the development of written materials for the purpose of patient and parent education (Centers for Medicaid and Medicare Services, 2012; Joint Commission, 2010; Office of Disease Prevention and Health Promotion, 2010; Pleasant, McKinney, & Rickard, 2011; Ross & Waggoner, 2012). The Centers for Medicaid and Medicare Services (CMS) offers an online Toolkit for the Development of Written Materials that provides comprehensive information about a reader-centered approach to the development and assessment of written information (CMS, 2012). In addition, the NCHAM Resource Guide for Early Hearing Detection and Intervention provides additional guidance and information for parent information (NCHAM, 2015).

Conclusions

Significant variation in readability estimates was found depending on the formula used. For example, the majority of EHDI newborn hearing screening brochures (88%) met the sixth grade or lower reading level criteria recommended by National Literacy Work Group on Literacy and Health when using the F–K Grade Level estimate. In contrast, only 48% met this criterion when the FOG was used and only 23% when the SMOG estimate was used. For this reason, we recommend readability assessment with at least two formulae when designing or revising parent educational material. The F–K and SMOG are recommended as they are the most widely used formulae to estimate grade level for health information. Use of readability software or an online calculator for readability estimation is recommended (Adamovic, 2009).

The checklist developed by Arnold et al. (2006) was valuable in assessing layout, use of illustrations, message,

Figure 4. Percentage of Evidence for Presence and Ease of Location for 7 Key Content Components Recommended by the American Academy of Pediatrics (2000) for Newborn Screening Brochures.



Note. 1= Infant will Receive a Birth Hearing Screening; 2= Benefits of Birth Hearing Screening; 3= Possibility of Need for Rescreening; 4= Notification of Need for Rescreening; 5= Action Steps if Rescreening Needed; 6= Motivation to Act Quickly; 7= Who to Contact for More Information.

information management, and cultural appropriateness of these materials. Our results demonstrated the majority of EHDl newborn hearing screening brochures could benefit from limited improvement (65%) to make them more user-friendly. Use of this checklist during the design and revision of materials can help ensure efforts are focused. In addition, our results support the use of parent reviewers to ensure materials and illustrations meet the needs of the target population.

Of particular importance is the inclusion of key content components that can be easily located in the parent education materials. Davis and colleagues (2006) advocate for inclusion of parents as critical stakeholders in the development stages of program development as do other authors (Ross & Waggoner, 2012). We developed a simple checklist to assist in the review of newborn screening materials to make sure that the information parents want to know is readily available. Specific attention should be paid to the action steps included in the brochure. Readily available resources for use in the development process are also included in the CMS Toolkit for Development of Written Information (CMS, 2012) and the NCHAM Resource Guide for Early Hearing Detection and Intervention (NCHAM, 2015).

Recommendations

As a beginning point, readers are provided with the subsequent simple steps as best practice to follow during brochure design to maximize the message in parent education materials when designing or revising patient education brochures for newborn hearing screening programs.

1. Develop draft test of newborn hearing screening brochures following established guidelines (i.e., readability, user-friendliness, and key content).
2. Use two automated readability calculations (software or free online applications) to estimate grade level. Adjust text accordingly so as not to exceed the recommended sixth grade reading level.
3. Ask parent stakeholders (or a parent stakeholder focus group representative of your target population) to use the User-Friendliness Checklist and Key Content Analysis Checklist to evaluate the brochure content, layout, illustrations, message, information, and cultural appropriateness.
4. Evaluate stakeholder input and make suggested improvements in the brochure text, layout, and illustrations.
5. Maintain a record of quality improvement efforts in brochure development and revision to include in reports to grant agencies and state advisory boards.

Inclusion of parents who are representative of the cultural

and ethnic groups in the target audiences will facilitate effectiveness of the health information. EHDI programs should make every effort to establish a routine of periodic review of parent information materials.

Limitations

Our study provides a comprehensive view of readability, user-friendliness, and key content analysis for EHDI newborn hearing screening brochures published by 48 U.S. states and territories; however, it is not without limitations. First, brochures were downloaded from those available on the NCHAM website, which does not guarantee the most recent version. In the future, it is recommended that researchers check with the state EHDI coordinator to obtain the most recent brochure or to verify that the brochure is current. Second, only English language brochure versions were evaluated; studies in Spanish or other languages could result in different findings. In addition, the criteria used to assess user-friendliness and key content were not clearly defined and were not assigned a point value based on specific features, but left to the discretion of the rater. Lastly, reading skills of the parents receiving these brochures was not tested; assumptions about readability were based on extrapolations from other studies (Hauser et al., 2005; Kutner et al., 2005, 2006, 2007).

Future Research

Evidence supporting the use of readability, user-friendliness, and key content analysis in the development of patient education information is important in the field of early hearing detection and intervention. Future research should include a comparison of the Arnold et al. (2006) User-Friendliness Checklist and the SAM (Doak, Doak, & Root, 1996). More research is needed to determine the validity, reliability, and efficiency of the User-Friendliness Checklist and Key Content Checklist in comparison to SAM.

The inclusion of parents in stakeholder assessment groups cannot be over emphasized, particularly with regards to cultural appropriateness as well as language implications. Inclusion of diverse ethnic and cultural groups in stakeholder populations might increase the efficacy of brochure dissemination. In addition, brochures with strong action steps clearly stated and targeted to specific populations could improve loss to follow-up/documentation rates. Furthermore, readability estimates of EHDI brochures written in Spanish would be very informative. There are a few readability formulae designed specifically for this purpose available as free online calculators. Lastly, future research should include parent focus groups to help professionals evaluate, assess, and confirm the presence of key content components as well as the ease in which this critical information can be located.

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Promoting Immigrant Parents' Engagement in Early Intervention Through Culturally and Linguistically Responsive Service Delivery

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Abstract

This article focuses on the use of culture-based play, songs, and games in the early education of newcomers to the United States. Current studies examine culturally inclusive practices in PreK-12 schools in America, Canada, and Australia and suggest that parents participate more enthusiastically when their cultural orientation is honored. Although there is scant research regarding in-home early intervention for infants and toddlers who are deaf or hard of hearing for recent immigrants to the United States, the same principle may hold true for this group of immigrants. The type of parent involvement that an early interventionist in the U.S. hopes to elicit in new immigrant families thoughtfully builds on a family's own knowledge—engaging them in activities that promote child development, language, and literacy using cultural and linguistic practices that respect and support them. The article concludes with one deaf educator's account of using informal cultural assessment with newcomer families that leads to strategies to engage them in early intervention activities with their infants and toddlers who are deaf or hard of hearing (Appendix A). We include an appendix of songs, nursery rhymes, and games for infants and toddlers in Spanish and English (Appendix B).

Many of you have immigrated to this country at great personal cost, but in the hope of building a new life. Do not be discouraged by whatever challenges and hardships you face....Please do not be ashamed of your traditions...Do not forget the lessons you learned from your elders, which are something you can bring to enrich the life of this American land. (Pope Francis, 2015)

Introduction

The United States of America is home to the largest number of international migrants in the world. Approximately 53% of the foreign-born in the United States hail from Latin America, 25% from Asia, 14% from Europe and 8% from other regions of the world (International Organization for Migration, n.d.). A family's culture and the way they play with their children intersects with child development in early intervention services to these families who are newcomers to the United States and who have very young children with special needs. Parental engagement is reciprocal, based on relationships, and is culturally and linguistically responsive (Amorsen, 2015; Georgis, Gokiart, Ford, & Ali, 2014). Although most current research focuses on the effect of cultural and linguistic responsiveness on school age students and their families, this article focuses on ways to more effectively engage families who speak Spanish in early intervention for their infants and toddlers who are deaf or hard of hearing. After looking at background research into broad concepts of culture and play, this article shares observations of common barriers that interventionists experience when working with immigrant families and discusses strategies that work best to engage parents in early intervention activities to benefit their children (see Appendix A). The use of culturally appropriate games, songs, and rhymes as well as an understanding of and respect for a family's cultural traditions, beliefs, and values gives parents a better understanding of how to promote child development through family-led routines.

Changing Populations

"America is a nation of immigrants. That diversity is the backbone of our arts, industry, and culture" (U.S. Department of Homeland Security, 2015, overview para 1). According to the Department of Homeland Security, the United States welcomes an average of 3000 new citizens daily and grants residency to an additional 3400 people. In recent decades, the United States has seen large-scale immigration, particularly among Hispanic peoples. Nearly 25% of children under the age of 18 in the U.S. are either immigrants themselves or the children of immigrants (Hernandez, Denton, & Maccartney, 2008).

The Youngest Immigrants

Although public schools are often the first interactive point for immigrant families who have school-aged children, early intervention for children who are at risk for or have special needs creates particularly delicate situations in which interventionists visit these infants and toddlers in the family home. Parent involvement in early intervention is especially necessary to promote rapid development of skills and language development during the first three years of life (DesJardin, 2006; Kuhl, 2010; Moeller, 2000; Yoshinaga-Itano, 2013). When a child is deaf or hard of hearing, early intervention services focus intensely on language access and development, most of which occurs within a family setting. When a family speaks a language other than English, parents' abilities to interact with the interventionist may be noticeably limited by language barriers as well as restricted in more obscure ways by cultural differences. Family interactions with their child may be misunderstood or undervalued by monolingual interventionists, or by those

professionals who are, most often unwittingly, tethered to a western cultural perspective. Opportunities for language learning through cultural resources may be overlooked. Parent-engagement and child development can be successfully primed when an educator is attuned to the desires and expectations of the family within the framework of their specific culture (Purcell-Gates, Lenters, McTavish, & Anderson, 2014).

Culture-What Is It And How Do We Talk About It?

Culture is notoriously difficult to define. “Every culture is characterized, and distinguished from other cultures, by deeply rooted and widely acknowledged ideas about how one needs to feel, think, and act as a functioning member of the culture” (Bornstein, 2015). Children form their very earliest identities within their families and the culture their families embrace (Becker, 2014; Guo, 2015). Bronfenbrenner (1979) considered culture a macro-system. This over-arching system is the framework in which parenting beliefs and practices shape the development of children. The voices of parents become the internal voices of children as they grow, even as they adapt to a new country and learn a new language.

Educators as Cultural Workers

Research that examines classrooms that promote multicultural activities and parental engagement look at best practice in supporting children and parents who are recent immigrants (Amorsen, 2015; Bentley, 2012; Friedrich, Anderson & Morrison, 2014; Georgis et al., 2014; Guo, 2015; Marschall, Shah, & Donato, 2012; Purcell-Gates et al., 2014). Public schools’ receptivity to immigrant parents has a positive effect on parent involvement. The involvement of parents of immigrant students must be supported by the use of cultural brokers, teacher training, and in-service professional development. Principals of color, particularly, take more active roles in addressing the needs of immigrant and minority parents (Marschall, Shah, & Donato, 2012). Although public schools are the “frontline of receiving immigrants to this country” (Marschall, Shah, & Donato, 2012, p. 130), early intervention for children who have disabilities, including children who are deaf or hard of hearing, actually interacts with families long before the children enroll in Preschool or K-12 public schools. There are few studies of immigrant parent involvement in Pre-K settings and in home-based early intervention.

Although parents and teachers form strong partnerships and families place high value on bilingualism, early interventionists regularly miss opportunities to identify family routines and areas of expertise and interest (Puig, 2012). Studies of preschool classrooms indicate that teachers are consciously able to create equitable and socially just learning environments, but often cannot let go of their own pedagogical foundations enough to fully understand what parents value. Guo (2015) studied how educators responded to the interests and needs of children

of minority cultures in a multicultural program in an early childhood setting. She found that although the teachers cared deeply about children and felt they were devoted to children’s interests and needs, parents were not completely satisfied with the program. Her study illustrated that these parents and teachers had different perceptions about their children’s needs and interests. Teachers were unable to put aside their own, culture-bound pedagogical foundations and responded to children within the constraints of that knowledge. Parents’ understanding of their children’s needs and their expectations about learning were quite different and based on their cultures. This gap between the teachers’ and the parents’ cultural understanding kept educators from building complete awareness of children’s learning needs. It was only through work with the parents that teachers were able to build knowledge about those students from minority cultural backgrounds (Guo, 2015).

Another study of a Canadian literacy program found a similar pattern of culture-blindness:

Time and again, our field notes indicated that “our” perspectives on the role of families and parents in the literacy development of their children were not the perspectives held by the families with whom we were working. Because we all considered ourselves good “cultural” researchers, we continued to focus on this uncomfortable fact and tried to understand it. (Purcell-Gates et al., 2014, p. 20)

As these teachers came to understand how to work toward their stated goal of preparing youngsters for Canadian kindergartens while also embracing the importance of the cultural frames of the families, they found that the parents became their teachers. They understood that culture is not simply something other people do, but that teachers, as “cultural workers” (Freire, 1970), value and learn about diverse cultures, while also critically acknowledging and examining their own. A social constructivist perspective suggests that teachers are catalysts for empowering children and families and for giving them voice (Freire, 1970).

Cultural Capital

There is still a tendency among teachers to perceive parental involvement in relation to parents’ *cultural capital* (Georgis et al., 2014). Whereas middle-class parents from the dominant culture may be valued as participants in educational settings, those who are from a different culture and may “speak English as a second language... are portrayed as empty containers, which need to be filled before they can give anything of value to the schools or their own offspring” (Lightfoot, 2004, p. 93). Engagement with families from different cultures goes well beyond superficial cultural awareness activities typified by yearly teacher-training regarding race, culture, and equality or a printout synopsis of cultural differences and highlighting a few, token, stereotypical or geographically limited cultural practices as representative of a larger group of quite

diverse families (Bentley, 2012). The cursory nature of this type of training continues to reinforce the idea that groups other than White and English-speaking families are the exception and bring less capital to the relationship. The ability to recognize the value of other cultures may be limited by the saturation of the predominant culture's social bias.

Cultural Brokers

Cultural brokers facilitate recognition of cultural value. Cultural brokering is defined as the act of bridging, linking, or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change (Jezewski, 1990). A cultural broker acts as a go-between, one who advocates on behalf of another individual or group (Jezewski & Sotnik, 2001). Cultural brokers bring a deep understanding of a culture and the respect that comes with this awareness. The use of cultural brokers in school settings has succeeded in including parents who are newcomers in the school community. Marschall et al. (2012) looked at parent involvement in American schools and found that parent involvement may look different, but occurs with immigrant families if one has the vision to recognize it. Their findings indicate that cultural brokers, as defined by Jezewski and Sotnick (2001), successfully facilitate family engagement. However, "teachers who do not share linguistic or racial/ethnic background with their students can...function in ways similar to cultural brokers....as a result of enhanced education, training, and professional development focused on issues of culture, language and immigration" (Marschall et al., 2012, p. 147). Targeted training gives those who are not bilingual or bicultural tools with which to more successfully engage newcomer families.

Using Culturally Familiar Educational Content

Parent engagement can be achieved by drawing from culturally familiar pedagogical practices using "culturally familiar and relevant content" in the first language of the community along with some English (Friedrich et al., 2014, p. 72). In this study, families of preschoolers generated songs and rhymes in their first language, sometimes followed by an English version, as many parents were in the process of learning English. Parents reported that they valued the opportunity to maintain their first language because they felt that if they did not, "kids will forget their own language, [and] the relationship between parents and children will be hard" (p. 76). The use of their own cherished songs and rhymes brought participants together in learning. Using song, rhyme, and daily language involvement when working with children who are deaf or hard of hearing and their families is important to help the children develop listening and language skills. During these early years, a firm first language is an essential need for a child (Watkin et al., 2007). This language most likely is not English when parents are not fluent English-users. In fact, parents need to know how valuable their own language is to their child's optimum development.

What is Play?

Play is central to children's development of mental functions during the preschool years (Vygotsky, 1978). Play occurs in a social context that is framed by cultural beliefs and parenting practices (Whiting, 1963). Academics have had a good deal of trouble defining play (Johnson, Christie, & Yawkey, 1999). When researchers examine play, they tend to characterize play and types of play according to their specific research focus, scholarly discipline, and ideology (Cheng & Johnson, 2010). Cultural orientation also influences the ways that play is observed and described. For the purposes of this article there is no single, clear definition that will cover all the different meanings given by parents, educators, researchers, and even children themselves. Although there is not one clear definition of what constitutes play, there is a good deal of research about the characteristics of play as well as the common themes in human play. Common themes in children's play according to Lindon (2001) are:

- Very young children display playful behavior when they explore sounds, engage in simple actions, experiment with objects of interest... and engage in simple give and take or copying games with their peers, older siblings, or adults.
- Children choose games or activities they enjoy.
- Children enjoy and learn from repetitive songs, rhymes, and games.
- Play activities are not essential to meet basic physical survival needs, but play does seem to support children's emotional well-being as well as a wide range of learning.

Culture Shapes Play

In all societies, parents influence the way children play (Cote & Bornstein, 2009) and play is an activity through which cultural values are transmitted (Tamis-LeMonda, Katz, & Bornstein, 2002). Play within the framework of a child's culture promotes socialization, learning, bonding, self-identity, and the security of structure and routine that encourages youngsters to thrive. Families from different cultural backgrounds share commonalities and differences regarding child-rearing goals and views about children's play. Children are taught to play in ways valued by the culture in which their parents were raised. Immigrant families may be disconcerted by aspects of play in their culture of destination "and culture-specific aspects of play from the immigrants' culture of origin may be interpreted by clinicians, teachers, or others as problematic simply because they differ from those of the culture of destination" (Cote & Bornstein, 2009, p. 355).

Identity and Play

Children create their identities very early on through their family and culture. Play is situated in culture both in the spontaneous ways that parents engage their children in play and through the formal games, songs, and play activities that are passed on from one generation to another as part of a "cultural template" (Zarnegar, 2015).

Recognizing the importance of the social and cultural spaces in which play occurs, researchers have recently intensified their focus on “examining the nature and quality of interactions during play as they relate to cultural socializations patterns” (Roopnarine & Davidson, 2015, p. 239). This involves valuing the family culture in its entirety. Play is one vehicle for cultural transmission. It is through play that children, parents, and extended family members enjoy each other while building and reinforcing self and family. The use of a family’s traditional play, songs, and stories not only brings teachers into equal relationship with parents; but also allows them to better perceive the children’s skills and developmental trajectories. Play is one part of a cultural template that guides parents in facilitating successful child development and allows teachers to recognize this important development. The use of play in early intervention can capitalize on family routines and values with a focus on family-identified vocabulary, social language, and the language of home routines.

Play Flows!

When challenges are balanced by skills, attention is heightened and allows the person to enjoy the experience of being fully engaged in an activity (Abuhamdeh & Csikszentmihalyi, 2012). Like children engrossed in play, this attitude in adults is optimum for learning and creativity. It is similar to Vygotsky’s *zone of proximal development* where a child, at the peak of their developmental level, is intrinsically motivated yet challenged; the optimum state for learning (Vygotsky, 1978). When families play together the enjoyment enhances the child’s self-esteem and builds family relationships. When parents engage children in play, it is a special time (Lieberman, 1993). Barbara Rogoff (2003) documents the efficacy of *intent participation learning* in which children from an early age participate actively and imaginatively in culturally meaningful activities. Rituals that express parents’ enjoyment of play with the willing participation of infants create loving linguistic connections that draw on traditional songs and actions that are treasured (Trevarthen, 1999).

Traditional Cultural Games

Every country has traditional games that have been part of their culture for generations. These games were a way to teach the skills needed to survive in that particular society as well as global developmental skills and were passed down from generation to generation. Unfortunately due to globalization, migration, the disintegration of the extended family, acculturation, and assimilation, many of these games are disappearing and with them wonderful opportunities for children to practice needed developmental skills as well as learn the families’ cherished cultural heritage.

Although the Latino/Hispanic ethnic groups share some common cultural values and beliefs, they are a diverse population that includes different races, mixed races, and different countries. Although some celebrations are

shared, there may be variations of celebrations and even different rituals in the many countries that are part of Hispano America. They also have different foods, music, and dances. When it comes to games, stories, and songs there may be different variations of the same themes (for example there are different variations of an infant game named *Acerrín Acerrán* (see Appendix B) or completely different games, such as *la Huerfanita* in Central America, and different nursery rhymes and songs, such as *pon pon tata* in Mexico.

Play in Society and Culture

The study of play, as reviewed in educational and developmental journals, tends to focus on the context of play and play as related to intervention with children who have special needs (Cheng & Johnson, 2010). The role of play as a vehicle for cultural transmission and to assist in bridging language and cultural barriers between the dominant culture and newcomers to the United States has been given little attention. There are many ethnographic studies of cultural and traditional plays and songs in African, Chinese, Javanese, Lithuanian, and other cultures, but none have focused on how using traditional play can help build relationships, language, and other developmental skills within immigrant communities. Immigrant children often lose touch with their indigenous play as they acquire high tech toys, video games, computers, and other technological gadgets. In their rush to assimilate into the new culture they leave their birth-culture behind (Khasandi-Telewa, 2012).

Play and the Preservation of Cultural Heritage

Traditional games are a way to teach the needed skills, values, and norms of a specific culture (Garoz & Linaza, 2008). Play, in addition to being important in child development, serves as an acculturative mechanism (Hyun, 1998). Teachers must strive to provide their students with an environment that is culturally inclusive and to remember that “traditional games are a precious intangible cultural heritage inseparable from community [and family] life.” (United Nations Educational, Scientific and Cultural Organization (UNESCO) Bangkok, n.d). Traditional games share the characteristic of having been passed on through oral tradition from generation to generation. Children learn these games from their parents, grandparents, and the older children in their extended families as well as from teachers at school. In many Latin countries, traditional games are part of physical education classes. Cultural content is often embedded in the songs and chants, gestures and movements, roles assigned, and goals of the game (UNESCO, Bangkok, n.d.)

Children Who Are Deaf Or Hard Of Hearing

Children who are deaf or hard of hearing may have language delays that put them at risk for developing positive social skills, self-esteem, and academic readiness. Early intervention for those children often has a primary

focus on potential language deficits due to inability to access language either auditorily or visually. These children may also exhibit different or limited play skills in comparison with same age peers who are typically developing (Sualy, Yount, Kelly-Vance, & Ryalls, 2011). When partnering with families who have different cultural expectations about play and whose traditions in play differ from those in the United States, understanding how and why a child plays as she or he does, as well as the language used in play, will help enhance a child's competencies.

Helpful R's: Resources, Respect, and Responsiveness

There are many resources available on ways to play with children who are deaf or hard of hearing and developing listening and language skills, notably through cochlear implant company support websites:

- www.advancedbionics.com
- www.cochlearamericas.com
- www.medel.com

These include listening games, songs, books, and play materials, most with a focus on Western culture and English language. However, some resources include materials in other languages. Materials in *The Listening Room* at the Advanced Bionics site include vocabulary and songs in Spanish, English, and French. Resources for infants and toddlers who are learning visual language, from such organizations as the American Society for Deaf Children (<http://deafchildren.org/knowledge-center/parents-and-families/early-visual-language/>) provide excellent support, mostly in English and American Sign Language (ASL). Gallaudet University and the Laurent Clerc National Deaf Education Center offer a variety of programs and services that meet the needs of deaf children, parents, and professionals (www.gallaudet.edu). A good resource for cultural background can be found at Pocketcultures.com (Pocket Cultures, 2012).

Low-tech play materials are better than high-tech for encouraging cognitive development and creative play. Toys and objects that have meaning within the cultural community should be considered when working with families who may encourage play with toys and objects based on their culture of origin. The use of real objects or toys that look real can help children learn to problem-solve and participate in routines within the social and cultural context of their own families (Roopnarine & Davidson, 2015). Songs and games in the family language encourage important cross-generational play (Zero To Three, n.d.). Literacy activities can include books in the home language or stories from rich oral traditions. The best practice for professionals should involve research, receptivity, and outreach for families' unique cultural resources.

Although there is insufficient research on the efficacy of using traditional nursery rhymes, songs, poems, stories, and games while delivering services in early intervention, there is little dispute about the importance of delivering these services in the family's home language and including

traditional celebrations, songs, and stories (Gutierrez-Clellen, 1999; Kohnert, Yim, Nett, Fong Kan, & Duran, 2005). Increased engagement and participation by parents in preschool and school age programs that use cultural brokers and include parent generated literacy activities has been well documented. (Purcell-Gates et al., 2014). It was difficult to find any studies of very early intervention with the 0-3 populations of newcomers to the U.S. We can only hypothesize that the same holds true for the early intervention setting and anecdotal reports suggest that we are right. There is a dearth of empirical evidence regarding the use of traditional songs, games, and parenting techniques in early intervention for children who are deaf or hard of hearing and their immigrant parents.

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Appendix A

Lucia and the Families She Visits

Lucia has been working with Spanish speaking families in the Charlotte, North Carolina area for the past 10 years. She was a Spanish-English Interpreter for the Early Intervention Program for Children who are Deaf or hard of hearing for three years.

Observations of Teachers

When working as an interpreter she observed several teachers from Early Intervention in the home environments. When those teachers tried to teach English songs and games “to new arriving parents to the United States who were not yet acculturated or did not speak the language, parents did not follow through. The parents were not fully engaged and didn’t follow-up with activities.” Initially, this was attributed to three factors. (a) Families dealing with the trauma of suddenly finding themselves raising a child who was deaf or hard of hearing without having a frame of reference about hearing loss. (b) Families dealing with culture shock or struggling to acculturate while having strangers coming into their homes with a well-intentioned, but disability-focused agenda. (c) The intensity of early intervention services, which may be quite alien to these families, could have also been scary for them, which could have paralyzed or slowed down reaction/action time.

Providers sometimes erroneously interpreted this lack of participation by parents as being stubborn, uncooperative, or non-compliant. Many early intervention providers thought parents did not care about therapy or their children, in part because they didn’t understand the manner in which these families parented (Becker, 2014; Bentley, 2011; Guo, 2015; Roopnarine & Davidson, 2015).

Lucia reported, “Other teachers asked me to translate the songs and games and this worked better. Parents did learn the songs, rhymes, and games and used them but had a neutral rapport with their providers.” It was only when a few teachers asked Lucia to teach them traditional songs, games, and rhymes and asked for help with understanding appropriate behaviors, toys, or comments that the family finally bonded with their interventionists. The Early Interventionists commented on how they felt the family was participating more eagerly and that they had a better relationship with the Latino families.

Assessing Family Culture

Lucia was asked by colleagues to observe them in their

work with parents: not just those from Spanish speaking countries, but also various newcomer parents from Pakistan to Burma with whom they were having trouble building rapport or obtaining joyful participation. Lucia first researched as much as she could about the family: appropriate behaviors of houseguests, views of teachers, important words such as *Hello*, *Good*, *Thank you*, and *Goodbye* in their language to let them know they were important and that she and the teacher valued their language and culture. A pre-session was conducted with interpreters being used in sessions. The interpreters were asked to repeat exactly what everyone said and to offer “no chit chat or opinions.” They were to act as a cultural broker only when there was a misunderstanding or a cultural issue that needed clarification. When interpreters were intimately familiar with a region, they were asked to share songs and games they might remember to share with the family.

After observing the providers, Lucia wrote recommendations based on what was the norm for that culture. Two good examples of norms that, when not followed, could cause barriers to a productive intervention relationship:

- For one Pakistani family a pig toy, a frequently used animal sound in early intervention, was perceived as dirty and insulting.
- A family from Burma expected the teacher to sit a bit higher than they were sitting.

These norms were learned through observation and conversation that gently probed to assess cultural expectations. It was vital to assess how families interacted with providers and each other, gender roles, household chore division, appropriate toys, celebrations, routines and family traditions, words that they felt provider should know and, of course, games, songs, and rhymes that were cherished by the family. Teachers reported that a good cultural analysis helped them to create better rapport with families and improved their service delivery.

Lucia as a Teacher

When she first shifted from being an interpreter to an Early Intervention teacher working with Spanish speaking families, Lucia found it easier to use the translated songs she already had because they were tied to listening and language activities she had learned. She did not, initially, take into consideration the families’ various places of origin and the implications for each specific family culture. Only some of the families learned the songs and rhymes that were designed to promote language and infant development. Some parents did enjoy these songs and games, but others did not use them at all. Some parents expressed discomfort at showing how they used the songs and games during the week. This led to feeling constrained and not making a real connection with these families.

Based on the success of those teachers who had asked her to provide traditional songs and games that were

specific to the culture of specific households of new immigrants, Lucia began to research the culture of all of “her families.” She began to conduct an informal cultural assessment where she asked about each family’s values, routines, family dynamics, and health beliefs. Lucia specifically asked if they remembered any games, songs, or rhymes from their own childhoods. Some did and some said they did not. Lucia remembered songs and rhymes from her own country of origin, Ecuador, but found that immigrant families sometimes didn’t know her country’s songs and rhymes because their country had a different version or nothing even similar.

If the parents did not remember songs and games, Lucia made an effort to talk with extended family members, especially the elderly. Often grandparents still carried with them precious and invaluable traditional children songs, rhymes, stories, and games. These are intangible cultural resources that are sometimes lost because of migration. The elderly’s cultural oral libraries may be left behind as younger immigrants search for a better life. If the extended family was not in the picture, Lucia researched the family’s country of origin to learn games, stories, and nursery rhymes typical from the family’s country.

Using the cultural assessment information, and doing deep research, Lucia affirmed, “When I showed up with the games and songs I researched that were traditional from that culture, [parents’] faces lit up and they [said] things like ‘I remember that song from when I was a little girl, I love it! I want to teach it to my child.’” This led to a compilation of songs, rhymes, and games from different countries with their diverse versions according to each region. Parents were more receptive when she changed from using American songs in English or translated to Spanish to using their own traditional songs and games. The families she worked with began to participate more fully using their traditional songs and rhymes. Through these songs and rhymes, Lucia coached families on how to implement strategies for listening and spoken language skills as well as visual and manual language skill. These families “became savvy in teaching skills using traditional songs, games and rhymes and were better able to explain language strategies.” Parents were able to show how they used the songs and games to work on skills and better share what their children learned. Through observation, parental report, and seeing the joy on their faces when a song or rhyme resonates with their deep memories convinced the interventionist that the family was involved in the process.

When culturally responsive service is delivered in which the routines and traditions of the family, including songs and games, are used, the following can be observed:

1. Parents are thrilled to be asked about their culture. They freely and joyfully share the songs and games they are able to remember.
2. Grandparents and other older family members are incredible resources for obtaining traditional games,

- songs, and stories. Input from elderly relatives encourages collaboration within the extended family.
3. Rapport between early interventionist and family improves.
 4. Early interventionists gain a better understanding of the family, not just culturally but as a functioning bonded unit.
 5. Parents are more likely and eager to use the traditional stories, rhymes, songs, and games as listening and language activities.
 6. Although the initial intention was not to create a traditional cultural continuum for families, precious games and songs were rescued from loss and the importance of a family's cultural heritage was validated.

Pride and Engagement

The families with whom Lucia adopted this approach were more engaged and participated more as team members with the early interventionist. When their cultural heritage was supported, they had a greater rapport with the provider compared to the families for whom adapted or translated games and songs from English to Spanish were utilized. However, using songs and stories in the family's native tongue, even if they are only translations of American songs, still provides better results than only using songs and games in the language of the host country. Further study of the most supportive and effective ways of working with families from different cultures is needed to describe the most effective ways of exploring the rich cultural resources families bring with them to the United States.

Insightful teachers must seek to elevate "teaching" beyond cultural sensitivity and into critical social constructivism. This type of connection with families can elicit wonderful stores of engaging knowledge that promotes child development, self-esteem, language, and literacy while honoring and preserving cultural and linguistic treasures.

Conclusions

Although limited in scope and qualitative in nature, this individual account of success in Early Intervention with families who are recent newcomers to the United States suggests that interventionists can be prepared through pre-service or in-service training with tools and skills to help facilitate family engagement in Early Intervention with these newcomers. The use of informal or formal cultural assessment and research into each family's cultural background can help build rapport between interventionists and parents.

Songs, rhymes, and games that are a cherished part of family culture can provide a shared platform for enhancing the development of children who are deaf or hard of hearing during the important early years. However, if this is not possible, using songs and stories in the family's native tongue, even if they are only translations of American songs, still provides better results than only using songs and games in the language of the host

country. Additionally, collecting and sharing these cultural resources is valuable for promoting child development and for preservation of valuable cultural treasures. Further study of the use of language and culturally specific songs, rhymes, and games with infants and toddlers who are deaf or hard of hearing and their families is recommended. Since empirical studies of recent immigrant groups in early intervention are scarce, additional studies with a deliberate focus on ways to positively engage these families are needed.

Appendix B

Rhymes and Games for Infants and Toddlers

The traditional games, songs, and rhymes presented here are a sample from a compilation by Lucia Quiñonez Sumner.

Game

Aserrín Aserrán (Peruvian version)

This is an old rhyme/game that Hispanic parents have played with their little children through generations. It was brought to Latin America by the Spaniards. Usually the parent sits the child in his/her lap facing himself/herself and then holds the child's hands or arms and rocks the child back and forth while singing the song. In some countries the parent tickles or kisses the child at the end of the rhyme. The McArthur Bates Communicative Development Inventories ask if a child knows this rhyme in "Games and Routines" under "Actions and Gestures." There are different versions in different countries. Here are two of the several versions.

Version #1 (Peruvian versión)

Aserrín, Acerrán
 Los maderos de San Juan
 Piden pan, No les dan
 Piden queso menos eso
 Piden vinos si les dan
 Se marean y se van

Translation

Saw, saw,
 The woodworkers of San Juan
 They ask for bread
 They get none
 They ask for cheese, they get none
 They ask or wine, they get some
 They get dizzy and then go home (parents tickle child).

Version #2 (Version de México, Argentina, Chile, Ecuador, and certain areas in Spain)

Aserrín, aserrán,
 los maderos de San Juan,

piden pan, no les dan,
piden queso les dan hueso
y les cortan el pescuezo

Translation

Saw, saw,
The woodworkers of San Juan
They ask for bread
They get none
They ask for cheese, they get a bone
and their necks get cut off.

(at this point the parent either tickles the child's neck or lightly touches the child's neck simulating the neck cutting. This may seem crude to American sensibilities but it is a rhyme that has prevailed throughout generations and the passage of time like the American nursery rhyme Ring Around the Rosie).

Finger Play

The following is a segment of a song from Spain that can be used as finger play,

Credits
Writer(s): Ramon Ortiz Del Rivero
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Lyrics powered by www.musiXmatch.com

Hola Don Pepito

Hola Don Pepito
Hola Don José
Paso usted por mi casa
Por su casa yo pasé
Vio usted a mi abuela
A su abuela yo la vi
Adiós Don Pepito
Adiós Don José

Translation

Hello Don Pepito
Hello Don Jose
Did you drop by my house?
I did just as you say.
Did you see my grandma
She's looking well today.
Goodbye Don Pepito
Good bye Don Jose

Cinco lobitos

Cinco lobitos tenía la loba. Cinco lobitos detrás de la escoba. Cinco tenía, cinco criaba y a todos los cinco tetita les daba. Cinco lobitos tenía la loba. Cinco lobitos detrás de la escoba. Cinco lavó, cinco peinó y a todos ellos, a la escuela mandó.

Translation

Five little pups had the Wolf. Five pups behind the broom. She had five, she raises five and to all five she gave milk. Five little pups had the Wolf. Five pups behind the broom. Five she bathed, five she combed, and all five she sent to school.

Tortas, tortitas (A Latino traditional "Patty cake" game)

Tortas, tortitas que viene mama. Tortas, tortitas que pronto vendrá. Y trae un perrito que hace guau, guau. Palmas palmitas, que viene mama. Y trae una obeja que dice: baaa baaa.

Translation

Pancake, Little pancake, mom is coming, pancake, pancake she will be here soon. She brings a doggie that goes woof woof. Clap clap mom is coming and brings a sheep that goes baaa-baaa.

Song

La Vaca (A song created by Lucia Q. Sumner to the tune of London Bridge)

Tengo cuernos y hago mu
hago mu, hago mu
Yo doy leche y hago mu
Mu, mu, mu, mu, mu

Translation

The Cow
I have horns and I say moo
I say moo, I say moo
I give milk and I say moo
Moo moo moo

Maternal Anxiety Associated with Newborn Hearing Screening

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Abstract

The purpose of this study was to determine if newborn hearing screening increases maternal anxiety. Mothers whose infants were screened for hearing were asked how worried they were prior to hospital discharge and again six weeks later. They were also asked if they were more concerned about their baby's hearing than they were about other aspects of the infant's health and behavior.

Results showed that mothers worried as much or more about many other aspects of their infants' health and behavior as about hearing. Mothers whose infants had a false positive screening result were initially more worried about hearing than other aspects of their infant's health, but this effect disappeared within six weeks. There were no significant differences at Time 1 or Time 2 for maternal anxiety as measured by the STAI between mothers whose infants had a false positive hearing screen compared to mothers of infants who passed their initial hearing screen. Participation in newborn hearing screening is not associated with undue worry among mothers of newborns

Acronyms: CDC = Centers for Disease Control and Prevention; CVS = Child Vulnerability Scale; IHCS = Infant Health Concerns Scale; STAI = State-Trait Anxiety Inventory

Over the past twenty years, newborn hearing screening has become the standard of care in the United States (White, 2014), expanding from 3% of newborns in 1993 to 97% in 2013 (Centers for Disease Control and Prevention [CDC], 2015). During this period of expansion, some experts have suggested that participating in newborn hearing screening might create higher levels of parental anxiety, concern, and worry than would be the case if infants were not being screened for hearing (Bess & Paradise, 1994; Clayton & Tarpe, 1998; Mencher & Devoe, 2001; Paradise, 1999).

Subsequent research conducted in response to such suggestions can be divided into two broad categories. The first category is comprised of articles that used a 4 to 5 point Likert-type scale to address the primary question of whether newborn hearing screening leads to high levels of parental worry¹. These studies reported that 4% to 15% of mothers of all screened infants, and 14% to 25% of mothers of infants who failed the initial hearing screen were *moderately worried* or *very worried* about their infant's hearing. (Barringer & Mauk, 1997; Hergils & Hergils 2000; Clemens, Davis, & Bailey, 2000; de Uzeategui & Yoshinaga-Itano, 1997; Mohd et al., 2011; Van der Ploeg et al., 2008; Vohr, Letourneau, & McDermott, 2001; Weichbold & Welzl-Mueller, 2001).

As discussed in detail by Tueller (2006), most of the existing research on this topic has been of limited value in deciding whether newborn hearing screening is associated with undue levels of parental worry because the studies (a) lacked comparison groups, (b) only asked about worry in the context of the hearing screening result (which may have suggested to mothers that they should be worried), (c) did not collect follow-up data, and (d) had no explicit

basis for comparison (i.e., were parents any more worried about infant hearing than other aspects of infant health and behavior?).

The second category of studies used multi-item scales to measure worry. These studies usually compared mothers of infants who had a false-positive initial hearing screen to mothers of infants who passed the initial screening or to mothers of unscreened infants. All of these studies reported no statistically significant differences between groups on levels of maternal anxiety (Crockett, Baker, Uus, Bamford, & Marteau, 2005; Crockett, Marteau, Uus, & Bamford, 2004; Kennedy, 1999; Suppiej et al., 2013; Watkin, Baldwin, Dison, & Beckman, 1998), as measured by the State-Trait Anxiety Inventory (STAI; Spielberger, 1983) or its short form for state anxiety (Marteau & Bekker, 1992), parental stress (Stuart, Moretz, & Yang, 2000) as measured by the Parenting Stress Index (PSI; Abidin, 1995), or maternal perceptions of child vulnerability (Poulakis, Barker, & Wake, 2003) as measured by the Child Vulnerability Scale (CVS; Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996). Not only were many of these studies underpowered (see Nelson, Bougatsos, & Nygren, 2008, for further discussion of this issue), but given that these measures assess anxiety, worry, and stress at a very broad level, it is possible that more specific, but important levels of worry caused by newborn hearing screening could have been missed.

To more fully evaluate whether newborn hearing screening is associated with undue levels of worry among mothers, the current study included comparison measures, group comparisons, and follow-up assessments to answer the following questions: (1) Do mothers whose infants were

¹ The term *worry* will be used in the remainder of this article to represent the constructs of worry, concern, anxiety

screened for hearing worry more about their child's hearing than other aspects of infant health and behavior? (2) Do mothers whose infants had a false-positive initial hearing screening worry more about their infant's hearing than mothers whose infants pass the initial hearing screening?

Patients and Methods

Prior to the initiation of the study, approval was obtained from the Utah State University Institutional Review Board. The approved surveys and questionnaires were distributed to mothers under the direction of newborn hearing screening coordinators in a heterogeneous group of 11 hospitals in Utah. All mothers of infants who failed the inpatient hearing screening and similar numbers of randomly selected mothers whose infants passed the inpatient hearing screening were invited to complete two questionnaires—the first within a week of hospital discharge and the second at approximately six weeks after birth. By the time mothers completed the second questionnaire when the infant was six weeks old, all infants who had failed the inpatient screening and needed an outpatient screening had completed the outpatient screening. At the request of hospital administrators, mothers of Newborn Intensive Care Unit (NICU) babies were not invited to participate in the study. Mothers agreed to the follow-up questionnaire by including their contact information when returning the initial questionnaire. A total of 286 mothers were invited to participate, and 192 completed the Time 1 questionnaire (a 67% response rate). Among those that completed a Time 1 questionnaire, 95 completed the Time 2 questionnaire (49% of the initial responders). The numbers of mothers and percent in each screening result group are presented in Table 1.

The initial questionnaire included the Infant Health Concerns Scale (IHCS, Tueller, 2006) the STAI—short form (Marteau and Bekker, 1992) and demographic questions. The follow-up questionnaire included the STAI, and the IHCS. The IHCS was developed for this study and is comprised of items assessing the respondent's level of worry about 21 aspects of infant health and behavior (e.g., eating habits, sleeping habits, digestion, eyesight, hearing, etc.) on a 4-point Likert type scale (*not at all worried, somewhat worried, moderately worried, or very worried*). One of the items was about hearing and is similar to the items in previously referenced studies that used a single item to assess worry about infant hearing. The STAI was included because it has been used frequently in previous research on this topic. See Table 2 for information about the reliability of the instruments used in the study.

Results

To answer the question of whether mothers of infants who were screened for hearing are any more worried about hearing than other aspects of their infant's health and/or behavior, the mean level of worry about hearing was compared to each of the 20 other aspects of infant health and behavior measured by the IHCS. As can be seen in Table 3, at Time 1 (i.e., within one week of hospital discharge), the average mother was not very worried about any of the 21 aspects of infant development on the IHCS. The highest average level of worry at Time 1 was 1.65 (on a 4-point scale) for *eating habits* (see Table 3). At Time 1, hearing was the 6th highest worry and was not statistically significantly different from 14 of the other aspects of infant development². Six weeks later at Time 2, hearing was the 8th highest worry and was not statistically significantly different from all 20 of the other aspects of

² Results from the IHCS at Time 2 are not included in this article but are available from Tueller (2006).

Table 1. Number of Participants in Each Screen Result Group

	<i>n</i>	
	Time 1	Time 2
Passed Initial Hearing Screen (initial pass group)	83	60
Failed Initial Screen/Passed Post-Discharge Screen (fail/pass group)	34	18
Failed Initial Screen/Fail Post-Discharge Screen	9	7
Screen Result Unknown	66	10
Total	192	95

Table 2. Reliability of Instruments

Instrument	α in prior development	Current Study		
		Time 1	Time 2	Test-Retest
STAI	$\alpha = 0.82$	$\alpha = 0.79$	$\alpha = 0.81$	$r = 0.39$
IHCS	NA	$\alpha = 0.91$	$\alpha = 0.87$	$r = 0.66$

* STAI = short form for state anxiety. The correlation between the short form and the 20-item state anxiety subscale of the full form of the STAI is $r = 0.91$

* IHCS = short form for Infant Health Concerns Scale

infant development. (Whenever more than two tests of statistical significance were done for the same subjects using different items or subtests, a Bonferroni correction for dependent samples *t*-tests was applied.) As shown in Table 4, among the full sample (i.e., including those babies that passed and those babies that failed the initial screening test), 14.6% of mothers were moderately worried or very worried about their infant's hearing at Time 1, but only 4.3% continued to be worried 6 weeks later.

In the subset of mothers whose infants had a false-positive hearing screen (the fail/pass group), hearing had the highest level of worry among the 21 IHCS items at Time 1, but was not statistically significantly different from 15 of the other IHCS items. At follow-up, hearing had the 8th highest level of worry, and was not statistically significantly different from any of the 20 other IHCS items. Within this subset, 15% of mothers were moderately worried about their infant's hearing at Time 1 and none were very worried. At follow-up, no mothers in this subgroup were moderately worried or very worried about their infant's hearing, although 17% remained somewhat worried.

A second research question was whether mothers whose infants had a false-positive initial hearing screening were more worried about their infant's hearing than mothers

whose infants passed the initial hearing screening. To answer this question, we first examined whether mothers in the two groups varied with respect to overall levels of worry. As shown in Table 5, the average IHCS scores for mothers in the initial pass group were not statistically significantly different than mothers in the fail/pass group at either Time 1 ($t = .84, p = .40$), or Time 2 ($t = .66, p = .51$).

In comparing mothers in the initial screen pass group with those in the fail/pass group on the item, "Please check the box that shows your level of concern about [your baby's] hearing, there were no statistically significant differences at either Time 1 ($t = 1.7, p = .09, d = .35$) or Time 2 ($t = 1.0, p = .31, d = .27$). There were also no statistically significant differences between groups for the STAI at either Time 1 ($t = .134, p = .89, d = .03$) or at follow-up ($t < .01, p = .99, d < .01$).

Discussion

This study found that 14.6% of mothers of infants from the well baby nursery who were screened for hearing were moderately worried or very worried about their infant's hearing shortly after the time of birth. This finding is consistent with the 4% to 15% reported in earlier articles. However, different from most previous studies, this study

Table 3. Time 1 Mean Level of Maternal Worry on IHCS Items and Frequencies for Response Options (N = 191*).

Aspect of Infant Health	Mean worry (SD)	Percent ‡ (n)			
		Not at all worried	Somewhat worried	Moderately worried	Very Worried
Eating Habits †	1.65 (.83)	53.1 (102)	37.8 (61)	10.4 (20)	4.2 (8)
Getting a major disease †	1.61 (.83)	56.3 (108)	29.7 (57)	8.3 (16)	4.7 (9)
Irritability, crying, or colic †	1.58 (.71)	52.1 (100)	39.1 (75)	6.3 (12)	2.1 (4)
Sleeping habits †	1.55 (.72)	56.8 (109)	31.8 (61)	9.9 (19)	1.0 (2)
Not waking up from sleep †	1.54 (.77)	59.9 (115)	28.1 (54)	7.8 (15)	3.1 (6)
Hearing	1.53 (.82)	64.6 (124)	20.3 (39)	11.5 (22)	3.1 (6)
Getting enough fluid †	1.45 (.71)	65.6 (126)	25.5 (49)	6.3 (12)	2.1 (4)
Digestion †	1.43 (.68)	65.6 (126)	25.5 (49)	6.3 (12)	1.6 (3)
Lungs working right †	1.39 (.76)	74.0 (142)	16.1 (31)	5.7 (11)	3.6 (7)
Heart working right †	1.39 (.77)	73.4 (141)	17.2 (33)	4.7 (9)	4.2 (8)
Weight †	1.37 (.70)	72.4 (139)	19.8 (38)	4.7 (9)	2.6 (5)
Temperament †	1.35 (.45)	70.8 (136)	24.0 (46)	3.6 (7)	1.0 (2)
Eyesight †	1.32 (.64)	75.0 (144)	19.3 (37)	3.1 (6)	2.1 (4)
Intelligence †	1.32 (.70)	76.6 (147)	17.2 (33)	2.1 (4)	3.6 (7)
Physical growth †	1.31 (.65)	76.0 (146)	18.2 (35)	2.6 (5)	2.6 (5)
Bowel movements	1.29 (.58)	75.5 (145)	19.8 (38)	3.1 (6)	1.0 (2)
Ability to pay attention	1.28 (.65)	79.7 (153)	15.1 (29)	1.6 (3)	3.1 (6)
Recognizing you/bonding with you	1.28 (.63)	78.6 (151)	15.6 (30)	3.1 (6)	2.1 (4)
Making Sound	1.20 (.52)	83.9 (161)	12.5 (24)	2.1 (4)	1.0 (2)
Ability to move/grasp	1.16 (.48)	87.5 (168)	9.4 (18)	1.6 (3)	1.0 (2)
Recognizing objects	1.15 (.42)	87.0 (167)	10.9 (21)	1 (2)	0.5 (1)
Average	1.39 (.67)	71.0 (130)	21.0 (39)	5 (9)	2.0 (4)

* = The number does not total 192 because of missing data

† = *t*-tests with a Bonferroni correction were used to compare the hearing item to all other items; these items were not statistically significantly different from the hearing item.

‡ = Percent of mothers completing a Time 1 questionnaire; percents do not add up to 100 due to rounding

Table 4. Percent of all Mothers “Moderately Worried” or “Very Worried” About the 21 Aspects of Infant Health Measured by the IHCS at Time 1 and Time 2

Aspect of Infant Health	Percent worried or very worried (N)			
	Time 1		Time 2	
Eating Habits	14.6	(28)	5.3	(5)
Hearing	14.6	(28)	4.3	(4)
Getting a major disease	13.0	(25)	6.4	(6)
Not waking up from sleep	10.9	(21)	5.3	(5)
Sleeping habits	10.9	(21)	3.2	(3)
Lungs working right	9.3	(18)	1.1	(1)
Heart working right	8.7	(17)	3.2	(3)
Getting enough fluid	8.4	(16)	4.2	(4)
Irritability, crying, or colic	8.4	(16)	11.6	(11)
Digestion	7.9	(15)	9.5	(9)
Weight	7.3	(14)	3.2	(3)
Intelligence	5.7	(11)	3.2	(3)
Eyesight	5.2	(10)	1.1	(1)
Physical growth	5.2	(10)	3.2	(3)
Recognizing you/bonding with you	5.2	(10)	2.1	(2)
Ability to pay attention	4.7	(9)	1.1	(1)
Temperment	4.6	(9)	3.2	(3)
Bowel movements	4.1	(8)	8.5	(8)
Making Sounds	3.1	(6)	1.1	(1)
Ability to move/grasp	2.6	(5)	2.2	(2)
Recognizing objects	1.5	(3)	3.2	(3)
Average	7.4	(14.0)	4.1	(3.8)

* IHCS = short form for Infant Health Concerns Scale

Table 5. Differences in IHCS Average Scores for Mothers Whose Babies Passed the Initial Screen Compared to Those Who Failed the Initial Screen and Passed an Outpatient Screen

	Infants' screening results for each group of mothers	Mean* (n)	Difference of Means	t	df	p
Time 1	Initial Screen: Pass	1.36 (83)	0.07	0.84	115	0.40
	Initial Screen: Fail Outpatient Screen: Pass	1.29 (34)				
Time 2	Initial Screen: Pass	1.21 (60)	0.04	0.66	76	0.51
	Initial Screen: Fail Outpatient Screen: Pass	1.17 (18)				

Note. IHCS = short form for Infant Health Concerns Scale

*The IHCS mean score is the average of scores on 21 four-point likert type items ranging from 1 (not at all worried) to 4 (very worried).

puts this finding in context by including information about results 6 weeks later and by comparing worry about hearing with worry about other aspects of the infant's health and behavior. At 6 weeks after birth (during which time all of the infants in the sample who failed the inpatient screen received an outpatient hearing screening test after being discharged from the hospital) only 4.3% of the mothers in the initial fail group continued to feel moderately

worried or very worried about their infant's hearing. Thus, newborn hearing screening does not seem to have a persistent negative consequence for more than 95% of mothers. Furthermore, hearing was found to be of no greater concern than many other aspects of infant health and behavior (e.g., eating or sleeping habits, irritability, physical growth, digestion, etc.) about which mothers may be concerned. These data provide convincing evidence that

hearing screening does not lead to higher levels of worry about hearing than is the case for many other aspects of infant health and/or behavior that mothers normally experience.

A major concern of many infant screening programs is whether a parent whose infant has a false-positive result will continue to worry that his/her infant may have a condition despite subsequent screenings or diagnoses indicating that the infant does not have the condition (e.g., Clayton and Tharpe, 1998; Paradise, 1999). In the study reported here, 15% of the mothers whose infants had a false-positive hearing screen (the fail/pass group) were moderately worried or very worried about their infant's hearing at Time 1, which is consistent with the 14% to 25% found in prior studies. However, at the follow-up assessment six weeks later, none of the mothers in the fail/pass group were moderately worried or very worried about their infant's hearing. Shortly after the birth of the baby, mothers in the fail/pass group were worried more about their infant's hearing than any of the 20 other aspects of infant development measured by this study, but most of these concerns had disappeared 6 weeks later.

In comparison to mothers whose infants passed the initial hearing screen, mothers in the fail/pass group did not have significantly higher levels of worry about infant hearing when the baby was about six weeks of age. This indicates that most mothers of infants who had a false-positive hearing screen were initially concerned (which is probably appropriate) about their infant's failed inpatient screen, but that this concern almost always disappeared after their infant passed an outpatient screen following discharge from the hospital. Consistent with prior research, there was no group difference on levels of maternal anxiety as measured by the STAI between mothers whose infants had a false-positive hearing screen and mothers whose infants passed the initial hearing screen at either Time 1 or at the follow-up at Time 2.

Conclusions

The results of this study provide even stronger evidence than was previously available that newborn hearing screening does not create undue maternal worry. The evidence is stronger because it included an assessment of the degree to which mothers were worried about their infant's hearing compared to other conditions or variables (e.g., sleeping habits, eating habits, vision, etc.) about which mothers may worry. Clearly, a few mothers were worried about their baby's hearing, but it is important to note that fewer mothers worried about hearing than about eating habits, irritability, sleeping habits, not waking up from sleep, and getting a major disease. Furthermore, there were no statistically significant differences shortly after the infant's birth or six weeks later between the number of mothers worried about hearing and those worried about such issues as digestion, lungs working right, weight, temperament, and eyesight. These data suggest that the relatively small number of mothers who worry about

hearing is a function of the normal concerns that mothers have about new babies and is not a negative reaction caused by newborn hearing screening.

Interestingly, even though much of the previous literature refers to parental worry virtually all of that research has been conducted with mothers. It would be good if future research on this topic could also include fathers.

The fact that a significant number of mothers whose infants failed the hospital-based newborn hearing screening are initially worried about hearing may be good because it should increase the motivation for mothers of these infants to follow-up with subsequent screening and diagnostic tests. Of course, the fact that mothers are initially worried underscores the importance of continuing to devote time and effort to parent education to ensure that parents understand why newborn hearing screening is being done and what steps, if any, they should take following screening. Future research on this issue would do well to include measurements of parental understanding of the screening results because misunderstanding may contribute to elevated levels of worry (Arnold et al., 2006). It would also be valuable for future research to examine the effects of providing information about screening results to parents in different ways with different content.

The bottom line is that the results of this study, in combination with previous research on this issue, provide convincing evidence that newborn hearing screening is not creating undue maternal anxiety.

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What Are Others Publishing about Early Hearing Detection and Intervention?

The aim of the Journal of Early Hearing Detection and Intervention (JEHDI) is to promote access to evidence-based practice, standards of care, and research focused on all aspects of Early Hearing Detection and Intervention. Taking a broad systems perspective, JEHDI publishes peer-reviewed articles that describe current research, evidence-based practice, and standards of care specifically focused on newborn and early childhood hearing screening, diagnosis, family support, early intervention, the medical home, information management, financing, quality improvement and other issues that contribute to improving EHD systems.

Whereas JEHDI is the only journal that focuses specifically on improving EHD systems, many other journals publish relevant articles as a part their journal's broader focus. To help JEHDI readers stay up-to-date about recently published material, we provide titles and abstracts of what has been published in the last 12 months that JEHDI editors think are most relevant to improving EHD programs. Titles of all articles are hyperlinked to the source.

1. Antoni M, Rouillon I, Denoyelle F, Garabédian EN, Loundon N.

Newborn hearing screening: Prevalence and medical and paramedical treatment of bilateral hearing loss in a neonatal series in the Île-de-France region of France. *Eur Ann Otorhinolaryngol Head Neck Dis.* 2015 Oct 28. pii: S1879-7296(15)00153-2. doi: 10.1016/j.anorl.2015.10.001

Objectives: We report results for newborn hearing screening in a cohort of children born in the Île-de-France region of France, as part of a national screening program set up by the French national health insurance agency.

Materials and Methods: A prospective study was performed on neonates undergoing hearing screening by automated auditory brainstem response at 35dB in maternity departments between 2005 and 2011. In case of positive findings, a further check was performed; if this was also positive in one or both ears, the child was referred to the diagnostic center.

Results: The study recruited 27,885 births; 96% of neonates were tested. Retest was positive in 0.84% of cases. Bilateral hearing loss was diagnosed in 0.63% of infants. Fifty-nine percent of these had ≥ 1 risk factor. Hearing normalized by end of follow-up in 25% of cases. Hearing loss was moderate in 59% of hearing-impaired children, severe in 12% and profound in 29%. Mean age at hearing aid fitting ranged from 4months in profound hearing loss to 11.4months in moderate hearing loss. In children receiving a cochlear implant, mean age at implantation was 14 months.

Conclusion: Newborn hearing screening is now public policy. It is effective in terms of exhaustiveness, age at diagnosis and early management. Caution is appropriate in the treatment of moderate hearing loss. In case of moderate hearing loss associated with otitis media serosa, transtympanic aerators should be suggested as of the age of 6months to enable hearing threshold measurement. Hearing aid fitting can then be considered around 9months of age if hearing has not improved.

2. Avison J & Jactett R.

Traceability in newborn hearing screening via an auditory-evoked response simulator. *International Journal of Audiology* 2015; 54: 559–561

More than 0.75 million babies are born each year in the UK and each is offered hearing screening within the first few days of life through newborn hearing screening programmes (NHSPs). Similar practices are also adopted in many other countries. With the wellbeing of so many infants riding on the efficacy of each screening programme, it's essential that quality assurance measures are in place for every part of the screening process. The technology and techniques used in hearing screening have developed at a rapid rate and a wide variety of screening devices are in use. Standardization and calibration methods inevitably lag behind any new technology and as a consequence there are some traceability gaps that need to be filled (Durrant et al, 2007). The authors propose the use of an auditory-evoked response simulator to provide a traceability route for hearing screening devices.

For any measurement to be meaningful, it must be traceable to some reference standard. In pure-tone audiometry, for example, traceability of the acoustic stimulus is achieved through the use of ear simulators (BS EN 60318-1:2009) which are in turn calibrated using calibrated reference microphones. This method of reference standard dissemination ensures that all pure-tone audiometry measurements are of well-defined accuracy and are directly comparable. This is not currently the case for evoked response measurements. Here, both the acoustic stimulus and the response must be considered. Calibration methods for the stimulus already exist (BS EN 60645-3:2007; BS EN 60645-6:2010; BS EN 60645-7:2010), and a current European project, EARS (EMRP 2014), is attempting to further improve their accuracy for neonatal ears. However, there are no objective methods that provide measurement traceability or interpretation of the response, whether acoustical as in the case of OAE, or electrophysiological as in the case of ABR.

As it stands, the efficacy of any NHSP relies on proprietary algorithms and hardware and is without a mechanism for independent or ongoing verification. The auditory-evoked response simulator is proposed as an objective and independent solution to that problem. It could be used in a variety of ways: not only for providing traceability during annual maintenance but also for detecting equipment faults in situ on a daily basis; for demonstrating the equivalence of different models of screening device; and as a tool to aid the training and competency assessment of newborn hearing screeners.

The authors anticipate that the primary application of the auditory-evoked response simulator would be the verification of automated hearing screening devices. These devices make decisions with minimal human input, and their operators will not necessarily have the time, tools, or technical expertise to identify when faults have occurred. The simulator could additionally be applied to audiological assessment, providing realistic and repeatable signals for testing, hardware development, demonstrations, and training.

3. Caluraud S, Marcolla-Bouchetemplé A, de Barros A, Moreau-Lenoir F, de Sevin E, Rerolle S, Charrière E, Lecler-Scarcella V, Billet F, Obstoy MF, Amstutz-Montadert I, Marie JP, Lerosey Y.

Newborn hearing screening: analysis and outcomes after 100,000 births in Upper-Normandy French region. *Int J Pediatr Otorhinolaryngol.* 2015 Jun;79(6):829-33. doi: 10.1016/j.ijporl.2015.03.012

Objectives: Neonatal hearing impairment is a common disorder with a prevalence of 1 to 2‰ worldwide, with significant consequences on overall development when rehabilitated too late. New-born hearing screening has been implemented in the 1990s in most European countries and the USA. The Upper-Normandy region of France has been conducting a pilot program since 1999. The aim of this prospective study was to evaluate and critically analyse it.

Methods: The Upper-Normandy universal new-born hearing screening program is performed in two steps. Between 1999 and 2004, first, we administered a Transient Evoked Oto Acoustic Emission (TEOAE) test was administered a few days after birth for healthy newborns without risk factors. For newborns admitted to a neonatal intensive care unit (NICU) or presenting risk factors, was administered an automated auditory brainstem response (AABR) test prior to discharge. Second, newborns who failed the initial hearing screening were retested as outpatients using TEOAE. Since 2004, infants who failed the initial screen were tested with AABR 3 to 4 weeks later as outpatients, providing an opportunity to compare the two protocols.

Results: Overall screening coverage in the Upper-Normandy region is 99.8%. First step coverage is 99.58% in well-infant nurseries and 97.09% in the NICU. The test-retest procedure during the first step and the use of AABR for the second resulted in higher follow-up rates and lower false positive rates.

Conclusion: The Upper-Normandy region universal newborn hearing screening program facilitated diagnosis and rehabilitation of infants before age of 9 months, most notably when severe to profound hearing impairment was found.

4. Chan KT, Wong EC, Law CW, Chong HM, McPherson B.

Improving newborn hearing screening: Are automated auditory brainstem response ear inserts an effective option? *Int J Pediatr Otorhinolaryngol.* 2015 Nov;79(11):1920-5. doi: 10.1016/j.ijporl.2015.09.008

Objective: Universal newborn hearing screening is an established practice among Hong Kong public hospitals using a 2-stage automated auditory brainstem response (AABR) screening protocol. To enhance overall efficiency without sacrificing program accuracy, cost reduction in terms of replacing the initial ear coupler-based screening with a more economical ear insert-based screening procedure was considered. This study examined the utility of an insert-based AABR initial screening approach and the projected cost-effectiveness of a combined probe-based plus follow-up ear coupler AABR screening procedure.

Methods: Following prenatal maternal consent, newborn hearing screening was conducted with 167 healthy neonates using a cross-sectional, repeated measures study design. The neonates were screened with AABR sequentially; using ear coupler and ear probe (insert) procedures, in both ears, with two different but comparable AABR instruments. Testing took place in the antenatal ward of a department of obstetrics and gynaecology, at a large public hospital.

Results: With the specific combination of instruments deployed for this study insert-based AABR screening generated a five-fold higher rescreen rate and took an additional 50% screening time compared to coupler-based AABR screening. Although the cost of consumables used in a 2-stage AABR screening protocol would reduce by 9.87% if the combined procedure was implemented, the findings indicated AABR screening when conducted with an ear probe has reduced utility compared with conventional ear coupler screening.

Conclusion: Significant differences may occur in screening outcomes when changes are made to coupler method. Initiating a 2-stage AABR screening protocol with an ear insert technique may be impracticable in newborn nurseries given the greater number of false positive cases generated by this approach in the present study and the increased time required to carry out an insert-based procedure.

5. Chen JL.

Newborn hearing screening may predict Eustachian tube dysfunction. *Int J Pediatr Otorhinolaryngol.* 2015 Sep 28. pii: S0165-5876(15)00468-1. doi: 10.1016/j.ijporl.2015.09.021.

Introduction: There is evidence for temporary hearing loss in neonates immediately after birth because of residual liquid derived from amniotic fluid in the ME cavity. This study examines whether a referred newborn hearing screen (NBHS) with subsequent testing confirming normal hearing can be attributed to persistence of middle ear effusion and predict poor Eustachian tube function manifested as recurrent otitis media or otitis media with effusion in the first year of life. The aims of the present study are to investigate the following: (1) whether infants who fail a neonatal hearing screen and subsequently pass are more likely to experience recurrent otitis media or otitis media with effusion, (2) whether these infants are more likely to obtain tympanostomy tubes.

Methods: This retrospective cohort study examined newborns who referred their NBHS and were subsequently noted to have normal hearing and a control group comprised of newborns who passed their NBHS. Univariate and multivariate analysis was performed on the data collected as well as generation mean cumulative function plots.

Results: The baseline characteristics of the case and control groups are not statistically significant with regards to gender, number of otitis media (OM), delivery mode, or the need for tubes in the follow up period. Within the refer group, those with bilateral refers were twice as likely to have otitis media than those with a unilateral refer ($p=0.012$). The logistic regression model for odds of subsequent otitis media was not statistically significant for bilateral or unilateral refer though the logistic regression model for odds of tubes demonstrated a statistically significant increased risk in bilateral refer patients. With time to event analysis, it was seen that bilateral refer patients are more likely to have OM than control and unilateral refer patients.

Conclusion: There is no difference in the incidence of subsequent OM between those infants who passed the NBHS versus those who initially referred and then passed subsequent audiology examination. However there was a difference in the number of otitis media between those infants who referred bilaterally versus those who referred unilaterally.

6. Elpers J, Lester C, Shinn JB, Bush ML.

Rural Family Perspectives and Experiences with Early Infant Hearing Detection and Intervention: A Qualitative Study. *J Community Health.* 2015 Aug 28.

Infant hearing loss has the potential to cause significant communication impairment. Timely diagnosis and intervention is essential to preventing permanent deficits. Many infants from rural regions are delayed in diagnosis and treatment of hearing loss. The purpose of this study is to characterize the barriers in timely infant hearing healthcare for rural families following newborn newborn hearing screening (NHS) testing. Using stratified purposeful sampling, the study design involved semi-structured phone interviews with parents/guardians of children who failed NHS testing in the Appalachian region of Kentucky between 2012 and 2014 to describe their experiences with early hearing detection and intervention program. Thematic qualitative analysis was performed on interview transcripts to identify common recurring themes in content. 40 parents/guardians participated in the study and consisted primarily of mothers. Demographic data revealed limited educational levels of the participants and 70 % had

state-funded insurance coverage. Participants reported barriers in timely infant hearing healthcare that included poor communication of hearing screening results, difficulty in obtaining outpatient testing, inconsistencies in healthcare information from primary care providers, lack of local resources, insurance-related healthcare delays, and conflict with family and work responsibilities. Most participants expressed a great desire to obtain timely hearing healthcare for their children and expressed a willingness to use resources such as telemedicine to obtain that care. There are multiple barriers to timely rural infant hearing healthcare. Minimizing misinformation and improving access to care are priorities to prevent delayed diagnosis and treatment of hearing loss.

7. Fitzpatrick E, Hamel C, Stevens A, Pratt M, Moher D, Doucet S, Neuss D, Bernstein A, Na E.

Sign Language and Spoken Language for Children with Hearing Loss: A Systematic Review.

Pediatrics. 2015 Dec 18.

Children with mild bilateral and unilateral hearing loss are now commonly identified early through newborn hearing screening initiatives. There remains considerable uncertainty about how to support parents and about which services to provide for children with mild bilateral and unilateral hearing loss. The goal of this study was to learn about parents' experiences and understand, from their perspectives, the impact of hearing loss in the mild range on the child's functioning. Parents of 20 children in Ontario, Canada, participated in the study. The median age of identification of hearing loss was 4.6 months (interquartile range: 3.6, 10.8). Parents appreciated learning early about hearing loss, but their experiences with the early process were mixed. Parents felt that professionals minimized the importance of milder hearing loss. There was substantial uncertainty about the need for hearing aids and the findings suggest that parents need specific guidance. Parents expressed concerns about the potential impact of hearing loss on their child's development, particularly at later ages.

8. Fitzpatrick E, Grandpierre V, Durieux-Smith A, Gaboury I, Coyle D, Na E, Sallam N.

Children With Mild Bilateral and Unilateral Hearing Loss: Parents' Reflections on Experiences and Outcomes. J

Deaf Stud Deaf Educ. 2015 Oct 3. pii: env047.

Children with mild bilateral and unilateral hearing loss are now commonly identified early through newborn hearing screening initiatives. There remains considerable uncertainty about how to support parents and about which services to provide for children with mild bilateral and unilateral hearing loss. The goal of this study was to learn about parents' experiences and understand, from their perspectives, the impact of hearing loss in the mild range on the child's functioning. Parents of 20 children in Ontario, Canada, participated in the study. The median age of identification of hearing loss was 4.6 months (interquartile range: 3.6, 10.8). Parents appreciated learning early about hearing loss, but their experiences with the early process were mixed. Parents felt that professionals minimized the importance of milder hearing loss. There was substantial uncertainty about the need for hearing aids and the findings suggest that parents need specific guidance. Parents expressed concerns about the potential impact of hearing loss on their child's development, particularly at later ages.

9. Giordano T, Marchegiani AM, Germiller JA.

Children With Sensorineural Hearing Loss And Referral To Early Intervention.

ORL Head Neck Nurs. 2015 Summer;33(3):10-4.

Objective: Sensorineural hearing loss (SNHL) is identified at a rate of 1-3 per 1,000 newborns in the United States. Timely referral to Early Intervention (EI) services is critical, as early EI referral has been shown to improve outcomes, including speech and language development, social and emotional development, and academic performance. The objective of this study was to determine the rate at which children diagnosed with SNHL at a large tertiary referral center were referred to EI, and, if so, by whom. In addition, we sought to determine the time from the diagnosis of SNHL to the completion of the referral, and what services were received.

Design: Prospective observational study

Methods: Data were collected by telephone survey and review of the electronic medical record

Results: Children with SNHL were referred to and participated in EI at a high rate. All children in this study (100%) were referred to EI. Most (92%) of the children were referred by 6 months of age, and almost all (98%) participated in EI.

Conclusion: At our institution, children with SNHL are being consistently referred to EI, meeting the goals of the Early Hearing Detection and Intervention program. Future outcomes research can now be designed to determine whether achieving these benchmark goals improves children's academic performance, expressive and receptive language skills, and development as compared to age-matched, normal hearing peers.

10. Harrop-Griffiths K.

The impact of universal newborn hearing screening. Arch Dis Child doi:10.1136/archdischild-2014-307867.

About 1 in 1000 children are born each year with hearing impairment sufficiently severe to compromise speech and language development and communication. There has been much work in recent years to reduce the age of diagnosis and intervention for these children. The paper by Pimperton et al,¹ provides important evidence to support the observations of those working clinically with these children, that early identification and habilitation of significant hearing impairment in children pays dividends in terms of education. The cohort of children on whom this paper is based was identified by universal newborn hearing screening before the establishment of NHSP, the national newborn hearing screening programme. The same cohort was studied earlier at an average age of 7.9 years² when significant benefit in language development was shown in those diagnosed before 9 months of age compared with those identified when older than 9 months. The particular value of this paper is that it has looked at performance in the second decade as well as the first, and there is a paucity of work in this age group. Pimperton et al have highlighted the value of early diagnosis and intervention in establishing good language skills, which underpin later reading comprehension.

11. Januário GC, Lemos SM, Friche AA, Alves CR.

Quality indicators in a newborn hearing screening service. Braz J Otorhinolaryngol. 2015 May-Jun;81(3):255-63. doi:

10.1016/j.bjorl.2014.08.008.

Introduction: Newborn hearing screening (NHS) programs are implemented across the globe to detect early hearing impairment. In order to meet this objective, the quality of these programs should be monitored using internationally recognized indicators.

Objective: To evaluate a newborn hearing screening service (NHSS) using international quality indicators.

Methods: A retrospective cohort study on the NHSS of Minas Gerais was conducted, analyzing the services performed between 2010 and 2011. Results were analyzed according to criteria from the American Academy of Pediatrics and the Joint Committee on Infant Hearing.

Results: This study assessed 6987 children. The proportions of cases that were referred for a retest, that followed through with retest, and that were referred for diagnosis were 8.0%, 71.9%, and 2.1%, respectively. The proportion of assessed newborn children in the first 30 days of life in this study was 65%. The median age of those children who failed both the NHS and the retest was significantly higher than the other children. The chance of a

child with a hearing impairment risk indicator to fail the NHS was 2.4 times higher than of those without a risk indicator. Conclusion: NHSS achieved three of four evaluated indicators. Despite this, it is still necessary to perform NHS earlier and to ensure that the subsequent steps are followed.

12. Kemalöglü YK, Gökdoğan Ç, Gündüz B, Önal EE, Türkyılmaz C, Atalay Y.

Newborn hearing screening outcomes during the first decade of the program in a reference hospital from Turkey.

Eur Arch Otorhinolaryngol. 2015 Jun 3.

In this study, the authors report the results of a three-stage newborn hearing screening (NHS) program for well babies at the Gazi University Hospital (GUH) in Ankara between 2003 and 2013. GUH-NHS was performed by automated transient evoked otoacoustic emission (a-TEOAE) at the first and second steps and by automated brainstem audiometry (a-ABR) at the third step. The data were analysed to assess not only rate of congenital permanent hearing loss (CPHL), but also the effectiveness of the program during the years. A total of 18,470 well babies were tested. The data showed that coverage ratio for the GUH-born babies was increased and more outside-born babies (OBB) were admitted by time (means 84.31 and 11.28 %, respectively). Mean CPHL was found to be 0.26 %. Mean referral rate was decreased to 0.81 % by a-ABR from 2.16 % by a-TEOAE. Mean of missed cases in any stage of GUH-NHS was 4.88 %. It was seen that neither CPHL nor referral rate, but only ratio of missed ones presented increase in parallel to increment in OBB. This paper first presents that clinically acceptable screening procedures developed in GUH by time, and secondly higher rate of CPHL in Turkey than in the Western countries, and benefits of third stage screening by a-ABR because it prevented referral of 251 children (1.29 %) to the clinical tests. We think that this number is reasonably important regarding not only economical point of view, but also waiting lists in the audiology departments in a developing country, in which audiological service is still limited.

13. Khoza-Shangase K, Harbinson S.

Evaluation of universal newborn hearing screening in South African primary care. *Afr J Prim Health Care Fam Med.*

2015 May 21;7(1). doi: 10.4102/phcfm.v7i1.769.

Background: Universal Newborn Hearing Screening (UNHS) is the gold standard toward early hearing detection and intervention, hence the importance of its deliberation within the South African context.

Aim: To determine the feasibility of screening in low-risk neonates, using Otoacoustic Emissions (OAEs), within the Midwife Obstetric Unit (MOU) three-day assessment clinic at a Community Health Centre (CHC), at various test times following birth.

Method: Within a quantitative, prospective design, 272 neonates were included. Case history interviews, otoscopic examinations and Distortion Product OAEs (DPOAEs) screening were conducted at two sessions (within six hours and approximately three days after birth). Data were analysed via descriptive statistics.

Results: Based on current staffing profile and practice, efficient and comprehensive screening is not successful within hours of birth, but is more so at the MOU three-day assessment clinic. Significantly higher numbers of infants were screened at session 2, with significantly less false-positive results. At session 1, only 38.1% of the neonates were screened, as opposed to more than 100% at session 2. Session 1 yielded an 82.1% rate of false positive findings, a rate that not only has important implications for the emotional well-being of the parents; but also for resource-stricken environments where expenditure has to be accounted for carefully.

Conclusion: Current findings highlight the importance of studying methodologies to ensure effective reach for hearing screening within the South African context. These findings argue for UNHS initiatives to include the MOU three-day assessment to ensure that a higher number of neonates are reached and confounding variables such as vernix have been eliminated.

14. Lammers MJ, Jansen TT, Grolman W, Lenarz T, Versnel H, van Zanten GA, Topsakal V, Lesinski-Schiedat A.

The influence of newborn hearing screening on the age at cochlear implantation in children. *Laryngoscope.* 2015

Apr;125(4):985-90. doi: 10.1002/lary.25045.

Objective/Hypothesis: To evaluate the influence of the introduction of newborn hearing screening programs on the age at cochlear implantation in children.

Study Design: Retrospective, multicenter cohort study.

Methods: All 1,299 pediatric cochlear implant users who received their implants before the age of 5 years between 1995 and 2011 in the Medical University Hannover, Germany and University Medical Center Utrecht, the Netherlands were enrolled in this study. Age at implantation and the number of children implanted within the first year of life was assessed for each center.

Results: Age at cochlear implantation gradually declined over the years in both centers. The introduction of the screening resulted in significant decline in the age at implantation in the Netherlands; simultaneously, the number of children implanted within their first year of life increased significantly. Comparing 4-year epochs immediately before and after introduction of the screening, the mean age decreased from 2.4 to 1.2 years, and the percentage of early implanted children increased from 9% to 37%. In the German population, a similar effect of the introduction of the hearing screening program was absent.

Conclusion: The introduction of the national newborn hearing screening program has reduced the age at cochlear implantation in young children in the Netherlands but not in Germany. Correspondingly, it resulted in an increase in the number of children implanted early in life. The difference between the Dutch and German population might be due to differences in the follow-up and referral after the hearing screening.

15. Lima MC, Rossi TR, França MF, Collela-Santos MF, Correa CR.

Analysis of neonatal hearing screening program performed on an outpatient basis: Analysis of an outpatient hearing screening program. *Int J Pediatr Otorhinolaryngol.* 2015 Oct 27. pii: S0165-5876(15)00516-9. doi: 10.1016/j.ijporl.2015.10.009. [Epub ahead of print]

Objective: The aims of the present study were to analyze the coverage of an outpatient hearing screening program in a public hospital for healthy newborns, to describe the social and demographic profile of the mothers and to identify the prevalence of infants with severe or profound hearing losses.

Methods: The method was descriptive and retrospective. In 2002 and 2003, the newborn hearing screening program was initiated in the maternity ward. Due to many logistic problems, in 2004, we implemented screening on an outpatient basis. Thus, upon discharge from the hospital, the mothers received a printed schedule referring the baby to an outpatient clinic. A two-stage screening protocol was implemented. The screening results were presented from 2004 to 2013.

Results: The program was initiated on an outpatient basis in 2004. From 2004 to 2013, 14,882 infants were screened but the complete data for 14,205 cases were obtained. The adherence of the families was 32% in 2004 and increased to 85% in 2013. The mean age of the screened newborns was 48.66 days in 2005 and 24.53 days in 2013. The number of newborns who failed the test and were referred for diagnosis decreased from 12.3% in 2004 to 3% in 2013. The majority of the mothers were young, 69.77% of them aged up to 29 years old and 74.86% had completed basic education.

Seventy infants showed hearing loss, totaling 0.49% or approximately 5 cases in 1000, with eight individuals diagnosed with severe or profound sensorineural hearing loss, totaling 0.06% or approximately six cases in 10,000.

Conclusions: The newborn hearing screening program offered by a public hospital in Brazil, over the years, has increased the coverage from 32% to 85%, and so, can be performed on an outpatient basis as an alternative to overcome the operating limitations that might occur in hospital hearing screening. The mothers of the newborns were young and had complete basic education; the prevalence was similar to international studies as hearing loss is concerned.

16. Moeller, Mary Pat; Tomblin, J. Bruce

An Introduction to the Outcomes of Children with Hearing Loss Study *Ear & Hearing: November/December 2015 - Volume 36 - Issue - p 4S–13S. doi: 10.1097/AUD.0000000000000210*

The landscape of service provision for young children with hearing loss has shifted in recent years as a result of newborn hearing screening and the early provision of interventions, including hearing technologies. It is expected that early service provision will minimize or prevent linguistic delays that typically accompany untreated permanent childhood hearing loss. The post-newborn hearing screening era has seen a resurgence of interest in empirically examining the outcomes of children with hearing loss to determine if service innovations have resulted in expected improvements in children's functioning. The Outcomes of Children with Hearing Loss (OCHL) project was among these recent research efforts, and this introductory article provides background in the form of literature review and theoretical discussion to support the goals of the study. The Outcomes of Children with Hearing Loss project was designed to examine the language and auditory outcomes of infants and preschool-age children with permanent, bilateral, mild-to-severe hearing loss, and to identify factors that moderate the relationship between hearing loss and longitudinal outcomes. The authors propose that children who are hard of hearing experience limitations in access to linguistic input, which lead to a decrease in uptake of language exposure and an overall reduction in linguistic experience. The authors explore this hypothesis in relation to three primary factors that are proposed to influence children's access to linguistic input: aided audibility, duration and consistency of hearing aid use, and characteristics of caregiver input

17. Müller J, Fechner H, Köhn A, Reißmann A.

Newborn Hearing Screening - Results of a Parental Survey in Saxony-Anhalt.

Gesundheitswesen. 2015 Jun 25.

Background: In recent years quality assurance has become an essential part of today's health-care system in the wake of the modern patient-oriented quality management. With the statutory introduction of newborn hearing screening (NHS) in 2009, a quality assurance of these early detection methods has become necessary. The aim of the study was to determine patient satisfaction in relation to the NHS in Saxony-Anhalt.

Patients/Methods: During the period from November 2013 to April 2014, 394 parents were retrospectively interviewed about their experiences and expectations in relation to the NHS, using a standardised questionnaire. In total, 21 child care centres and 6 paediatric primary care centres from all over Saxony-Anhalt were involved.

Results: It turns out that the majority of parents are satisfied with the NHS and 97.7% are in favour of the offer of an NHS. Of the surveyed parents, 69.3% felt the information as sufficient. However, only 66.2% of parents took a closer look at the leaflet issued by the G-BA. In addition, 17.7% of respondents are dissatisfied with the professional competence of the examining staff.

Conclusion: The study shows that the general attitude among parents towards newborn hearing screening was very positive. They felt reassured by it although there are some aspects still open to criticism.

18. Muñoz, Karen; Olson, Whitney A.; Twohig, Michael P.; Preston, Elizabeth; Blaiser, Kristina; White, Karl R.

Pediatric Hearing Aid Use: Parent-Reported Challenges

Ear & Hearing: March/April 2015 - Volume 36 - Issue 2 - p 279–287doi: 10.1097/AUD.0000000000000111

Objectives: The aim of this study was to investigate parent-reported challenges related to hearing aid management and parental psychosocial characteristics during the first 3 years of the child's life.

Design: Using a cross-sectional survey design, surveys were distributed to parents of children with hearing loss via state Early Intervention programs in Utah and Indiana. Packets contained one family demographic form and two sets of three questionnaires to obtain responses from mothers and fathers separately: the Parent Hearing Aid Management Inventory explored parent access to information, parent confidence in performing skills, expectations, communication with the audiologist, and hearing aid use challenges. The Acceptance and Action Questionnaire measured psychological flexibility, experiential avoidance, and internal thought processes that can affect problem-solving ability and decrease an individual's ability to take value-based actions. The Patient Health Questionnaire identified symptoms of depression. Thirty-seven families completed questionnaires (35 mothers and 20 fathers).

Results: Most responses were parents of toddlers (M = 22 months) who had been wearing binaural hearing aids for an average of 15 months. Both mothers and fathers reported that even though the amount of information they received was overwhelming, most (84%) preferred to have all the information at the beginning, rather than to receive it over an extended time period. Parents reported an array of challenges related to hearing aid management, with the majority related to daily management, hearing aid use, and emotional adjustment. Sixty-six percent of parents reported an audiologist taught them how to complete a listening check using a stethoscope, however, only one-third reported doing a daily hearing aid listening check. Both mothers and fathers reported a wide range of variability in their confidence in performing activities related to hearing aid management, and most reported minimal confidence in their ability to troubleshoot hearing aid problems. More than half of the parents reported child behavior and activities, such as playing outside, as a major hearing aid use challenge. Parents reported hearing aids were worn all waking hours by 35% of children and less than 5 hr/day by 31%. Almost half of the parents (47%) did not feel that they had enough time to talk about their emotions when speaking with their audiologist(s), 69% reported the audiologist did not help them know what to expect related to emotions about their child's hearing loss, and 22% reported symptoms of depression.

Conclusions: Parents reported an array of challenges, even after their child had been wearing hearing aids for a prolonged time, revealing critical implications for how to provide audiological care. Audiologists have an important role in partnering with parents to identify and jointly problem-solving challenges related to their child's hearing aid use. Supporting parents includes not only addressing technical aspects of hearing testing and hearing aid function but also addressing parent thoughts, feelings, and emotions.

19. Pitlick MM, Orr K, Momany AM, McDonald EL, Murray JC, Ryckman KK.

Determining the prevalence of cytomegalovirus infection in a cohort of preterm infants. *J Neonatal Perinatal Med. 2015 Jul 31;8(2):137-41. doi: 10.3233/NPM-15814057.*

Background: Preterm birth is a global public health problem that is a significant cause of infant morbidity and mortality. Congenital cytomegalovirus (CMV) infection has been proposed as a risk factor for preterm birth, but the rate of CMV in infants born preterm is unclear. CMV is the leading infectious cause of sensorineural hearing loss, which will affect 15% - 20% of congenitally infected infants later in their childhood. 90% of infected

infants are asymptomatic at birth and are not recognized as at risk for CMV-associated deficits.

Objectives: To determine the prevalence of CMV infection in a large cohort of preterm infants.

Methods: DNA was extracted from cord blood, peripheral blood, saliva, and buccal swab samples collected from preterm infants. A total of 1200 unique DNA samples were tested for CMV using a nested PCR protocol. The proportions of preterm infants with CMV was compared by sample collection type, race, gender, and gestational age.

Results: A total of 37 infants tested positive for CMV (3.08%). After excluding twins, siblings, and infants older than two weeks at the time of sample collection, two out of 589 infants were CMV positive (0.3%), which was lower than the proportion of CMV observed in the general population. All positive samples came from buccal swabs.

Conclusion: Our work suggests that while CMV infection may not be greater in preterm infants than in the general population, given the neurologic consequences of CMV in preterm infants, screening of this population may still be warranted. If so, our results suggest buccal swabs, collected at pregnancy or at birth, may be an ideal method for such a program.

20. Silva DP, Lopez PS, Ribeiro GE, Luna MO, Lyra JC, Montovani JC.

The importance of retesting the hearing screening as an indicator of the real early hearing disorder. *Braz J*

Otorhinolaryngol. 2015 Jul-Aug;81(4):363-7. doi: 10.1016/j.bjorl.2014.07.019.

Introduction: Early diagnosis of hearing loss minimizes its impact on child development. We studied factors that influence the effectiveness of screening programs.

Objectives: To investigate the relationship between gender, weight at birth, gestational age, risk factors for hearing loss, venue for newborn hearing screening and "pass" and "fail" results in the retest.

Methods: Prospective cohort study was carried out in a tertiary referral hospital. The screening was performed in 565 newborns through transient evoked otoacoustic emissions in three admission units before hospital discharge and retest in the outpatient clinic. Gender, weight at birth, gestational age, presence of risk indicators for hearing loss and venue for newborn hearing screening were considered.

Results: Full-term infants comprised 86% of the cases, preterm 14%, and risk factors for hearing loss were identified in 11%. Considering the 165 newborns retested, only the venue for screening, Intermediate Care Unit, was related to "fail" result in the retest.

Conclusion: Gender, weight at birth, gestational age and presence of risk factors for hearing loss were not related to "pass" and/or "fail" results in the retest. The screening performed in intermediate care units increases the chance of continued "fail" result in the Transient Otoacoustic Evoked Emissions test.

21. Sugaya A, Fukushima K, Kasai N, Kataoka Y, Maeda Y, Nagayasu R, Toida N, Ohmori S, Fujiyoshi A, Taguchi T, Omichi R, Nishizaki K.

Impact of early intervention on comprehensive language and academic achievement in Japanese hearing-

impaired children with cochlear implants. *Int J Pediatr Otorhinolaryngol.* 2015 Oct 8. pii: S0165-5876(15)00497-8. doi: 10.1016/j.ijporl.2015.09.036.

Objectives: Early hearing detection and intervention (EHDI) is critical for achievement of age-appropriate speech perception and language development in hearing-impaired children. It has been 15 years since newborn hearing screening (NHS) was introduced in Japan, and its effectiveness for language development in hearing-impaired children has been extensively studied. Moreover, after over 20 years of cochlear implantation in Japan, many of the prelingual cochlear implant (CI) users have reached school age, and the effect of CI on language development have also been assessed. To identify prognostic factors for language development, audiological/language test scores and demographic factors were compared among prelingual severe-to-profound hearing-impaired children with CI divided into subgroups according to age at first hearing aid (HA) use and whether they received NHS.

Methods: Prelingual severe-to-profound deafened children from the Research on Sensory and Communicative Disorders (RSCD) project who met the inclusion criteria were divided into groups according to the age (in months) of HA commencement (before 6 months: group A, after 7 months: group B), and the presence or absence of NHS (groups C and D). Language development and socio-economic data were obtained from audiological/language tests and a questionnaire completed by caregivers, respectively.

Results: In total, 210 children from the RSCD project participated in this study. Group A (n=49) showed significantly higher scores on comprehensive vocabulary and academic achievement (p<0.05) than group B (n=161), with no difference in demographics except for significantly older age in group B. No differences in language scores were observed between group C (n=71) and group D (n=129), although participants of group D was significantly older and had used CIs longer (p<0.05).

Conclusion: Early use of HAs until the CI operation may result in better language perception and academic achievement among CI users with prelingual deafness. A long-term follow-up is required to assess the usefulness of NHS for language development.

22. Song CI, Kang HS, Ahn JH.

Analysis of audiological results of patients referred from newborn hearing screening program. *Acta Otolaryngol.*

2015 Nov;135(11):1113-8. doi: 10.3109/00016489.2015.1063785.

Conclusion: As tools of confirmation of sensorineural hearing loss in neonates who are 'referred' from a newborn hearing screening program, both ASSR and DPOAE have high sensitivity and specificity. In addition, ASSR can be used as a substitute for ABR.

Objectives: To analyze the confirmative audiological results of patients referred from a newborn hearing screening program.

Patients and Methods: From January 2007 to December 2013, hearing tests were performed on 474 babies (804 ears) who were 'referred' from the hospital or other maternity centers. Auditory brainstem response (ABR), auditory steady-state response (ASSR), and distortion product otoacoustic emissions (DPOAE) were used for hearing evaluation.

Results: Of 474 babies (804 ears), 232 had normal hearing, while 242 babies (358 ears) had over 30 dB nHL threshold from ABR. Among the 156 babies (312 ears) who underwent both ABR and ASSR, the mean ASSR threshold had a strong correlation with ABR threshold ($r = 0.942$, $p < 0.001$). Assuming that ABR results were the yardstick of abnormal hearing, sensitivity and specificity of ASSR to ABR were 90.6% and 95%. DPOAE tests were performed on 180 babies (360 ears), with sensitivity of 85.9% and specificity of 84.4%.

23. Unlu I, Guclu E, Yaman H.

When should automatic Auditory Brainstem Response test be used for newborn hearing screening? *Auris Nasus*

Larynx. 2015 Jun;42(3):199-202. doi: 10.1016/j.anl.2014.10.005

Objectives: The aim of this study was to investigate the referral rate and when automatic Auditory Brainstem Response (aABR) should be used for newborn hearing screening.

Methods: The present study enrolled 2933 healthy full-term infants and 176 infants with perinatal risk factors. Hearing screening using Transient Evoked Otoacoustic Emissions (TEOAEs) was performed in newborns for the first time 5 days after birth except perinatal risk factors infants. The TEOAE was repeated to neonates failing to pass at the 15th day after birth. Neonates failing to pass the second TEOAE, repeated the test again at the 30th day after birth. Neonates failing to pass the third TEOAE were referred for the second stage screening using aABR. In addition, neonates with risk factors were tested with aABR directly.

Results: In this research, 85 (2.9%) infants who could not pass the TEOAE and 176 infants exposed to perinatal risk factors, underwent the aABR test. In the aABR, 14 (7.9%) of 176 infants exposed to perinatal risk factors and 10 (11.7%) of 85 infants who could not pass the TEOAE failed to pass. As a result, hearing loss was detected in only 10 (0.34%) of 2933 healthy full-term infants.

Conclusion: TEOAE should be performed at least twice in healthy full-term infants before aABR, because aABR is to be performed by specially trained personnel and takes a long time. In view of these results, it is our opinion that infants without perinatal risk factors should undergo TEOAE screening test and infants who did not pass control screening tests and have perinatal risk factors should absolutely undergo aABR test. But it should be remembered that TEOAE can cause a problem to miss auditory neuropathy in infants without perinatal risk factors.

24. Van Dyk M, Swanepoel de W, Hall JW 3rd.

Outcomes with OAE and AABR screening in the first 48 h--Implications for newborn hearing screening in developing countries. *Int J Pediatr Otorhinolaryngol.* 2015 Jul;79(7):1034-40. doi: 10.1016/j.ijporl.2015.04.021

Objective: Early discharge of newborns (<24h after birth) from birthing centres is an important barrier to successful newborn hearing screening (NHS) in developing countries. This study evaluated the outcome of NHS within the first 48 h using an automated auditory brainstem response (AABR) device without the need for costly disposables typically required, and transient evoked otoacoustic emissions (TEOAE).

Methods: NHS was performed on 150 healthy newborns (300 ears) with TEOAE and AABR techniques before discharge at a hospital. A three-stage screening protocol was implemented consisting of an initial screen with TEOAE (GSI AUDIOscreeener+) and AABR (BERAphone®) MB 11). Infants were screened at several time points as early as possible after birth. Infants were only re-screened if either screening technique (TEOAE or AABR) initially yielded a refer outcome. The same audiologist performed all TEOAE and AABR screenings.

Results: Over the three-stage screen AABR had a significantly lower refer rate of 16.7% (24/144 subjects) compared to TEOAE (37.9%; 55/145 subjects). Screening refer rate showed a progressive decrease with increasing age. For both TEOAE and AABR, refer rate per ear screened 24h post birth was significantly lower than for those screened before 24h. For infants screened before 12h post birth, the AABR refer rate per ear (51.1%) was significantly lower than the TEOAE refer rate (68.9%). Overall AABR refer rate per ear was similar for infants screened between 24 to 36 h (20.2%) and 36 to 48 h (18.9%) but significantly lower than for TEOAE (40.7% and 41.9%, respectively). Lowest initial refer rates per ear (TEOAE 25.8%, AABR 3.2%) were obtained after 48 h post birth.

Conclusion: In light of the early post birth discharge typical in developing countries like South Africa, in-hospital screening with AABR technology is significantly more effective than TEOAEs. AABR screening with a device like the MB 11 is particularly appropriate because disposable costs are negligible.

25. Vos B, Senterre C, Lagasse R; SurdiScreen Group, Levêque A.

Newborn hearing screening programme in Belgium: a consensus recommendation on risk factors. *BMC Pediatr.* 2015 Oct 16;15(1):160. doi: 10.1186/s12887-015-0479-4.

Background: Understanding the risk factors for hearing loss is essential for designing the Belgian newborn hearing screening programme.

Accordingly, they needed to be updated in accordance with current scientific knowledge. This study aimed to update the recommendations for the clinical management and follow-up of newborns with neonatal risk factors of hearing loss for the newborn screening programme in Belgium.

Methods: A literature review was performed, and the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) system assessment method was used to determine the level of evidence quality and strength of the recommendation for each risk factor. The state of scientific knowledge, levels of evidence quality, and graded recommendations were subsequently assessed using a three-round Delphi consensus process (two online questionnaires and one face-to-face meeting).

Results: Congenital infections (i.e., cytomegalovirus, toxoplasmosis, and syphilis), a family history of hearing loss, consanguinity in (grand)parents, malformation syndromes, and foetal alcohol syndrome presented a 'high' level of evidence quality as neonatal risk factors for hearing loss. Because of the sensitivity of auditory function to bilirubin toxicity, hyperbilirubinaemia was assessed as a 'moderate' level of evidence quality. In contrast, a very low birth weight, low Apgar score, and hospitalisation in the neonatal intensive care unit ranged from 'very low' to 'low' levels, and ototoxic drugs were evidenced as 'very low'. Possible explanations for these 'very low' and 'low' levels include the improved management of these health conditions or treatments, and methodological weaknesses such as confounding effects, which make it difficult to conclude on individual risk factors. In the recommendation statements, the experts emphasised avoiding unidentified neonatal hearing loss and opted to include risk factors for hearing loss even in cases with weak evidence. The panel also highlighted the cumulative effect of risk factors for hearing loss.

Conclusion: We revised the recommendations for the clinical management and follow-up of newborns exhibiting neonatal risk factors for hearing loss on the basis of the aforementioned evidence-based approach and clinical experience from experts. The next step is the implementation of these findings in the Belgian screening programme.

26. Wood SA, Sutton GJ, Davis AC.

Performance and characteristics of the Newborn Hearing Screening Programme in England: The first seven years. *Int J Audiol.* 2015 Jun;54(6):353-8. doi: 10.3109/14992027.2014.989548

Objective: To assess the performance of the universal newborn hearing screen in England.

Design: Retrospective analysis of population screening records.

Study Sample: A total of 4 645 823 children born 1 April 2004 to 31 March 2013.

Results: 97.5% of the eligible population complete screening by 4/5 weeks of age and 98.9% complete screening by three months of age. The refer rate for the 12/13 birth cohort is 2.6%. The percentage of screen positive (i.e. referred) babies commencing follow up by four weeks of age and six months of age is 82.5% and 95.8% respectively. The yield of bilateral PCHL from the screen is around 1/1000. For bilateral PCHL in the 12/13 birth cohort the median age is nine days at screen completion, 30 days at entry into follow up, 49 days at confirmation, 50 days at referral to early intervention, and 82 days at hearing-aid fitting.

Conclusion: The performance of the newborn hearing screening programme has improved continuously. The yield of bilateral PCHL from the screen is about 1/1000 as expected. The age of identification and management is well within the first six months of life, although there remains scope for further improvement with respect to timely entry into follow up.

27. Xiao H, Li W, Ma R, Gong Z, Shi H, Li H, Chen B, Jiang Y, Dai C.

Study on the factors impacting on early cochlear implantation between the eastern and western region of China.

Lin Chung Er Bi Yan Hou Tou Jing Wai Ke Za Zhi. 2015 Jun;29(12):1111-4.

Objective: To describe the regional different factors which impact on early cochlear implantation in prelingual deaf children between eastern and western regions of China.

Method: The charts of 113 children who received the cochlear implantation after 24 months old were reviewed and analyzed. Forty-five of them came from the eastern region (Jiangsu, Zhejiang or Shanghai) while 68 of them came from the western region (Ningxia or Guizhou). Parental interviews were conducted to collect information regarding the factors that impact on early cochlear implantation.

Result: Based on the univariate logistic regression analysis, the odds ratio (OR) value of universal newborn hearing screening (UNHS) was 5.481, which indicated the correlation of UNHS with early cochlear implantation is significant. There was statistical difference between the 2 groups ($P < 0.01$). For the financial burden, the OR value was 3.521 (strong correlation) and there was statistical difference between the 2 groups ($P < 0.01$). For the communication barriers and community location, the OR value was 0.566 and 1.128 respectively, and there was no statistical difference between the 2 groups ($P > 0.05$). The multivariate analysis indicated that the UNHS and financial burden are statistically different between the eastern and western regions ($P = 0.00$ and 0.040 respectively).

Conclusion: The UNHS and financial burden are statistically different between the eastern reinforced in the western region. In addition, the government and society should provide powerful policy and more financial support in the western region of China. The innovation of management system is also helpful to the early cochlear implantation.