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Loss to Follow-Up in Early Hearing Detection and Intervention

Working Group on Loss to Follow-Up

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About This Document

This technical report was developed by the American Speech-Language-Hearing Association (ASHA) Working Group on Loss to Follow-Up and was approved by ASHA's Board of Directors (BOD 46-2008) on December 9, 2008. Members of the group were Anne Marie Tharpe (chair), John Eichwald, Janet Farrell, Jeffrey Hoffman, Meredith Isola, Patti Martin, Amy M. Robbins, Lynn Spivak, Susan Wiley, and Pam Mason (ex officio). Gwendolyn D. Wilson, ASHA vice president for audiology practice (2007–2009), served as the monitoring officer.

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Background

Congenital, permanent childhood hearing loss affects 2%–4% of infants who spend time in neonatal intensive care units (NICUs) and 1–3 of every 1,000 infants in well-baby nurseries (Baroch, 2003; Centers for Disease Control and Prevention [CDC], 2008). In an attempt to improve outcomes for children with hearing loss and their families, the National Institutes of Health and the Joint Committee on Infant Hearing (JCIH) in 1993 and 1994, respectively, and the United States Preventive Services Task Force (2008) endorsed the goal of universal detection of hearing loss in infants. The American Academy of Pediatrics (AAP) Task Force on Newborn and Infant Hearing (1999) and JCIH (2000, 2007) endorsed universal newborn hearing screening (UNHS) and the early hearing detection and intervention (EHDI) goals of screening no later than 1 month, confirmation of hearing loss no later than 3 months, and receipt of appropriate intervention no later than 6 months of age. Today, it is estimated that UNHS is provided to 92%–95% of babies born in the United States and its territories (CDC, 2008; National Center for Hearing Assessment and Management [NCHAM], 2007).

Although screening for hearing loss in the newborn period is a good start, it is recognized that a fully functional and comprehensive EHDI program must include professional and family education and short- and long-term follow-up, following the example of newborn dried bloodspot screening programs. In those programs, *short-term follow-up* has been described as confirmatory diagnoses for newborns who do not pass the screens and referral and connection of infants and their families to treatment, and *long-term follow-up* as ongoing medical management through the medical home, evidence-based treatment, continuous program evaluation and quality improvement, and new knowledge discovery (Hoff, Hoyt, Therrell, & Ayoob, 2006; Kemper et al., 2008).

Based on national data (CDC, 2008) reported by 45 states, two territories, and the District of Columbia, nearly half (46.3%) of the infants born in 2006 who did not pass their final newborn hearing screen (32,496 infants) did not complete follow-up and were categorized as lost to follow-up (LTF)/lost to documentation (LTD). The percentage of infants who were documented as having received their recommended diagnostic evaluation in 2006 ranged from 1% to 99% among those jurisdictions reporting. Of those infants who were reported as having received an audiological evaluation, only 47% could be documented as having been seen before 3 months of age. Furthermore, more than one-third (39.3%) of infants with diagnosed hearing loss could not be documented as having been enrolled in Part C Early Intervention or having received other early intervention services.

Numerous recommendations have been proffered for reducing the LTF rate. However, there is a dearth of research literature demonstrating that such measures are effective. The purposes of this report are to

- define the terminology associated with LTF
- delineate and define the factors that have been identified as contributing to LTF rates
- delineate and define the factors that have been identified as decreasing LTF rates
- provide results of a current systematic review of research literature in the area of LTF.

Terminology

Loss to Follow-Up

Many jurisdictions recognize any baby who did not receive or complete the recommended diagnostic or intervention process as *lost to follow up* (*LTF*).[1] However, perhaps the most obvious difficulty encountered in tracking such infants stems from the variability in how the term is defined from site to site, as well as on the state and national levels. In an effort to obtain a more comprehensive view of operational definitions used by states, an informal review was undertaken in February 2008 of 23 state definitions (Hoffman & Farrell, 2008). The durational dimension of the definition varied among jurisdictions. For example, some states designated a child as LTF because of incorrect, incomplete, or expired contact information if not located within 2 months of age, while others attempted to follow a child until 3 years of age before classifying as LTF. Other jurisdictions, rather than using age of the child, declared a child as LTF according to the time transpired from the last EHDI system activity with the family—for example, 3–6 months with no known follow-up activity resulted in a designation of LTF. Inclusion of specific groups, such as babies who have expired, moved to another state, or whose parents refused the screening, in the LTF category varied among the states reporting.

In 2006, in an effort to provide more consistent reporting among EHDI jurisdictions, the CDC launched a national survey to better define the timelines for EHDI milestones based on recommendations of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (2004) and the CDC EHDI Data Committee (CDC, 2008). This survey, designed to report data for Healthy People 2010 and the EHDI 1-3-6 goals on a national basis, requested data that could be documented by the EHDI jurisdictions and might differ from that which is defined and collected specific to their locale and reporting needs (e.g., adjusted or corrected age for preterm infants).

In that CDC survey, "no documented diagnosis" included infants (1) who are in process, (2) who died, (3) whose parents declined services, (4) who are nonresidents, (5) who moved out of the jurisdiction, (6) who cannot be contacted, (7) whose parents are unresponsive, and (8) who have no documented diagnosis for unknown reasons.

[1] For purposes of this document, the term *lost to follow-up* refers to infants and the term *loss to follow-up* refers to the EHDI programmatic issues related to follow-up. The abbreviation *LTF* is used interchangeably to represent both terms in this document.

Clearly, there is not yet general consensus on how we record and report infants as LTF. This lack of consensus results in difficulty comparing old data to new data and comparing data across jurisdictions.

Loss to Documentation

The designation of *lost to documentation* (*LTD*) is becoming increasingly accepted as being distinct from LTF (Mason, Gaffney, Green, & Grosse, 2008). LTD includes those infants who did not pass their hearing screening and whose diagnostic or intervention status has not been reported to the EHDI program; thus, their status remains unknown by the EHDI program despite the fact that they may have received services. There are multiple points in the EHDI process at which a child might become LTD (e.g., following screening, following diagnosis, following referral to intervention). Although the factors contributing to LTD in NHS programs have not been thoroughly delineated at this time, factors identified as contributing to LTD in the parallel newborn dried bloodspot screening programs included, primarily, name changes and, to a lesser degree, data mismatches. In addition, inadequate or erroneous parental contact information and/or unknown or changed primary care provider contribute to LTD (Hoff et al., 2006). An additional factor contributing to LTD includes those infants who receive services in a jurisdiction different from the jurisdiction of the EHDI system in which they reside or in which they were born. These are often termed "border babies."

Loss to System

Combining the designations *LTF* and *LTD* under the broad heading of *lost to system* (*LTS*) has been suggested as a viable option to reduce the confusion and variability in capturing this data set within and across EHDI systems and to increase the effectiveness of follow-up strategies (Beauchaine & Hoffman, 2008).

Systematic Review of the Evidence

In early 2008, the ASHA National Center for Evidence-Based Practice in Communication Disorders (N-CEP) completed a review of the evidence related to LTF after initial identification by newborn hearing screening programs. The full report of that review is included in the Appendix. Specifically, their review addressed the following questions:

1. What characteristics of individuals, families, or populations have been found to be associated with risk of delays or LTF for infants with positive initial screens for hearing loss and evidence of need for an audiologic evaluation by 3 months?
2. What characteristics of individuals, families, or populations have been found to be associated with risk of delays or LTF for children with a positive diagnosis of hearing loss and evidence of need for audiologic intervention by 6 months?
3. What has been the effectiveness of initiatives designed to increase follow-up for appropriate audiologic evaluation by 3 months of age?
4. What has been the effectiveness of initiatives designed to increase follow-up for appropriate audiologic intervention by 6 months of age?

Studies pertaining to intervention were evaluated for methodological quality. The authors independently appraised each study on eight quality indicators:

- adequate description of protocol for replication

- adequate description of subjects (within-subject design) or groups comparable at baseline (between-subjects design)
- assessors blinded
- random sample adequately described
- evidence of treatment fidelity
- *p* value reported or calculable
- effect size and confidence interval reported or calculable
- analyzed by intention to treat (controlled trials only)

Studies received 1 point for each quality indicator, for a maximum possible score of 8. Fourteen studies were included in the final analysis—11 that investigated the characteristics of infants categorized as LTF and 3 that investigated actions to prevent LTF.

The authors concluded that the small number, substantial methodological shortcomings, and inconsistent findings within the available evidence do not provide meaningful direction for clinicians or policy makers in identifying the patients or families at the highest risk of LTF, nor how to decrease that risk.

Possible Points of Loss to Follow-Up

In the absence of strong evidence to identify the factors contributing to LTF, it is reasonable to seek additional guidance beyond those articles included in the systematic review (see the Appendix) to allow for broader acceptance of lower levels of evidence and expert opinion. Therefore, outlined herein are also those factors that have been suggested by other sources, including consensus data and policy statements, as possible contributors to LTF rates that warrant further consideration by professionals within the EHDI system but that were not included in the systematic review. It is recognized that reducing LTF will require the involvement of numerous groups and individuals, including, but not limited to, parents and other family members, physicians, audiologists, speech-language pathologists, educators of the deaf, early interventionists, and state and territory departments of health. Issues related to both short-term and long-term follow-up are considered here, and these are divided into systems and family issues.

Systems Issues

Primary Care Provider Barriers

The Newborn Screening Authoring Committee published a clinical report on recommendations for pediatricians and the medical home regarding newborn screening programs in 2008. They recommended that PCPs receive timely and accurate access to information about their patients to avoid missed opportunities for follow-up at multiple points of contact with the child and family. Furthermore, it has been recommended that PCPs develop strategies to use should newborn screening systems fail (AAP, 2008). More specifically, the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative found that failure by hospital personnel to identify the newborn's PCP or clinic was a contributing factor to LTF (Health Resources and Services Administration [HRSA], in press). In addition, PCPs can familiarize themselves with referral resources in their communities in collaboration with an otologist (Cunningham & Cox, 2003) and can form collaborative relationships with their EHDI American Academy of Pediatrics Chapter Champions (AAP, 2002).

Communication of Results (Family Education)
Most parents learn of newborn screening programs while in the hospital, not prenatally (Arnold et al., 2006). Through a series of focus groups and interviews, Arnold and colleagues found that all stakeholders (i.e., parents of infants experiencing the newborn hearing screening (NHS) process, parents of children with hearing loss, audiologists, technicians, nurses, PCPs) preferred having communication about the NHS process occur before birth and preferred that user-friendly patient education materials be used. However, clinicians had limited knowledge or awareness of current NHS practices. The providers did not consider family education about hearing screening to be a priority. Parents in the study recommended that expectant and new parents be informed prior to the screening of what the screening entails, the urgency of early diagnosis, and what the follow-up process will be (Alexander & van Dyck, 2006). This expanded parental education will require additional training of personnel.

Parents who have been through the NHS process expressed a strong desire to be present during the screening but were not given the opportunity (MacNeil, Liu, Stone, & Farrell, 2007). A survey by Kim, Lloyd-Puryear, and Tonniges (2003) revealed that states seldom defined who has the role and responsibility for informing and educating parents about newborn dried bloodspot screening. In addition, the approaches to parental education and the content of screening educational materials were variable across states. There is also no assurance that health care providers have the necessary tools to guide parents in the decision-making process.

Coordination Among Service Providers
A lack of communication between and among health care providers, families, and screening programs poses a barrier for follow-up success (Hoff et al., 2006). Furthermore, a lack of integrated data management and tracking systems creates barriers to sharing information among providers and between states (JCIH, 2007; Pool, 1996).

Privacy Regulations
Privacy regulations, including Health Insurance Portability and Accountability Act (HIPAA, 1996), Family Education Rights and Privacy Act (FERPA, 2004), Part C Privacy Regulations (IDEA, 2004), and state privacy reporting laws, may adversely affect the sharing of information among service providers. However, there has been some misunderstanding regarding HIPAA's and FERPA's influence on the disclosure of information from screening programs to primary referral sources. Because disclosure is mandated by law (i.e., IDEA 2004) and the information is to be shared for public health purposes, written authorization for referrals to Part C may not be required (Houston, Behl, & White, 2008; Surprenant, 2006). Furthermore, signed consent is not needed (under FERPA) to disclose general contact information, enrollment status, and attendance of children served (Houston et al., 2008). However, Part C has more privacy protections than FERPA and HIPAA. Signed consent is needed for Part C to share any personal information with nonparticipating providers (i.e., outside of the Part C system) but it is not needed for Part C to share information with participating providers. State laws can require more privacy protections, but not less. The NICHQ has recommended that

any required consent for release of information be obtained at first contact with early intervention so that information can be entered into an EHDI database (HRSA, in press).

Funding

Agencies and committees have recognized the need for maintaining consistent and stable state and federal funding for EHDI programs, including the AAP, JCIH, HRSA/Maternal and Child Health Bureau (HRSA/MCHB), and National Institutes of Health (JCIH, 2007; Lloyd-Puryear et al., 2006). A shortage of professionals with skills in pediatrics and hearing loss has been noted, as well as poor reimbursement of audiology services (JCIH, 2007; Lieu, Karzon, & Mange, 2006).

Personnel Involved

In a recent study of NHS program performance, Thomson (2007) found that when infants were born in hospitals where audiologists were involved in the NHS programs, they were 27% more likely to receive the outpatient rescreen when recommended as compared to those programs without audiologist involvement.

Family Issues

Possible family factors contributing to LTF examined by studies included in the ASHA systematic review of evidence (see the Appendix) addressed educational and literacy levels of mothers and the age of mothers, maternal marital status, maternal substance abuse, maternal smoking, number of children at home, insurance status, family history of hearing loss, receipt of prenatal care, and poverty level (Folsom et al., 2000; Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Oghalai, Chen, Brennan, Tonini, & Manolidis, 2002; Prince, Miyashiro, Weirather, & Heu, 2003). Child factors that might contribute to LTF that were examined by studies included in the review were severity of hearing loss, birth weight, race, gender, resident of neonatal intensive care or well-baby nursery, and neonatal surgery and ventilator status (Davis & Wood, 1992; Folsom et al., 2000; Liu et al., 2008; Prieve et al., 2000; Prince et al., 2003; Shoup, Owen, Jackson, & Laptook, 2005; Stein, Jabaley, Spitz, Stoakley, & McGee, 1990; Stewart et al., 2000; Uus & Bamford, 2006).

Factors that were not examined by studies included in the systematic review but that have been considered in other documents include the following:

- Proximity to resources: In a survey of approximately 1,000 families whose babies received NHS in Massachusetts, those families who were compliant with follow-up revealed that a long travel time to their appointments could be a barrier to follow-up. Related to this concern was that the appointments might not be convenient and the time parents spent away from work for these appointments could be problematic (MacNeil et al., 2007).

- Difficulty scheduling appointments: At least two surveys have suggested that difficulties scheduling appointments for follow-up have posed barriers for families (Harrison, Roush, & Wallace, 2003; MacNeil et al., 2007). The difficulties included making the telephone calls, finding someone to care for other children, and transportation.

Quality Assurance

The CDC emphasizes the importance of an EHDI tracking and surveillance system that can minimize LTF (CDC, 2003). Specifically, they set forth the following program objectives:

- Comprehensive system: Each state will have a computerized system that (1) maintains current information on all babies screened, including those who do not pass the screen, (2) contains diagnostic results for babies who were referred based on the results of their NHS test, and (3) documents interventions for those infants who were diagnosed with hearing loss.
- Policies and procedures: Each state will have written policies and procedures regarding their EHDI tracking and surveillance system.
- Privacy and confidentiality: Each state will develop policies, procedures, and informed-consent requirements regarding privacy and confidentiality of data in the EHDI tracking and surveillance system.
- Inclusion of all births: Each state will ensure that all live births in the state are included in the state EHDI tracking and surveillance system by matching with the state's birth certificate registry as allowed.
- Risk factors for hearing loss: The state EHDI tracking and surveillance system will ascertain risk factors for hearing loss for every infant by linkage with other state data systems.
- NHS results: The EHDI tracking and surveillance system will capture all hearing screening results at the birthing hospital within 1 week of discharge or transfer.
- Reporting mechanism for health care providers: Each state will provide a mechanism for hospitals, audiologists, and other health care providers to report NHS results, evaluations, and interventions.
- Identifying children who need screening and follow up: The state EHDI tracking and surveillance system will be able to identify, on a weekly basis, all infants and children who need initial hearing screening, rescreening, evaluation, follow-up, or intervention.
- Access to information: The state EHDI tracking and surveillance system will allow case managers and authorized health care providers to access relevant information about infants and children.

Summary

Today, 92%–95% of babies born in the United States and its territories receive hearing screening in the newborn period (CDC, 2008; NCHAM, 2007). Successful outcomes for children with hearing loss are within reach as a result of advanced knowledge, skills, and hearing technology available to these children and their families. However, only slightly more than half of the infants who do not pass hearing screening receive follow-up diagnostic testing and only a third diagnosed with hearing loss receive intervention by 6 months of age (NCHAM, 2005). Clearly, positive outcomes can only be achieved if babies identified with hearing loss receive appropriate early intervention services in a timely manner.

This report has included a systematic review of evidence as well as consensus data and policy statements. It remains unclear which babies are at greatest risk for LTF and how to lower that risk. There is a dearth of evidence to support effective and reliable models of follow-up in EHDI programs. Until such time that evidence-based guidance is available to inform professionals in the EHDI systems, it is recommended that ASHA develop practice guidelines, based on the best available evidence and expert opinion at this time, designed for improving short-term and long-term follow-up practices by audiologists, speech-language pathologists, and other professionals involved in the diagnostic and habilitative management of infants with permanent hearing loss.

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Appendix: Loss to Follow-Up in Newborn Hearing Screening Programs: A Systematic Review of the Evidence

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In 2000 and 2007, the Joint Committee on Infant Hearing released position statements supporting universal newborn hearing screening (UNHS) as a means to improve early hearing detection and intervention (EHDI). The Joint Committee recommended that all newborns be screened for hearing loss by 1 month of age. The U.S. Department of Health and Human Services (2000) gave further support to this effort by promoting the Healthy People 2010 "1-3-6" initiative. That is, in addition to being screened by 1 month of age, infants should receive diagnostic follow-up by 3 months of age and appropriate audiological intervention by 6 months of age.

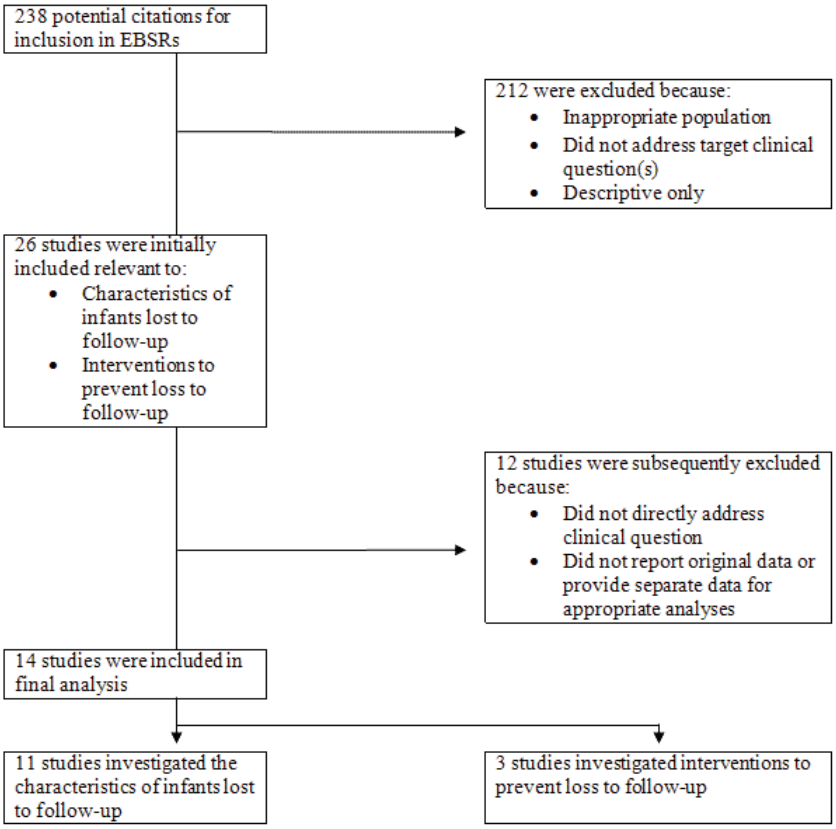
Today, the importance and benefits of universal hearing screening at birth have reached national recognition. Endorsements from a number of federal agencies and advocacy organizations have led to marked improvements in the identification of infants with hearing loss. Since the release of the Joint Committee's position statement, the percentage of infants screened for hearing loss has risen dramatically. Currently, 95% of all newborns are receiving hearing screens at birth, compared to 38% in 2000 (Centers for Disease Control and Prevention [CDC], 2005). In addition, 42 states now have legislation in place related to UNHS (National Center for Hearing Assessment and Management, 2008).

Although tremendous progress has been made as a result of these efforts, UNHS is only the first step in the "1-3-6" initiative. There still is little known about what happens to those infants who fail the initial hearing screen at birth and are in need of further audiological services. Despite the progress made in the proportion of newborns receiving an initial hearing screen at birth, it is not clear that similar success has been achieved with the recommended follow-up services. Research by Yoshinaga-Itano, Sedey, Coulter, and Mehl (1998) revealed that infants who received intervention by 6 months of age performed significantly better in language development compared to infants identified after 6 months.

Bridging the gaps between identification of hearing loss at birth, diagnostic follow-up, and intervention is crucial. Further measures must be taken to ensure that infants commonly referred to as "lost to follow-up" receive timely and appropriate audiological services. As a result, the aim of this systematic review was to examine the current state of the evidence pertaining to loss to follow-up after initial identification of newborn hearing loss. In constructing the questions for review, two important components related to loss to follow-up were considered: the characteristics of those populations at risk for loss to follow-up and the effectiveness of interventions targeted at improving follow-up rates. This review focused on four clinical questions:

1. What characteristics of individuals, families, or populations have been found to be associated with risk of delays or loss to follow-up for children with a positive initial screen for hearing loss and in need of an audiologic evaluation by 3 months?
2. What characteristics of individuals, families, or populations have been found to be associated with risk of delays or loss to follow-up for children with a positive diagnosis of hearing loss and in need of an audiologic intervention by 6 months?
3. What has been the effectiveness of initiatives designed to increase follow-up for appropriate audiologic evaluation by 3 months of age?
4. What has been the effectiveness of initiatives designed to increase follow-up for appropriate audiologic intervention by 6 months of age?

Figure 1. Process for identification of included studies.



Methodology

A systematic search of the literature was conducted from September 2007 to January 2008. Studies were considered for the review if they were published in a peer-reviewed journal from 1990 to 2008, were written in English, and contained original data addressing one or more of the four clinical questions. Twenty-two electronic databases were searched in addition to all ASHA journals, the EHDI Publications Database, the National Center on Birth Defects and Developmental Disabilities Publications Database, and a full search of relevant references and authors. Databases searched included CINAHL, Cochrane Library, CRD database, DIMDI, EBM Guidelines, Education Abstracts, EMBASE, ERIC, Health Source: Nursing/Academic Edition, Linguistics and Language Behavior Abstracts, Medline, National Electronic Library for Health, National Rehabilitation Information Center, PsycARTICLES, PsycBITE, Psychology and Behavioral Sciences Collection, PubMed, Science Citation Index, Social Science Citation Index, SUMSearch, Teacher Reference Center, and TRIP Database. A total of 24 expanded search terms were used to review the UNHS and EHDI literature, including key words related to newborn hearing screening, early intervention, and hearing screening follow-up.

The search schematized in Figure 1 includes a total of 238 articles. Two authors (RM and TF), blind to one another's results, reviewed each abstract and identified 26 articles as meeting the initial inclusion criteria, with 91% agreement. Of those initially accepted, 12 were subsequently excluded after review of the full text article. A total of 14 studies were included in the final analysis.

Studies pertaining to intervention were evaluated for methodological quality. The authors (RM and TF) independently appraised each study on eight quality indicators:

- adequate description of protocol for replication
- adequate description of subjects (within-subject design) or groups comparable at baseline (between-subjects design)
- assessors blinded
- random sample adequately described
- evidence of treatment fidelity
- *p* value reported or calculable
- effect size and confidence interval reported or calculable
- analyzed by intention to treat (controlled trials only).

Reliability of appraisal ratings between authors was assessed, and any discrepancies were resolved via consensus. Studies received one point for each quality marker that met the above criteria. Studies incorporating controlled trials could obtain a maximum quality score of eight. All other study designs where intention to treat analysis was not applicable could obtain a maximum quality score of seven.

Results

Question 1. What characteristics of individuals, families, or populations have been found to be associated with increased risk of delays or loss to follow-up for children with a positive initial screen for hearing loss and in need of an audiologic evaluation by 3 months of age?

The 11 studies included in this section of the review reported findings on a total of 19 different risk factors. As shown in Table 1, 6 of the studies (Davis & Wood, 1992; Prieve et al., 2000; Shoup, Owen, Jackson, & Laptook, 2005; Stein, Jabaley, Spitz, Stoakley, & McGee, 1990; Stewart et al., 2000; Uus & Bamford, 2006) compared follow-up in infants who had been in neonatal intensive care units (NICUs) with infants who had been exclusively in well-baby nurseries (WBNs).

In four of the six studies (Prieve et al., 2000; Shoup et al., 2000; Stewart et al., 2000; Uus & Bamford, 2006), findings were reported in terms of rates of follow-up during the study period (see Table 2). Prieve et al. found a significantly lower rate of follow-up in WBN infants, whereas in the other three studies no statistically significant differences were found between the populations. Interpretation of the findings across studies is difficult because none of the studies specified the time frame or cut-off for designating an infant as lost to follow-up. For example, in the Uus and Bamford study data are presented for the infant's age on the date of the evaluation, and the ages ranged up to 31 weeks. Data on age are not reported in the other studies, and one cannot tell whether an infant evaluated at 31 weeks would have been within or outside the parameters for designation as followed-up or lost in other studies.

In addition to Uus and Bamford (2006), two other studies (Davis & Wood, 1992; Stein et al., 1990) reported data on the infant's age at evaluation (see Table 3). In those two studies, the authors found that the age at evaluation for WBN infants was significantly higher than for NICU infants, whereas Uus and Bamford found a statistically significant difference in the opposite direction.

The Folsom et al. (2000); Prince, Miyashiro, Weirather, and Heu (2003); and Liu, Farrell, MacNeil, Stone, and Barfield (2008) studies reported data on maternal age. Folsom et al. found a mean maternal age of 27.5 years among mothers whose infants were followed up, compared to 26.0 years among mothers of infants lost to follow-up, a statistically significant difference. Liu et al. found significantly lower follow-up in mothers aged younger than 20. In contrast, Prince et al. (2003) found the lowest rates of follow-up among infants whose mothers were age 35 or older, but none of the differences in that study's follow-up rates by maternal age were statistically significant.

Table 1. Studies related to Question 1.

Study	*N*	Factors studied
Davis and Wood (1992)	39	• NICU versus WBN • Severity of hearing loss
Folsom et al. (2000)	4,911	• Number of children at home • Maternal age • Insurance status • Prenatal care • Maternal substance abuse • Race • Neonatal surgery • Ventilator status • Family history of hearing loss
Liu et al. (2008)	1,492	• Maternal age • Maternal education • Maternal marital status • Maternal smoking • Race • Gender • Birth weight • Insurance status • Laterality of hearing loss
Oghalai et al. (2002)	133	• Poverty
Parving (1993)	Not reported	• High risk for hearing loss
Prieve et al. (2000)	385	• NICU versus WBN
Prince et al. (2003)	1,013	• Maternal age • Maternal education • Maternal marital status • Race • Gender • Birth weight • Type of hospital
Shoup et al. (2005)	287	• NICU versus WBN
Stein et al. (1990)	135	• NICU versus WBN
Stewart et al. (2000)	214	• NICU versus WBN
Uus and Bamford (2006)	151	• NICU versus WBN • Severity of hearing loss

The same three studies also reported data on the infants' race, again with conflicting results. Folsom et al. (2000) found significantly higher rates of follow-up in non-Hispanic White infants (64.8%) than in infants of other racial/ethnic groups (51.5%). Liu et al. (2008) also found significantly higher follow-up in non-Hispanic White infants (92% vs. 85%). Prince et al. (2003) found significantly lower rates of follow-up in White infants (75.9%) than in infants of other races (85.6%).

The Davis and Wood (1992) and Uus and Bamford (2006) studies both looked at follow-up by severity of hearing loss. Davis and Wood found statistically significant differences in the mean age at evaluation: 9 months for infants with a hearing loss of 80+ dB, 17 months for hearing loss between 50 db and 79 dB, and 35 months for <50 dB. Uus and Bamford found no significant differences by degree of loss.

Table 2. Rates of follow-up for audiologic evaluation in NICU versus WBN infants.

Study	*N*	% follow-up NICU	% follow-up WBN	Statistically significant difference?
Prieve et al. (2000)	385	84	71	Yes
Shoup et al. (2005)	287	83	85	No
Stewart et al. (2000)	214	68	72	No
Uus and Bamford (2006)	151	100	100	No

Table 3. Age at follow-up for audiologic evaluation in NICU versus WBN infants.

Study	*N*	Age (weeks) NICU	Age (weeks) WBN	Statistically significant difference?
Davis and Wood (1992)	39	10	18	Yes
Stein et al. (1990)	135	13	16	Yes
Uus and Bamford (2006)	151	16	12	Yes

Folsom et al. (2000) and Liu et al. (2008) both looked at follow-up by insurance status. Folsom et al. found significantly higher follow-up in infants with health insurance (60.7%) than in those with no insurance (42.4%). Liu et al. compared private insurance, public insurance, and no insurance, and found that follow-up of infants with private insurance (94% follow-up) was similar to that of infants with no insurance (92% follow-up), and both were significantly higher than in infants with public health insurance (81% follow-up).

The Prince et al. (2003) and Liu et al. (2008) studies both looked at follow-up by birth weight. Prince et al. found significantly higher follow-up in infants weighing at least 2,500 g at birth (83.6%) than in infants weighing less than 2,500 g (72.0%). The Liu et al. study found no statistically significant differences by birth weight.

The Prince et al. (2003) and Liu et al. (2008) studies also looked at follow-up by mother's marital status. Prince et al. found no significant difference in follow-up by marital status, whereas Liu et al. found significantly higher follow-up in married versus unmarried mothers (93% vs. 83%).

Finally, the same two studies looked at follow-up by maternal education. Both studies found significantly higher follow-up in mothers who had completed high school or beyond. The Prince et al. (2003) study found 84.1% follow-up in high school graduates compared to 74.5% in nongraduates. The rates reported in the Liu et al. (2003) study were 92% in graduates and 79% in nongraduates.

Data on 12 other risk factors were included in only one study each. Delayed or no follow-up was found to be statistically significant in families with the following characteristics:

- more than two children at home (Folsom et al., 2000)
- mother had no or late prenatal care (Folsom et al., 2000)
- mother was a substance abuser (type of substance not specified; Folsom et al., 2000)
- mother smoked during pregnancy (Liu et al., 2008)
- infant underwent surgery during the neonatal period (Folsom et al., 2000)
- infant had not been on a ventilator (Folsom et al., 2000)
- no family history of hearing loss (Folsom et al., 2000)
- infant was born in a community hospital rather than an obstetric Level 2 or 3 medical center (Prince et al., 2003).

Table 4. Studies related to Question 2.

Study	*N*	Factors studied
Davis and Wood (1992)	39	• NICU versus WBN • Severity of hearing loss
Liu et al. (2008)	385	• Maternal age • Maternal education • Maternal marital status • Maternal substance use • Race • Gender • Birth weight • Insurance status • Laterality of hearing loss
Oghalai et al. (2002)	133	• Poverty
Stein et al. (1990)	135	• NICU versus WBN
Uus and Bamford (2006)	151	• NICU versus WBN • Severity of hearing loss

Single studies reported no significant differences in follow-up associated with these factors:

- infant's risk for hearing loss (Parving, 1993)
- laterality of hearing referral (Liu et al., 2008)
- gender (Prince et al., 2003)
- poverty (Oghalai, Chen, Brennan, Tonini, & Manolidis, 2002).

Question 2. What characteristics of individuals, families, or populations have been found to be associated with increased risk of delays or loss to follow-up for children with a positive diagnosis of hearing loss and in need of an audiologic intervention by 6 months of age?

Three studies reported data on the NICU versus WBN comparison (see Table 4). The Davis and Wood (1992) and Stein et al. (1990) studies both found 100% follow-up from evaluation to hearing aid fitting in both groups, and both studies found that the significant differences in mean age that had been observed at the time of diagnosis (see Table 3) were no longer evident at the time of habilitation. Davis and Wood reported a mean age at habilitation of 19.7 months in NICU infants versus 25.0 months in WBN infants. Stein et al. reported means of 20.0 and 20.8 months, respectively. Uus and Bamford (2006) reported a mean age of 25.7 weeks in NICU infants and 19.8 weeks in WBN infants (statistical significance was not reported).

Davis and Wood (1992) also reported findings on the relationship between the severity of hearing loss and follow-up. Here, the significant differences in follow-up observed at the time of evaluation continued to be reflected in age at time of habilitation. Mean age was 12 months in children with hearing loss of 80+ dB, 25 months with hearing loss between 50 dB and 79 dB, and 37 months with hearing loss of <50 dB. However, the gap between diagnosis and habilitation was not significantly different by severity of hearing loss. Uus and Bamford (2006) also reported findings of delayed habilitation in moderate, compared with profound, hearing loss, although data were not presented.

The Oghalai et al. (2002) study, which found no impact of poverty on age at diagnosis, found that infants born at a hospital serving a primarily indigent population had a significantly later mean age at time of habilitation (49.6 weeks vs. 28.2 weeks; $p = .041$).

The Liu et al. (2008) study reported findings on the same nine variables it addressed in Question 1. Loss to follow-up from diagnosis to early intervention services was significantly higher among the following groups:

- infants weighing <2,500 g at birth

Table 5. Intervention studies from initial to repeat screen.

Study	*N*	Intervention	Quality score from Appendix A
Françozo et al. (2007)	448	• Individual versus group counseling	3 of 7
Korres et al. (2006)	1,213	• Written comment in discharge notes • Personal contact with the parents • Schedule to monitor appointments	2 of 7
Whittman-Price & Pope (2002)	14	• UNHS module added to prenatal class	2 of 7

- infants with unilateral hearing loss
- infants with mild/moderate hearing loss.

The following factors did not reflect significantly different rates of follow-up in the Liu et al. study:
- maternal age
- race
- mother's marital status
- mother smoked during pregnancy
- mother's education
- insurance status

Question 3. What has been the effectiveness of initiatives designed to increase follow-up for appropriate audiologic evaluation by 3 months of age?

No studies were found related to this question.

Question 4. What has been the effectiveness of initiatives designed to increase follow-up for appropriate audiologic intervention by 6 months of age?

No studies were found related to this question.

Because no intervention studies directly relevant to Questions 3 or 4 were found, we made the decision to amend the inclusion criteria to include studies of interventions designed to reduce loss to follow-up from initial to repeat screen. We thought that the issues might be sufficiently closely related that the findings from those studies could have implications for follow-up from screening to evaluation.

Three studies (Françozo, Fernandes, Marconi Pinheiro Lima, & Rossi, 2007; Korres et al., 2005; Wittmann-Price & Pope, 2002) investigated the effectiveness of interventions to improve follow-up rates from initial to repeat screens. The three studies (see Table 5) examined three different types of interventions.

Françozo et al. (2007) compared the effectiveness of small-group versus individual counseling of mothers by a social worker. The results were not statistically significant. In the small-group cohort, follow-up was 60.2% (95% confidence interval [CI] = 52.5%–67.6%), and in the individual counseling cohort, follow-up was 74.3% (95% CI = 57.8%–86.0%).

Table 6. Patient populations by study.

Study	Country	Comment
Davis and Wood (1992)	England	
Folsom et al. (2000)	U.S	Multisite study in six states
Françozo et al. (2007)	Brazil	
Korres et al. (2005)	Turkey	
Lui et al. (2008)	U.S.	Massachusetts
Oghalai et al. (2002)	U.S.	Two Texas hospitals, one serving a primarily indigent and uninsured population, and the other a tertiary care hospital with a more economically diverse population
Parving (1993)	Denmark	
Prieve et al. (2000)	U.S.	New York
Prince et al. (2003)	U.S.	Hawaii
Shoup et al. (2005)	U.S.	Texas hospital serving a primarily Hispanic low-income population
Stein et al. (1990)	U.S.	Illinois
Stewart et al. (2000)	U.S.	Multisite study in four states
Uus & Bamford (2006)	England	
Whitmann-Price & Pope (2002)	U.S.	Pennsylvania

The Korres et al. (2006) study was the only one of the three to report statistically significant findings. In one cohort, parents received a written report of the screening results and recommendation for rescreening. That cohort had follow-up of 27.8% (95% CI = 24.6%–31.3%). The second cohort received, in addition to the written report, written comments in their discharge papers, personal contact, and monitoring of their compliance with rescreening appointments. Follow-up in that cohort was 41.8% (95% CI = 37.7%–46.0%). The changes to the protocol were bundled, and no data on the relative impact of the three individual changes were reported.

The Whittman-Price and Pope (2002) study examined the effectiveness of adding a 20-minute educational module on UNHS to a hospital-based prenatal class. In the cohort that did not receive the module, 7 of the 9 infants were rescreened. It was not reported whether the parents of those children attended the prenatal class before the addition of the UNHS module, whether they attended a different class, or whether they did not attend a class at all. In the cohort that did receive the module, all 5 infants were rescreened. These results were not statistically significant.

Culturally and Linguistically Diverse Populations

Questions 1 and 2, that is, those that dealt specifically with the characteristics of individuals or populations, were developed in part in anticipation that cultural and linguistic factors might be an important influence on follow-up. These factors, including educational level, poverty, race, and others were addressed by a small number of studies, and with little consistency among results. Table 6 describes the context in which these studies were conducted.

Nine of the 14 studies were conducted in the United States. In only one instance would separate consideration of the findings result in somewhat different conclusions. Of the six studies comparing follow-up from screening to evaluation in NICU versus WBN infants, five were conducted in the United States and one in England. The English study found better follow-up in WBN infants, whereas of the five U.S. studies, three found better follow-up in NICU infants and two found no differences. This raises at least the possibility that the contrasting findings between these studies could have been influenced by the different health care systems.

e diversity of study populations may have also influenced another aspect of the overall findings. As noted under estion 1, the three studies examining the rates of follow-up by infant race reached different conclusions. The Folsom al. (2000) and Liu et al. (2008) studies found higher follow-up in non-Hispanic White infants, whereas the Prince et (2003) study found significantly lower follow-up in non-Hispanic Whites. There is some indication, though, that non-Hispanic White populations may not have been comparable across the three studies. Although all three studies re conducted in the United States, Prince et al. pointed out that "a small percentage of White women [in the outer ands of Hawaii] may choose 'alternative lifestyles' preferring nontraditional health care rather than traditional vices" (p. 1205).

scussion

affect clinical practice and/or policy, it is desirable to have an evidence base of multiple studies of high thodological quality with generally consistent findings. The available evidence on issues surrounding loss to follow- in newborn hearing screening programs fails on all three counts.

nount of Evidence

studies were found that were directly relevant to Questions 3 and 4. Of the 20 potential risk factors examined in studies from Questions 1 and 2, most were examined in only one or two studies, and only one (NICU status) was amined in more than two studies.

ıality of Evidence

thodological quality was low. In none of the three intervention studies was subject comparability addressed, none re blinded, none had random samples, and none addressed treatment fidelity. In only one of the three intervention dies (Françozo et al., 2007) was the protocol described with sufficient detail for replication.

the epidemiologic studies related to Questions 1 and 2, quality concerns were also evident. None of the studies using e of follow-up (as opposed to age), for example, specified the time frames for designation of an infant as lost to low-up. If the de facto cut-off date for followed-up or lost was based on the data collection period, rather than each ld's age, then individual children within a study could have been inconsistently categorized, depending on when thin the study period they were born.

second quality concern among the epidemiologic studies involved another type of confounding. The Folsom et al. 00) study is an example of one that addressed a number of different potential risk factors. The factors, though, cluded items such as insurance status and prenatal care. Given the possible interaction between a lack of health urance and the availability and nature of prenatal care, it would be important in the analysis of the data to control possible interactions. Only in the Liu et al. (2008) study, however, were such controls evident.

hird quality concern involves some confusion as to whether additional risk factors were studied, but the results were t reported in the studies because they were not statistically significant. The Prince et al. (2003) and Liu et al. (2008) dies, for example, did report that some of the factors they studied, such as mother's marital status, were not significant. lsom et al. (2000), on the other hand, reported data on nine risk factors that had statistically significant results. It is t clear whether those were the only nine factors they studied, and all were significant, or whether those were the only tors found to be significant out of a larger total number that were studied.

e final quality concern involves multisite studies. It was noted earlier that the consistency of findings across studies an important consideration. Also important is the consistency of findings across sites within a single study. The ewart et al. (2000) study, for example, involved more than 200 infants at five sites. The overall findings indicated a nsignificant difference between NICU and WBN in follow-up from screening to evaluation. Data were not presented parately for the five sites, however, and as a result it is unclear whether the findings were consistent across sites.

Consistency of Findings Across Studies

There were eight instances of multiple studies examining the same intervention or risk factor (in this case, risk factors). For only one of the eight factors were the findings completely consistent. In these two studies, both found that mothers who completed high school were more likely to follow up from screening to evaluation. One of these two studies, however, found no significant differences in follow-up from evaluation to treatment by mother's education.

In summary, the small number, poor quality, and inconsistent findings within the available evidence do not provide meaningful direction for clinicians or policy makers in identifying the patients/families at the highest risk of loss to follow-up, nor how to decrease that risk. More high quality epidemiologic studies with precise definitions of terminology and incorporation of multivariate statistical analyses are needed, as are high quality experimental or quasi-experimental studies of well-defined interventions targeted at increasing follow-up.

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ɹendix A: Quality Scores for Intervention Studies

Factor	Françozo et al. (2007)	Korres et al. (2005)	Wittman-Price and Pope (2002)
Protocol *Described sufficiently for replication?*	Y	N	N
Subjects *Adequately described and comparable at baseline?*	N	N	N
Blinding *Assessors blinded?*	N	N	N
Sampling/allocation *Random and adequately described?*	N	N	N
Treatment fidelity *Procedures in place?*	N	N	N
Significance *P value reported or calculable?*	Y	Y	Y
Precision *ES and CI reported or calculable?*	Y	Y	Y
Intention to treat *Analyzed as randomized?*	N/A	N/A	N/A
Total score	**3/7**	**2/7**	**2/7**

Note. ES = effect size; CI = confidence interval.